

**SENSING THE WORLD: MEANING, SENSORY
EXPERIENCE AND CONTESTATION OF FAMILIES WITH
AUTISTIC CHILDREN**

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Thesis
Entitled

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AND CONTESTATION OF FAMILIES WITH AUTISTIC
CHILDREN**

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SENSING THE WORLD: MEANING, SENSORY EXPERIENCE AND CONTESTATION OF FAMILIES WITH AUTISTIC CHILDREN

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ABSTRACT

This study aims at examining meaning, sensory perception of autistic individuals and the striving for normalcy of families with an autistic child. It is a qualitative study of 23 autistic individuals including in-depth interviews with 14 families with autistic members in Lopburi and Singhburi Provinces.

The findings indicate that autism has diverse meanings. The mainstream explanation of autism is based on a bio-medical model, viewing autism as an impairment to be corrected by medical intervention. Families hope that medical treatment will provide normalization processes so as to have their children able to study in an inclusive educational system. Many families have experienced dealing with the abuse of authority, stigmatization and discrimination. Some families have suffered from, and were willing to comply with, the requirements of professional authorities for a while, before refusing further intervention.

The meanings given to autism in local culture are diverse and fluid. Perception of autism as a disease category is relatively recent. Autistic children with severe symptoms are often labeled as “crazy.” The labeling, however, has not been without contest. Families felt miserable and struggled to deny such imposed meaning. To lessen their suffering and enable their normal existence within society, families have had to construct their own more acceptable meanings, drawing on various local beliefs, for example, the belief that their child has been frightened by evil spirits, or the belief that it is a matter of karma. Such explanations help make their misery more acceptable. Treatment and care for an autistic child reflects medical pluralism, combining treatment of various medical systems as well as Buddhist and Brahministic rituals. Some families have chosen to disregard their child’s disability and focus instead on the child’s strong points, such as exceptional language skills; Children with exceptional skills were sometimes perceived as “Thep” (or god).

Autistic children exhibit an ability to understand their normal world through their specific sensory perceptions. The sensual relationship is crucial not only for their capacity for development as an individual person but also critical in how they relate to the world around them. They feel attached to certain places and relate to individuals through their memory of their sensations. The world of familiarity is constructed by and memorized through specific sensory perceptions, i.e. visual, acoustic, touch or tactile. The sensing of the world constitutes a normal lifeworld to which autistic individuals are comfortably related. It is a world of sensitivity seen by others as the cause of their unwanted behaviors.

This study argues for a more humanistic approach by first accepting and understanding the different sensory modalities employed by autistic individuals to relate to the world. It is only by understanding differing sensory experiences and a unique sense of self among autistic individuals that we will be able to restore and restate the dignity of autistic individuals and create an inclusive society.

KEY WORDS: AUTISM/ MEANING / SENSORY EXPERIENCE / CONTESTATION

211 pages

โลกของผัสสะ : ความหมาย ประสบการณ์การรับรู้ และการดิ้นรนของครอบครัวออทิสติก

SENSING THE WORLD: MEANING, SENSORY EXPERIENCE AND CONTESTATION OF FAMILIES WITH AUTISTIC CHILDREN

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ปร.ด. (สังคมศาสตร์การแพทย์และสาธารณสุข)

คณะกรรมการที่ปรึกษาวิทยานิพนธ์: เพ็ญจันทร์ เซอร์เรอร์, ปร.ด., พิมพวัลย์ บุญมงคล, ปร.ด., โกมาตร จึงเสถียรทรัพย์, ปร.ด.

บทคัดย่อ

การศึกษานี้มีวัตถุประสงค์เพื่อศึกษาความหมาย ผัสสะการรับรู้ของบุคคลออทิสติกและการดิ้นรนสู่ความเป็นปกติของครอบครัวออทิสติก วิจัยเป็นการศึกษาเชิงคุณภาพใช้การสังเกตแบบมีส่วนร่วมกับเด็กออทิสติกจำนวน 23 คน และการสัมภาษณ์เชิงลึกครอบครัวออทิสติกจำนวน 14 ครอบครัว ในพื้นที่จังหวัดลพบุรีและสิงห์บุรี

ผลการศึกษาพบว่า ออทิสติกมีความหมายที่หลากหลายแตกต่างกัน ในกระแสหลักให้ความหมายออทิสติกตามคำอธิบายทางการแพทย์ โดยมองออทิสติกเป็นเรื่องของความบกพร่องที่ต้องแก้ไขให้ใกล้เคียงกับปกติมากที่สุด กระบวนการทำให้เป็นปกติ จึงเป็นความหวังของครอบครัวที่ต่างดิ้นรนเพื่อให้ลูกได้รับการรักษาและเรียนร่วมกับเด็กปกติ หลายครอบครัวต้องเผชิญกับอำนาจ การตีตราและการกีดกัน บางครอบครัวยอมทนทุกข์และให้ความร่วมมือในการรักษา แต่ท้ายที่สุดก็เลือกวิธีปฏิเสธการรักษา

ส่วนความหมายของออทิสติกในวัฒนธรรมท้องถิ่น มีความเลื่อนไหลตามชุดคำอธิบายของชาวบ้าน หากเด็กออทิสติกมีอาการรุนแรงไม่ตรงตามภาพตัวแทนของสังคมจะได้รับการนิยามในทางลบว่าเป็น“บ้า” ครอบครัวรู้สึกขมขื่นและพยายามปฏิเสธความหมายนี้ หนทางพ้นทุกข์และสามารถดำรงชีวิตอย่างปกติในสังคม ครอบครัวต้องรื้อสร้างความหมายใหม่เชื่อมโยงกับความเชื่อท้องถิ่น เช่น สาเหตุที่เด็กไม่พูดเกิดจากผีทำให้ตกใจ หรือมองว่าเป็นกรรมของสรรพสิ่ง การอธิบายเช่นนี้ช่วยให้ครอบครัวยอมรับและทนทุกข์กับชีวิตได้มากขึ้น การรักษาจึงมีทั้งพฤติกรรมบำบัดร่วมกับการ พิธีกรรมแบบชาวพุทธและพราหมณ์ ในขณะที่บางครอบครัวเลือกที่จะมองข้ามความพิการและหันมาองสัจภาพในตัวคน เช่น การที่ครอบครัวรับรู้เด็กที่มีทักษะความสามารถทางภาษาในลักษณะของความเป็น “เทพ”

เด็กออทิสติกมีความสามารถและเข้าใจโลกปกติผ่านการรับรู้ผัสสะต่างๆ ความสัมพันธ์ในผัสสะการรับรู้จึงมีความสำคัญไม่เพียงเรื่องพัฒนาการความสามารถในตัวบุคคลเท่านั้น แต่ยังมีสำคัญถึงวิธีการที่เขาเหล่านั้นติดต่อกับโลกที่อยู่รอบๆตัวตน บุคคลออทิสติกมีความรู้สึกผูกพันกับบุคคลและสถานที่ โลกของความคุ้นเคยประกอบสร้างผ่านความทรงจำและผัสสะการรับรู้ด้านต่างๆ เช่น ผัสสะการมอง การได้ยิน และการสัมผัส โลกชีวิตของบุคคลออทิสติกจึงเป็นการรับรู้ร่วมกับสิ่งที่มีความผูกพัน และบางครั้งอาจเกิดพฤติกรรมที่ไม่พึงประสงค์ จากความไวต่อการรับรู้ในสิ่งที่ไม่คุ้นเคย

การศึกษานี้จึงเสนอแนะคำนี้ถึงความเป็นมนุษย์ของบุคคลออทิสติก ด้วยการยอมรับและเข้าใจความแตกต่างในผัสสะตัวตนที่มีลักษณะเฉพาะ ตลอดจนวิธีของบุคคลออทิสติกในการรับรู้ความเป็นไปในโลก ทั้งนี้เพื่อธำรงไว้ซึ่งศักดิ์ศรีและสร้างเสริมการอยู่ร่วมกันในสังคม

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CHAPTER I

INTRODUCTION

1.1 Background and significance of the problem

“In others’ mind, autism could be genius child as Rainman who can count toothpicks falling down and has good memory. Autism has delayed speech but has ability to get in inclusive education. In real world, there are still autistic persons who could not talk, scream, use alien language, uncontrolled urine and feces, hyperactivity, self-injury, destroy things and/or has mental retardation.”

“My son is an autistic person who has criteria as above. During 13 years, my family as an autistic family usually faces the questions of unacceptable nurturing from others; such as do you has stress during pregnancy? Does your family have autism? Why don’t you take your son to see the doctors? Why don’t you take him to speech therapist? Or why do you encourage him to talk? And there’re many questions about “why”? Family has caring experience. We don’t think our child has his own world and impaired social relationship as medical explanation. Autistic person has his social world but the way of making interpersonal relationship is different. To be living with autistic child in our experience are different from other feelings. Our experiences are diverse and subjectivity upon to our embodiment. Family with autistic person has self, emotion, and thought. We give meaning of lives’ experience all the time. Personhood of Family and autistic person has meaning beyond others’ understanding and typical autism in medical regimen.”

“Autism” was categorized as a psychiatric illness through its definition by the medical profession. It was first described by Leo Kanner, a psychiatrist at Johns Hopkins Institute, in 1943. However, according to the first Diagnostic and Statistical Manual (DSM-I), published by the American Psychiatric Association (APA) in 1952, children with autistic symptoms would be diagnosed as having a “Schizophrenic reaction, children type”. This definition was also retained in the DSM-II (1968). The DSM-III begun to use the diagnostic term “Infantile autism”, which was changed to

“Autism Disorder” in 1987, characterized by four key abnormalities: repetitive behaviors, abnormal social development, abnormalities in the child’s ability to convey meanings, speak, or use language, and lack of imagination.

Dr. Penkhae Limsila, working at Yuwaprasart Waithayopatum Child and Adolescent Psychiatric Hospital in Samut Prakan Province, introduced the term “Autistic” to Thailand in 1967. It has not been studied what children with this kind of characteristics were called, or how they were categorized in Thailand prior to that time. In the current understanding, besides being categorized as an illness, Autism is also recognized as a kind of disability by the Ministry of Social Development and Human Security, as well as by the definition of “a disabled person” in the Development of Quality of Life for Disabled Persons Act, B.E.2550.

Definitions matter, because they put people into categories using professional power and knowledge, which are considered legitimate by society (Foucault, 2006). Whatever way physicians define a phenomenon, the definition tends to be accepted with no questions asked. It is universally accepted that children defined as autistic need medical care. This is reflected by the establishment of World Autism Organization and the use of Western diagnostic and treatment protocols for Autism in both Western and Eastern countries, such as Latin American countries, Japan, China, or Korea. They are used even in India, despite its strong indigenous religio-cultural system; however, there may be differences in the age of diagnosis, and treatment uses a combination of modalities also including Indian indigenous medical practices (Daley, 2002).

The prevalence of autistic spectrum disorders in Thailand has increased from 1.43 per 10,000 in 1998 to 6.94 per 10,000 in 2002 (Plubrukarn, Piyasil, Mounghnoi, Tanprasert, & Chutchawalitsakul, 2005) and 9.9 per 10,000 in 2005 (Poolsuppassit, Panyayong, & Liknapichitkul, 2005), mirroring epidemiological data from other countries that suggest a 1.5-2.5-fold increase in the prevalence of Autism – from 7 per 10,000 in 1985 to 10 per 10,000 (E. Fombonne, 1999). If Asperger’s Syndrome and other PDDs are included, the overall prevalence of these conditions has been estimated to be 3.4 per 1,000 (Yeargin-Allsopp et al., 2003).

Two major explanations have been given for this increase in these conditions’ prevalence. The first is that environmental factors like vaccines, bacterial

or viral infections, convulsions, surgeries and environmental toxins are behind the increase (Lingam et al., 2003). The second explanation has been proposed from a social science point of view; it asserts that the perceived increase in autism is due to broader diagnostic criteria and increased awareness of autism among physicians and the general public, resulting in a greater number of children being diagnosed (Grinker, 2008; Silverman, 2008). After almost 70 years, the causes and treatment of autism remain a grey area. In the 1960s and 1970s, it was believed that autism was caused by upbringing, especially cold mothers branded as “refrigerator mothers” (Bettelheim, 1967; Fombonne, 2003; Silverman & Brosco, 2007) and treatment consequently emphasized family psychotherapy approaches.

This perspective stigmatized families with autistic children; family movements emerged to oppose it. Some ten years later, the treatment approach shifted to behavior therapy, possibly combined with medication, to control such children’s behavior, and speech therapy, to enable them to communicate (Silverman & Brosco, 2007). In the mid-1990s, genetic factors and nervous system abnormalities were identified as causes of autism (Gurney et al., 2003; Pornprot Limprasert, 2008; Silverman & Brosco, 2007; L. Wing & Potter, 2002; Yeargin-Allsopp, et al., 2003), which paved way for new research avenues and treatment modalities, for example the Autism Genome Project, aimed at developing gene therapies for autism; or treatment with hyperbaric oxygen and bone marrow transplants. This period in the treatment of autistic children is thus characterized by experimentation on the bodies of autistic children and their families, objectified under medical discourses.

Medical treatment emphasizes correcting impairments and normalizing individuals. Such normalization is a tool of the medical profession that most people consider correct; it becomes a social norm. Families thus try to seek such normalizing systems by any means. If unable to correct the identified impairment, families are stigmatized as providers of bad upbringing. Autistic children themselves are redefined as disabled; the operations of cultural beliefs and social and political norms make them to be seen as a social problem and be marginalized. This results in lack of various opportunities in employment, education and access to various resources.

“Normality” is what society considers desirable and expects of people. Thus, when new treatments become available, families of autistic children tend to do

their utmost to gain access to such treatments, regardless of the costs involved, believing that it is for the best. This pattern is further intensified by the medical assertion that the sooner diagnosis and treatment take place, the better the prognosis and chances for a near-normal life for a child with autism (Pongsak Noipayak, 2009). No questions are asked, because we have been socialized into believing in medical facts, and when new treatments emerge, only positive effects are ever publicized. Problems related to autism are spreading to ever wider circles; they are not individual problems contrary to a popular misconception.

Normalization processes not only affect the bodies of autistic children; but also the bodies of their parents embedded this processes, as well. Medical normalization processes serve the symbolic value society gives to perfection. This means; the capitalist society gives importance to the perfection of the products produced. Mothers of children with disabilities can be compared to producers of faulty wares, and the children themselves to faulty goods that have not passed quality control (Phillips, 1990). When these children grow up, they may be seen in the same light as broken machinery that cannot be used and thus as second class citizens, devoid of value, and a burden to society. Therefore, all families have a burning desire for their children to reach both bodily and mental perfection; nobody wants to give birth to a child with disabilities.

When families desire strong, healthy children, the medical profession with its involvement with high technology enters the picture. Often, use of such technology is not a medically indicated necessity, especially in private sector, commercial entities providing medical services; rather, if the client has the money, anything can be obtained. The use of medical technology has been embodied in both male and female bodies, for example through genetic counseling, the Human Genome Project, sperm screening among couples who have trouble having a child, or ultrasound and amniocentesis tests performed to detect chromosomal abnormalities.

Although autism has been hypothesized to result from genetic abnormalities, it is not possible to check for these abnormalities, unlike in the case of Down syndrome. Nevertheless, parents whose children have disabilities face questions from society as to whether the mother took proper care of her body during the pregnancy – for example, if she smoked or worked too hard. These questions are

posed by both individuals and media outlets in this era when parents face heavy pressure to have “perfect” children without disabilities (Landsman, 1998). In this sense, technological advances based on the symbolic value afforded to perfection provide a context to the discourse controlling the parents’ bodies.

Besides the symbolic value afforded to perfection, society also values “able” individuals more than “disabled” ones. This phenomenon, which is called “ableism”, devalues individuals with disabilities and limits their opportunities within society. When individuals with autism are classified as people with disabilities, they face the same kinds of myths, fears and stigmatization that other people with disabilities face in their everyday lives. Nevertheless, they have to live on in society that lacks understanding in their value and humanity. Cultural beliefs and values, for example the belief that disability is the result of karma, or negative value afforded to individuals with disabilities, result in discrimination and marginalization against them. Conversely, societies believe that individuals with disabilities are gods or otherwise supernatural, treat them in a way characterized by acceptance and admiration. For example, ultra-orthodox Jews in Israel, who believe in reincarnation, view that autistic children have high spiritual status and thereby have special abilities in performing religious ceremonies; they view these children as heaven’s messengers – not sinners but reincarnated souls of Jews (Shaked, 2005). Similarly, in Sri Lanka, families accept autistic children, viewing them as reincarnated warriors (Leonard, 1985).

In societies with negative beliefs, myths and culture about individuals with disabilities, bringing up an autistic child is no easy feat. In such contexts, families face difficulties in caring for both the mind and body of their child; they have to struggle and negotiate with a society laden with negative ideals. Many families that face such physical, psychological and financial difficulties cannot withstand the pressure. Their families’ lives became broken, separated and divorce (Supornthum Mongkolsawadi & Akaraphan Khwunchuen, B.E.2546). The problems of caring autism vary depending on the individual’s age. Parents of a small child have to get used to being defined as parents of a child with disabilities; they also have to manage developmental and communication issues. When the child reaches puberty, sexual issues, societal integration and emotional problems present new issues and can be difficult to understand because of communication difficulties (Midence & O’neill, 1999). The

level of stress faced by families with autistic children can be so high that it has been found necessary to study the prevention of filicide in such families (Palermo, 2003). Numerous families are thus in search of ways to manage stress within the family. Studies in Thailand have focused on group therapy (Panida Srikhachin, 2000) or group counseling (Gunvipa Hongngam, 2003); the development of individual family service plans (Meena Wongsalee, 2005); coping strategies of families (On-Siri Pisek, 1999) adaptation and needs of parents with autistic children, viewed in terms of psychological reaction stages (Wongdern Tacharin, 2003); strengthening self-efficacy among caregivers (Patrabul Puttahraksa, 2005); preparedness to be a caregiver among parents of autistic children (Somjit Pheephimai, 2004); and on social support among them (Nareelak Mongkholsirigul, 2003).

Most of these studies are in the fields of physicians, nurses and psychologists, under the medical paradigm. They have an individualistic view that families face problems as a result of having an autistic child. They therefore suggest addressing the problem at the level of the family or the autistic child, without consideration to problems resulting from society, discrimination, or limited work and educational opportunities that make the lives of such families and children ever more difficult. Only one previous investigation of autism from the perspective of social science has been conducted in Thailand. It analyzed the negotiation power and power relations between families and the state, as well as problems in the educational system and state policies of assisting individuals with disabilities (Suporntum Mongkolsawadi & Akaraphan Khwunchuen, B.E.2546). It did not address cultural issues or Buddhist beliefs, which are important in the study of the lives of autistic people and their families.

Thus, the study of autism should not only be conducted from the medical point of view according to which autism is an impairment to be corrected. Studies on the issue must see beyond medical discourse, because medical practices are not the best way to make the lives of autistic people more valuable (Silverman, 2008). Thus, the present study focuses on the ways families continue their lives – ways that are constructed by society, culture, the medical profession, and the learning that takes place in families that have to live with the shortcomings of an autistic child, such as inability to speak or control oneself – or in other words, how families perceive related

issues and what they do about them. Because autistic individuals perceive their sensory experiences in a special way, their sensory problems are difficult to understand. Medical personnel generally believe that the problematic behaviors of autistic individuals stem from psychological factors; from these beliefs follow their attempts to modify the behavior of such individuals to make it match that of normal individuals. Many autistic children who cannot speak tend to touch, knock or smell objects around them a lot; these behaviors help them to understand what objects there are around them. This can be likened to the use of the cane among blind people who use it to find their way. Autistic individuals have eyes and ears, but the processes of transmitting visual and auditory data do not take place properly. For some autistic individuals, sensory perception is a painful process; because of their impairments in perceiving their own bodies, they may have to hit themselves to find out where their own body is (Classen, 2005). Some learn by touching before seeing; for example, they may not know if they have put on a shoe on the correct foot, unless they touch their leg and foot to ascertain the matter.

While the medical profession describes the behaviors of autistic individuals as sameness and repetitive, Grandin (2005), an autistic writer, has stated that autistic individuals have a very sensitive sense of touch. This contributes to their difficulty accepting changes. For example, donning new panties can produce a scraping sensation, and an autistic woman might prefer to wear the same bra until it is about to fall apart. At least, she might need to have a new one washed ten times before it would feel wearable. Or, she might have to remove any stitching not to feel like she is being pricked by needles. Overly sensitive skin is a common problem among autistic people. Some may refuse to be hugged, because it can feel highly uncomfortable. They may also use special equipment to apply pressure on their bodies; as such pressure can help to reduce their anxiety and feelings of panic (Classen, 2005).

The family's lives with autistic children therefore differ from those of ordinary children, especially among children who cannot speak. Misunderstandings can lead to screaming episodes known as "sensory-induced tantrums." From my own experience as the mother of an autistic child, who cannot speak, I have found out that communication has to take place through staring each other in the eyes. The medical

understanding is that autistic individuals do not take eye contact, but in practice, my child is able to communicate with me through facial expressions, touching, actions and crying in a different tone of voice to communicate different needs and feelings. Families need to be able to perceive such auditory, visual, touch-based or even telepathic signals to understand the feelings of an autistic family member. This aspect makes it impossible for the study of the families of autistic children to be objective; it is necessarily subjective. To understand aesthetic life, the study should go beyond autism as a disease, but should see autism as human being.

This study therefore adopted a medical anthropology perspective that views autistic individuals as human beings, and considers autism as a socio-cultural phenomenon. The study of autism must not be limited to the individual level but also consider the social and cultural levels because understanding autistic individuals requires more than experimental or psychological study. However, studies on autism from a cultural point of view are scarce. This is true despite the proliferation of studies on disability in non-Western countries in the past decade— studies that focus on cultural differences in the treatment individuals with mental and physical disabilities receive across contexts, and how these differences shape the identities and social role of the individuals involved (Benedicte Ingstad & Whyte, 1995). However, these questions remain to be asked about autistic individuals.

For this reason, this study uses postmodern and phenomenological framework in studying disability. Using a postmodern understandings of disability helps to see how social meanings and values are constructed about people with disabilities, including autism, and how power/knowledge operate through categorization and normalization processes and cause the public image of individuals with disabilities be laden with negative meanings that are accepted as factual in all strata of society. Phenomenological understandings, on the other hand, help to understand the life experiences of families with an autistic child, laden with interwoven, complex meanings – sensory experiences, interpretations, and familial practices. Different families understand the behavior of an autistic family member differently; some communicate with their child through telepathy, some rely on the medical profession and socially prevalent values. The latter try to find a cure for their child's impairment so as to escape the condition of "disability." Yet others use

Buddhist principles to be able to accept the reality and find happiness in everyday life with the autistic family member. This highlights how diverse the perceptions, practices and interpretations of families can be. This diversity depends on the Buddhist concept which embedded in their families' experiences. A phenomenological approach will help to deep understand through personal experience and elucidate the meanings behind various practices. Importantly, this perspective enables to approach aesthetic life, as well as appreciating the value of complicated lives and individuals' ability to sense the world (R. R. Desjarlais, 1992, 2003).

I hope that this study on the life experiences of families with an autistic child will open new perspectives on the lives of autistic individuals and their families. The study will not wallow on descriptions of impairments or repetitive, robot-like behaviors, but rather emphasize seeing the autistic individual as a human being capable of feeling and thinking, endowed with a life in body, mind and spirit, and living within society together with other people. Thereby, this study helps to build in-depth understandings of the lives of autistic individuals and their families. These understandings can be used in developing projects and processes for taking care of autistic individuals and their families. To increase the social space of autistic individuals and their families in society, the guiding light of such interventions needs to be understanding and acceptance of diversity and of the principle that it is not necessary for everyone to follow standards of normality crafted by so-called normal people.

1.2 Objectives

1.2.1 General Objective

To study life experience through sense, perception and interpretation of families with autistic children

1.2.2 Specific Objective

1) To study meaning and sensory experiences of families with autistic children

2) To analyze contestation of families with autistic children within medical discourse and socio-cultural discourse about disability

1.3 Research Questions

How the families with autistic children sense, perceive, and interpret in their everyday experiences?

1) In families' experiences, how are they being and living with autistic children? How do they perceive and interpret their experiences? And, how do they practice?

2) How do persons with autism sense the world? What do their sensory modalities perceive?

3) What do the medical discourse and socio-cultural discourses work on autism? What is the meaning of "autism" in society? How do this meaning penetrate to the body of families with autistic child? How they embody the autistic meaning?

1.4 Scope of this Study

The samples in this study are persons with autism and their families. Their socio-cultural settings are semi urban and rural in Lopburi Province and Singhburi Province, which in the central part of Thailand. Therefore, these findings reflect socio-culture of central part of Thailand.

1.5 Operational Definition

Families with autistic children: the persons who are nurturing and living with autistic children, i.e. father, mother, grandfather, grandmother. \

Sensing the world: Perceiving begins within the body, which interact the world. That means the individuals perceive in human action and the dynamic surroundings, such as perceiving the social value, perceiving given meaning of self, etc. Another meaning, the human senses include 5 senses (sight, hearing, smelling

tactile/touch, and taste), and other senses which produced by a stimulus, such as sense of place, sense of time, sense of order, and sense of security, etc.

Sensory experience: the individual's subjective experience. That means the experiences which the individuals share understandings or perceptions through feeling, tasting, memorizing and expressing in everyday life. To consider the experience of individuals would be seen ego and consciousness of them and their sphere of life (R. R. Desjarlais, 1992).

Contestation: Striving for normalcy under medical and socio-cultural discourse. The family with autistic person struggle with the negative attitudes toward disabilities that are accepted as factual in all strata of society. They attempt to escape from the image of disability through the normalizing process, in order for their children would be free from the status of disable children to become normal.

CHAPTER II

CONCEPTS AND LITERATURE REVIEW

The purpose on Sensing the world: Meaning, sensory experience and contestation in families with autistic children is to study meaning of autism through experiences of the families with autistic children in terms of living with impairment of autistic children, and the way of living under circumstantial of medical practices and the values of society-ableism and perfection-which affected the system of thinking and the ways of practices of Thai families with autistic children. For better understanding of this aspect, I, as a researcher, had reviewed the related literature concerning autism as constructed meaning. The study framework was applied the Postmodern conceptual framework and Phenomenology. The details are as follows:

2.1 Autism as constructed meaning

- Meaning of autism in the medical construction
- Autism in Anthropological perspective
- Autism study in Thailand

2.2 Disability in Postmodern perspective:

- the constructed meaning of disability with sociocultural construction
- Meaning of disability in historical contexts

2.3 Phenomenological approach

2.1 Autism as Constructed Meaning

Autistic disorder is constructed meaning, categorized as disability. To clarify this, it should begin with considering the autistic meaning in medical perspective through analyzing of medical diagnosis and remedies in historical context.

The scientific medical discourse was being challenged. Many occurrences of new discourses were questioning the results of scientific medical remedies. Once the medical remedies were criticized, the new way of autistic study in anthropological

perspective has begun. It was deviated from the original belief that the autism was an infantile disease; instead, it looked at the autistic person as a human being and as the sociocultural phenomenon only. This study presents meaning of autism in the medical construction; the sample studies of autism in anthropological perspectives; and the autism studies in Thailand.

(1) Meaning of autism in the medical construction

In mainstream concept, the “autism” meaning is given through the medical model as “being disability”. By the medical model, the autism is categorized in the group of Pervasive Development Disorder in the Diagnosis and Statistical Manual; DSM. It can be diagnosed in the childhood at very young age. The name of “autism” was originated from Greek. The word “Auto” literally means *self* which is referring to the behavior of being on their ownself in their world as if there was a clear wall or a mirror separated them. They were lacking sense of surrounding. Autism is categorized in 4 aspects as follows: having repetitive behavior, abnormal social development, lacking of verbal communicative development, wrong language usage, and lacking of imagination. These diagnostic criteria have been used and accepted world wide. It then became social mainstream discourse that influenced over the other perspectives, including reflected in its remedies and its education system.

Autism is categorized in the group of mental illness. Before the medical diagnosis has been used, the society understood that the severe autism children were Feral Children since they sounded like the wild animal. They were unable to speak. They only kept crying out loud, screaming, running around naked, and biting people around them when they were angry. They also ran away from people they met, etc. Some societies believed that these children were fed by wolves, which was not true at all (Bettelheim, 1959). In the medical science, the autism was first recorded in the year 1943 or B.E. 2486 by Doctor Leo Kanner, Psychologist of John Hopkins Institution. However, this had not been identified in Diagnostic and Statistical Manual yet.

In the First Diagnostic and Statistical Manual; DSM-I, 1952, the autistic children were diagnosed as having Schizophrenic reaction, children type. In DSM-II, 1968, the diagnosis was still the same. Until, DSM-III, 1980, there was the beginning of diagnosis called “Infantile autism” and later changed to “Autism Disorder” in 1987.

It was stated that the children with autism had 4 characteristics: repetitive behavior, abnormal social development, lacking of verbal communicative development and wrong language usage, and lacking of imagination. The DSM-IV has put Autistic Spectrum Disorder in the group of Pervasive Development Disorder; PDD. One symptom in this group is Asperger Syndrome or the former known as High functioning autism. With the wide range of criteria, there is a continuation of autism meaning and categorizing.

At the present, the DSM-5, unlike the DSM-IV, defines autism as a single “spectrum disorder,” with a set of criteria describing symptoms in the areas of social communication, behavior, flexibility, and sensory sensitivity. It is categorized in 3 levels: requiring support in level 1, requiring substantial support in level 2, and requiring very substantial support in level 3. For example, level 3 means the autistic individuals who are severe deficits in verbal and nonverbal social communication skills, which cause severe impairments in functioning, very limited initiation of social interactions, and minimal response to social overtures from others. If a person who is able to speak in full sentences and engages in communication but whose to-and-fro conversation with others fails, and whose attempts to make friends are odd and typically unsuccessful; they are in level 1. (American Psychiatric Association, 2013)

Causes and Remedies of autism

Based on analyzing historical contexts of causes and remedies of autism during 1960s, there was a belief that autism was caused by psychological impacts. Since the mothers showed their coldness and kept the distance from their children. This concept was influenced from Bruno Bettelheim who explained the autism based on Freud's Psychoanalytic theory. Bettelheim stated that the autistic person was an individual with weak ego as he/she was abandoned from the parents. It was the feeling kept in unconscious level. Bettelheim transferred this concept into the book called “The empty fortress” (Bettelheim, 1967). This was an original of the word “refrigerator mother”. Therefore, the remedy was started with psychotherapy. This remedy was known throughout the decade from 1970-1980. Ten years after that this theory had been fallen down (Silverman, 2008). In Thailand, this concept still has been hidden in the medical staff. From my direct experience, everytime I took my child to

receive the medical treatment or talked with the other autistic families, the issue of the mothers providing insufficient love and care for children was still questionable. Moreover, there are books or other printed media underlined this issue such as a book called “Roag tee mae tum” (the disease caused by mother.) and one of these diseases was autism. The author of the book was a pediatrician who had a good intention to tell mothers, caretakers, teachers, doctors, nurses and general people to be aware and understand the behaviors of autistic children. He attempted to point out the causes of autism that made the children become abnormal and having the mental and physical problem, in order to raise them correctly (Shigemori Kuetogu, B.E.2550). This is one example of reproduced imperfect mother which reflected the concept of Bruno Bettelheim, and proved that it was still being applied.

In another aspect, the attention was drawn to the cause of autism in relation with the genetics. This concept started during the decade of 1960s, Bernard Rimland defined the autism as a neurodevelopment disorder as he found the relevance evidence in the identical twins. Later, there were more studies about genetics in related with autism. Especially in the middle of 1990s, most of the studies were conducted to support the concept of genetic problem and neurodevelopment disorder (Pornprot Limprasert, 2008). Then, there were more intensive studies under the Autism Genetic Resource Exchange program. Ten years later, it became the Autism Genome Project supported by the National Institute of Mental Health (Silverman & Brosco, 2007). The Genome Project would help developing of autistic remedies through genetical modification. The remedy result was believed to help the autistic children able to live with normal children in general contexts.

The scientific researches on the autistic cause were dynamic. The reason might be that many researchers believed in the philosophy of absolute truth. Therefore, almost of researches were focusing on the causes with biological basis. It was believed that autistic children were the persons with Pervasive Development Disorder or with Psychological /mental problems. This concept was accepted worldwide as seen in the establishment of World Autism Organization and developing several new remedies; e.g. Hyperbaric Oxygen treatment, Bone Marrow Transplant, psychomedication, and applied behavioral therapy, etc. Especially, the applied behavioral therapy has been accepted widely from 1960s until present. This treatment emphasized on managing the

proper behaviors and usually combined with speech therapy, e.g. the Augmentative and Alternative Communication (ACC).

The mainstream discourse that relied on the medical paradigm has been challenged. There were some questions about the results of scientific way. Since the parental groups had doubts about the external causes of autism e.g. vaccine injection, virus and bacteria infection, seizure, operation, and toxin from the environment (Lingam, et al., 2003). All these factors affected to the affective psychopathology system as the children had regressed development at age of 2 years old (DeLong, 1999). At this point, many parents had turned to the alternative medicine, such as nutritional supplementation, detoxification therapies including chelation. Some cases understood that the autistic caused by allergies and immune problems, while the others actively responded to the claim that MMR vaccine was the cause of autism. Until the Institute of Medicine Review Committee insisted that there was no linkage between the neurodevelopment disorder and the use of thimerosal containing vaccine. Although there was such a declaration, this issue has been discussed continuously until nowadays. It has been seen clearly that the causes and remedies of autism have been changed and dynamic all the times. However, the establishment of constructed medical knowledge had created trusts and reliabilities to the autistic families. So they still struggled in testing new remedies for their children.

Although most of research studies were in the medical paradigm which viewed the autism as an infantile disease, there were still some studies criticizing the medical remedies. Some researches pointed out that the behavioral therapy was divided, and not in holistic view. It also overlooked the human value of the autistic individual.

In the first point, the medical professionals realized holistic care and believing in concept of inclusive society. However, its remedy was still separated them out. For example, the applied behavioral therapy focused on changing children behaviors only without considering their families or parents. The therapists did not concern the parents' stress, the limitation as being teachers, conflicts in the families, and being broken families. These were invisible to the professionals. Therefore, the autism remedy should not emphasize at the individual level only. The applied behavioral therapy should be organized with the family therapy (Harris, 1984).

Moreover, there were some studies criticizing the family therapy without family-centered practice. The family-centered concept was only in principle theory, not in the practice. It was still depending on the experts, would call “the professional-centered”. By principle, the therapists should have transferred their authority of decision making and practicing to the families. Some researches showed that the therapists did not pay respect and realize value of family decisions. The practicing of family-centered should be applied in order to encourage the family to take care of the disabled children based on the decision making and taking their needs and necessity as a priority (Dodd, Saggars, & Wildy, 2009b).

The second point, some professionals did not realize the human value of the autistic person. The study on Ethnography done by Hendriks (1998) identified that the behavioral therapy in some institutes where using the traditional practices. The therapists looked at the autistic children as robots, which was the reductionism view. It meant that the medical perspective viewed an autistic person as a person with social impairment and inability in interaction with other people. Even the autistic children in high functioning autism group, it was difficult for them to understand rules of living in the society and understand other people. The autistic persons, thus, were compared as autistic robots who unable to understand the interpersonal relationship as well as having a machine-like behaviors such as repetitive behavior, emotionless and not playing with others. With this attitude, the autistic person become like useless person. Hendriks suggested the deconstruction of human and machine concept and emphasis on the humanistic issue in order to get rid of reductionism since it created unclear vision of autistic person. Also, the practice towards autistic person in the institutes or in the in-patient services should be in the frame of human rights respects. There shall not be any strong structures without flexibility. The structure with flexibility would help autistic people meet with the happier life (Hendriks, 1998).

Reflection of the research studies, it showed that the autistic people had to live in the structure that was identified by the therapist. In such a structure, the autistic people were treated like the objects since they needed caregiving all the time. However, they were alive. The ways of their communication were meaningless for other people; but it actually had hidden meanings that need to be comprehended.

Therefore, viewing the autism as a disorder and defining the constructed meaning in the institute would destroy their being and living.

(2) Autism in Anthropological Perspectives

When there was the question about the medical construction concerning the autism causes and remedies, the medical anthropologist looked at the phenomenon occurred with autism as the establishment and negotiation of the experts. Given the meanings of autism as neurodevelopment disorder and learning disorder were very narrow. Also this given meaning had been penetrated through the way of people living. It became the medical culture that transferred its knowledge as well as changing the knowledge in terms of history, politics and society. The autism was, then, happened in powerful culture (Lawlor, 2010). The anthropological study had begun applying of Phenomenological and ethnographic approach to search for capacity and capability of autistic people.

Relying on the principle of physical disabilities in the medical discourse had been accepted and respected widely. Current researches reflected that this concept needed to be replaced and changed. In the autistic issue, the medical discourse had identified the autistic person as impairment in communication, while the anthropological researches pointed out that though they had defectiveness in communication, their communication was meaningful. Sterponi and Fasulo (2010) had applied the phenomenology approach to clarify that the communication happened based on trustfulness in intersubjectivity between children and parents. In the Ethnography study done by Bagatell (2010), the community of high functioning autism group age between 21-58 years old was studied. It analyzed how autistic person challenged Bio-medical model. Its result found that the new discourse about autism realized the value as a person of the autistic people who were not necessary to get the remedies or be separated from the social world. According to the medical diagnosis, the symptom of autism was impairment and limited interests in environmental surroundings. But being and living as autism was not the problem. The autistic person had his/her own identity. Also there was the autistic community happened in the social network which helped communication among the autistic people become successful. Such happened community was like a tool in developing the identity of the autistic

people. Therefore, the autistic people would become like the other disabled groups who were socially constructed through mainstream discourse. The problem was not with the autistic people but with the attitudes of society towards the autism (Bagatell, 2010). This research study, thus, tried to reflect the concept of disability with social construction, which was outside the framework of Bio-medical paradigm.

Anthropological studied issue was deviated from the belief that the autism was a childhood disease and turned to look at the autistic people as common human beings. This was considered a socio-cultural phenomenon, so the study of autism should not be at the individual level. It should be at the social and cultural level because the learning and understanding of autism must be more than experimental study or psychological study only. However, at present there are a few studies on autism in cultural aspects. Though, in the past decade there were studies of disability in non-western countries concerning the questions about how physical and mental disabled people would be treated, how is the differences in each culture and how it impacts to the identity adjustment of the disabled person and how is social consequence (Benedicte Ingstad & Whyte, 1995). In fact, these questions are rarely found in the autism researches.

Tamara C.Daley (2002) identified the necessity in cross-culture autism study and criticized many researchers' conclusions that autism was hardly found in the non-western countries or categorized the autism as a modern illness (Sanua, 1984). The reason was the cultural researches seemed to be insufficient. Daley had studied the autism in Indian culture and found that the causes of autism did not come from biological factors or organic factors only, but also being explained in psychological and environmental causes too. Such a symptom like lacking of social relatedness was the beginning symptom which found in the children at the average age of 7 months. This study result was rather different from the diagnosis in the western countries, though the autism diagnostic criteria also based on DSM and ICD as well as conclusion of the opinions from Psychiatrist, Psychologist, and Pediatrician was same as those practices in the western countries. The problem of slow speech was normally found later period. Daley had set the hypothesis that since Indian society was highly values social conformity much more than American society. In addition, it was found that the study of child psychology in India during the decade 1990s shown that most

Indian parents did not look at these symptoms or behaviors of children as problems, instead they could accept them in their families. As in the sample case of the parents with 3 years old autistic child, they believed that their child was just stupid, not autistic. Indians have sought for several remedies of autism but mostly were the western style treatments. Moreover, there were other kinds of remedies such as Megavitamin therapy as in USA but the Indians called it “SuperNuThera” and there were others e.g. panic healing, reflexology, astrologists, acupuncture, speech therapy, vitamin therapy, Siddha, behavioral therapy and yoga (Daley, 2002).

Moreover, there were studies on folk concepts of conditions similar to autism such as a child known as “Nit-ku-bon’ or ‘marvelous children’ in Senegal had some characters similar to autism e.g. do not speak, no socially responses with other people (Ellenberger, 1968). In Sri Lanka, the families accepted the autistic children as they believed that these children were reincarnation of the warriors who become severe injured and died in the wars (Leonard, 1985). In Latino culture, there was a belief called “fatalism” which meant that no ones could change their own fates which they were born with. Such belief had affected to the searching for folk remedies or folk illness beliefs, it also reflected on slow or delayed remedies (Flores, Bauchner, & Feinstein, 1999; Pachter, 1994).

In Isreal, there was the study in the ultra-orthodox Israeli community, which found that the community had Spiritual discourse as a vehicle to take autistic children in the inclusive society. As they explained that the autistic children were in high spiritual status or having special ability in religious ritual since they were mediums from heaven as mentioned in Theosophical view that a disabled child was re-born of Jewish soul, so the autistic children were not considered sinners. This belief was also based on the reincarnation theory (Shaked, 2005). Besides, the community also has ceremony of facilitated communication (FC) which was in a mystico-religious perspective that helped physical or mental disabled person be able to contact with the pure souls, and inserted the moral teaching for the daily practices of the autistic children in the same way of teaching about the belief of prohibition of sexual activity during the menstruation period (Bilu & Goodman, 1997).

In the United States of America, there were also cross-culture studies, which found that the interpretation of the autism causes was differed in each culture.

In African-American, Asian/Pacific Islander and Latino families with autistic children believed that the cause of autism from having relationships in the family (Yeh, Hough, & McCabe, 2004). In the family of Caucasian (white people) often used medical terms of biological explanations to explain their children problem more than in African-American families (Bussing, Schoenberg, & Perwien, 1998). For the belief on the autism remedy, the families believed that autism was long-term illness and similar to disabilities. They would not focus on remedy but to provide caregiving to relief the symptoms instead. Some families believed that there was no complete healing of autism so they would not pay attention on the remedy (Mandell & Novak, 2005). In the anthropological studies, the results shown that there were various remedies in modern and alternative medical ways. It depended on the beliefs of the families with the autistic children. Anthropological perspective gave an importance to life and living with the autistic person which was an overview as a whole rather than individual focusing. That's why, this study of meaning, sensory experience and contestation in families with autistic children is very important to comprehend caretaking for autistic children as well as other disabled children.

Furthermore, the study of autism in the historical context (Silverman, 2008) shown that the families had availed in finding new remedies, in analyzing the other causes besides medical perspective. In the past, the parents were criticized as a problem, but in the historical study the families also helped supporting the autism researches and stimulating movements to adjust the social attitudes towards disabilities, promoting children to access health services and education services. There were projects to encourage the inclusive education and set the special educational programs for the children. Then, the parents and families become expertized and understanding the autistic children most. Therefore, this research study has to make the best understanding of autism through analysis of the families' experiences.

In this study, the literature reviews were mainly of the researches on experiences of the families with autistic children, but they were rarely anthropological studies. However, they reflected the medical discourse influencing over the other sciences, and these already penetrated through the culture of several countries. The most referenced study was *Unstrange minds* by Richard Roy Grinker (2008) which was Ethnography study that written about the experience in raising his autistic

daughter and the experience in living with the autistic children of the families in Korea, South Africa and India. Base on the study results of Grinker exhibited that the frequency of autism was highly found. It was believed that because of the diagnostical criterion was wider. The medical diagnosis impacts the autistic person to be less value. Grinker also found that the autistic families were different depended on cultural contexts but they were embraced by medical definition of autism rather than its cultural definitions. The experiences of the families in several countries, they had to face with the problems concerning acceptance and access through the medical services as those happened in the same way in USA (Grinker, 2008).

The study of Midence and O'niel (1999) found that the life problem of families with autistic children occurred in different periods of age. The families with young autistic children had to face with the problems in defined meanings and giving a new definition to themselves. This meant that they were defined meaning as parents with disabled children. They had to search methods for caring and living with their children since their children always had new behavioral problems. For the families with autistic children who were in school age, they had to find special program for their children. Once they were grown up, they had to face with the new problem of oversize growing which was incoherent with their intellectual and emotional development. At this age, if they had normal brothers or sisters, their brother or sisters had to adjust themselves to accept the disabled sister/brother. Many had bitter bad experiences; the parents had to confront with the hard works of making their children living together happily. Many used time allocation to keep their parenthood; this was considered complicated roles of the parents (Midence & O'Neill, 1999).

(3) The studies of Autism in Thailand

In Thailand, the word "autism" had been known for about 20-30 years, in the beginning it was only known in the medical field only. The first hospital for this autistic group was Yuwaprasat Vitayopadhum Hospital in Samut prakarn Province. Later, the remedy was extended to other hospitals, under Department of Mental Health in medical training schools, but it had not been generally known. Until the time that the Highest Princess Ubonrat Rajakanya Siritwattapanawadee, *the oldest daughter in His Majesty the King*, returned to Thailand with her youngest son "Khun Pum" who

was autistic child. The Princess had realized that the autistic people had not been provided the opportunities in many aspects equally as the common people. She was kindly devoting herself in the social works to put “autism” issue and gained attention from Thai people. She had contributed her own personal fund to establish the foundation called “Khun Poom Foundation” on 14 January B.E. 2548 (2005) in commemorate to the late Khun Poom who was passed away by Tsunami in the previous year. The foundation had official objectives to help disadvantaged autistic children and youth as well as the poor autistic people in Thai society. (attached from <http://www.khunpoom.org> / 2 July 2010)

The remedy of autism in Thailand had commenced in B.E. 2510 (1967) by Doctor Penkhae Limsila, in Yuwaprasat Vitayopadhum Hospital, Samut prakarn Province and the remedies have been improved continuously. During the year, B.E. 2510-2533 (1967-1990), they emphasized on providing remedies for in-patient services only by having the hospital personnel as the main trainers. Until, during the year B.E. 2533-2540 (1990-1997) the emphasis was extended to the parents, by having the parents of autistic children to train their children and tried to stay overnight at the hospital as least as possible, and used one-day return remedy. Then, during the year B.E. 2540-2544 (1997-2001) the hospital expanded the remedies for external people with the method called “group of parental training” as principle (Dusit Likanapichitkul, B.E. 2545).

At present, the autistic remedies in Thailand have been provided both government and private sectors, including the education sector. They all have applied the western medical care with multidisciplinary team: pediatricians, speech trainers, behavioral therapists, and special teachers. They emphasized on improving the development of autistic children until they could learn, work and be independent living in inclusive society. However, this framework was still relied within the medical paradigm as a principle.

Similar to the researches in Thailand, most of the researches were in the medical, nursing and psychological fields which were all in the medical paradigm as a mainstream (Chammak, 2004; Chayamon Boonluk, 2005; Gunvipa Hongngam, 2003; Itchaya Khueanman, 2002; Kannika Permpoonputtana, 2006; Meena Wongsalee, 2005; Nareelak Mongkholsirigul, 2003; On-Siri Pisek, 1999; Panida Srikhachin, 2000;

Patrabul Puttahraksa, 2005; Siratchaya Soichan, 2007; Somjit Pheephimai, 2004; Supapak Phetrasuwan, 2003; Wongdern Tacharin, 2003). The above mentioned researches, partly would take a look at the problem in life of families with autistic children. However, the “culture” aspect was always missing. Also, most of the researches were quantitative studies but the qualitative studies that reflected the living condition and problems of autistic children and their families, were considered very few in the society. Such a research was “Roles of the families in recovering the autistic children in Khon Kaen Province” (Supornnum Mongkolsawadi & Akaraphan Khwunchuen, B.E.2546). This study has shown the way of living of the families with autistic children, and how hard to raise their children, all the difficulties they were facing with all physical, mental and income of the families. Moreover, there was also analysis of the negotiation and power relations of the families and the government sector; the problem in education system; and the policies for the disabled group, etc.

The above mentioned perspectives in the research were based on medical paradigm mostly. For the autism considered as development disorder that was believed as malfunctions of the brain system, thus, the autism was a disease. Such a disease was a representative of biomedical and physiological process. The treatment of autism in this view was based on biomedical paradigm e.g. solving of speech problem, restoring of the learning capabilities, restoring of the social relating abilities, improving the working/careers capabilities, and using psychomedication in some cases that unable to control their behaviors. Although the treatment of autistic children needs to combine several remedies and rehabilitations, this illness was not the only one-sided perspective as it was a network of perspectives. In my experience, I found the cultural belief in the healthcare system was important; as example, the belief in *Bhudism Karma* linked to having autistic child, praying to spiritual things for better conditions or recovering of autism children.

Religious discourse, then, was related to the caregiving for the autistic children. Even though Thai society has been modernized as the western countries, the Thai identity was still deeply related to the cultural belief. Obvious sample of this was that Thai hospitals were constructed in modern form, there were high buildings with modern western medical equipments, and the medical staffs were educated and expertized as in the western society. The difference from the west was every hospital

had 'spirits house' or other kinds of sacred items of the hospital which the medical staff also pay respect to as well as the patients and their families to worship when they come to the hospital. Therefore, no matters how modern the medical treatment is or whether it gives positive or negative responses to the patients, the patients and their families still need to rely on their hope and cultural belief as well as Buddhist teaching to strengthen their minds.

The literature reviews about the Buddhism belief and caregiving for the disabled children, it found that the philosophy of Buddhism had influenced and helped the families to be able to take care of mental illness patients very well. The belief in good karma, bad karma, sin and dhamma words could help the mothers to relief their negative feeling and caring problems. The caregiving in the concept of compassion could help caregivers able to pay attention to the patients, provide assisting and supports to the patients based on Buddhist teaching on mercy kindness, compassionate, 8 Noble paths and detachment. This Dhamma principle helped the families truly accepted the patients as well as accepted the fact that these illness were unable to completely cure, and all illness was natural events, also all the patients have to live their lives as others (Rungreangkulkij & Chesla, 2001)

Based on the studies of disabilities discourse in the context of "compassion" in Isarn (Northeast region) of Thailand (Sethabouppha, 2002), they found that 'compassion' had complex meanings of both positive and negative ways or it had both refused and accepted by disabled person in order to adjust themselves. This meant that the refusing group was the group that did not like getting compassion from others as they had a belief in physical, immanent and metaphysical incompleteness. On the other hand, the accepting group who were able to accept their disabilities. This group showed their understanding of culture and Buddhism philosophy. Interestingly, the results shown the almost of disabled men felt they were excluded from the society. This might come from the reason that value of being male gender as a role of family leader, penetrated through their experiences. While, the severe disabled people who could not take care of themselves and unable to work, often looked at themselves as useless person, feel suffering from being disabilities, were discriminated. Some of them did not like when others feel 'compassion' to them as it seemed like "pitiful" for them. Some others could accept that they deserved to get compassion, accept their

limitation of their own disabilities, this group used the compassion to encourage themselves to do activities and participate in the society. Another study indicated that Buddhist notions of love and compassion (meta and karuna) informed appropriate responses to people with disabilities. Local distinctions of ability and disability informed expression of sympathy and compassion (Songsarn). This implication was useful for the social participation of disabled people (Naemiratch & Manderson, 2009). Therefore, it was clearly seen that Buddhist had important part as philosophy and cultural idealism. It created social construction and attitudes towards Thai disabled people.

For the autistic people, whether the society viewed the autism as disabilities or not, it was the issue to be studied in this research. The meaning of autism in Thailand was how it constructed. According to the hypothesis of this study, the autism should not be defined in the medical perspective only. The study of the experiences of families with autistic persons would provide meaning in other perspectives. Especially, the meaning was embodied with Buddhism and cultural beliefs which were penetrating in its social identity. The family practices in taking care of autistic children in Thai society were unique and different from those in other cultures. Concerning all these issues, there were a plenty rooms for further studies.

2.2 Disabilities in Postmodern Perspective

Postmodern perspective has viewed that naming is important in categorization process. That is naming or medical diagnosis labeled persons into which group of society such as homosexual group, disabled group, criminal group, and mental illness group, etc. All this categorization is a matter of exercising power. The powerful people had authority to make decision in classification process. Autism was categorized in a groups of disabilities, according to *Ministry of Social Development and Human Security*, issue 'Type and Categorization of Disabilities, B.E. 2550' which classified disabilities into 6 groups as follows;

1. Visual Disability
2. Hearing or communicative Disability
3. Locomotor or physical movement Disability

4. Mental and behavioral Disability or Autism
5. Intellectual Disability
6. Learning Disability

The criteria for “Autism disability” are that a person has restriction in routine in activities or social activities as a result from the impairments in social interaction development, language and communication impairments, including behavioral and emotional impairments. The cause of these impairments is from the neurological deficit. The appearances of these symptoms are before two and a half years old. Similar to the diagnosis criteria for other autism spectrum such as Asperger (the definitions according to Ministry’s Announcement of Ministry of Social Development and Human Security, issue ‘Type and Category of Disabilities’ in Government Gazette 29 May, B.E, 2552 Volume 126 Speicla Issue 77Page 2)

As above mentioned, the autism meaning is defined through the explanation of medical model since the medical concept has strong influence in categorization; such as normality / abnormality, abled/disabled, etc. The medical knowledge has power and authority in categorizing. Thus the disability meaning is the constructed knowledge in postmodern perspective. Foucault criticized this issue that we did not often see this power and the knowledge in modern era, since the power or authority was existing everywhere. Power could not give to each other but it was existed where exercising power only (Foucault, 2006). Power is expanded through individuals and the individual has to do self-surveillance all the time. Finally, it becomes an identity and makes ‘a doing’ becomes ‘being’ (Valentine, 2006).

In the modernist concepts, everything must be harmonized, balanced and sameness. If there are abnormal or different things, that things must be eliminated. Otherwise, it has to be adjusted closely to normalcy as much as possible. The medical science has played significant roles in this normalization. For example, there are using the hearing tools, putting artificial organs, using computer in learning assistance, and studying on Chromosomes to prevent disabilities in new born baby, etc. However, the postmodern concepts criticized this issue as the exercising of power since the individual body has been categorized by the experts’ power. The abnormalities or disabilities are metaphor of bodily defects which is the results of bio-power that makes the disabled people become objects by having control of social norms and cultural

idealism. Disabilities are challenging issues in modern era, in terms of developing therapy and inventing new technology for individuals when they were classified in any disability group. However, such a classification is denied in postmodern concept. This concept pointed that the modern concepts focusing on universal standard, so the disabled people were considered different from others and having weaker identity than others. This process was also linked to the power relations. Finally, the weaker qualities of disabled people are seen as ordinary in the society (Abberley, 1987).

In postmodern, the disabilities were social constructed which were given the definition through truth and knowledge under scientific discourses. Medico-legal practices were controlling and making disabilities become common issues (Tremain, 2006). Therefore, naming and framing of disabilities were treated as objects in the knowledge and power contexts. Moreover, there was a reproduction of binary opposition discourse between 'normality' and 'disability' until it became the right thing. Disabled people then were marginal. The society itself tended to ignore the capacity and capability of the disabled people by linking their abilities to the image of impairments. So, the disabled people were devalued their social status and human dignities.

Postmodern concept has criticized the study on disabilities in modernist concept that the belief in truth and all those things had definite qualifications. When society looked at the disabilities in negative view, applying of modernist concept would be unable to see various identities of the disabled people as well as unable to refuse the identity that society provided. That meant, if we viewed the disabled people as a group of people with handicap, unable to work and different from common people. All these views would push away the disabled people to become otherness.

The postmodern concept viewed that the identity were constructed within the power exercising, which the social image of the disabilities that was created negative meaning and less value from the past until now. Each disability discourses were constituted in order to maintain the power's will in each different era. Thus, the postmodern concept had questioned about the normality as social norm. However, the truth was that the discourse had power and knowledge in controlling through the social norms. The discourse also made people thought this was right as universally accepted. The word 'power' by Foucault was not an oppressive power or the violent power, but

the power in controlling things through the norms by having disciplines as the major tools in controlling people to be in the norms. It was also controlling daily details in micro level, then penetrating to human bodies (Foucault, 1981, 2006). Disciplines and regulations then were a new form of power, which Foucault called “anatomy-politics. It had penetrated to manage space, time and body in order for effectiveness in work. The body was under controlled by the politics. Then, the human body was become a docile body (Foucault, 1979).

Considering the body of disabled person, it was not different from the docile body. Disabled people allowed all kinds of power to act over their bodies, accepted being blamed and discriminated as the same as the mad person. Their body was looked unreasonable and dangerous. Thus, they were gazed all the time (Foucault, 1977). In particular, when they got therapeutic treatment in the institutes, they would be gazed of every single movement from the medical treatment team. They could not have their personal life in the very strict schedule. Based on the knowledge, if the patients spent more time in their own world, their symptoms would be more severe. Closely gazing would help preventing dangers as safety protocols towards the patients themselves and other people as well as increasingly effective treatments. Similar to the explanation of Foucault in ‘Panopticon’ which Jeremy Bentham had created in 1787 and it was used as a model pattern for prison, school, hospital and orphanage house. Foucault viewed that Panopticon was a new form of power, which had influenced over mind. Though, the controllers were not in the center of Panopticon, the people who stayed in their room still felt like being gazed all the time. It was the experience of being gazed, in this case shown that **power made a loss of individuality’s identity and penetrated into the individual person.** This meant that whether people were in prison, school, hospital or orphanage house, they would be controlled and surveillanced all the time. This power did not need any tools. It was only used light and sight. Finally, the power seemed like having democracy, actually it was the exercising of power. Therefore, people who were controlled would feel like being gazed all the time, no freedom to do anything. It was necessary to control behaviors by themselves following the expectation of controllers. Moreover, the details of setting, such as the scheduling, were developing techniques of surveillance dramatically. This was complicated and hidden power rather than using power directly (Foucault, 2006).

In self-surveillance, the disabled person was categorized as an impaired body, and unable to work or even take care of themselves. The person tended to agree to what s/he had been categorized into. This understanding was an important tool that a person acting as the representative power in self-surveillance accordingly. For example, a disabled person with spinal cord injuries had to receive the rehabilitation program. There was a provided program to be able to take care themselves, especially about excretion. The disabled person would care the hygiene of the wound. They must often check the pressed areas from their pressure ulcer or bedsore. Such a duty of self-caretaking, it was a tool in controlling a disabled person to surveillance themselves. It was also a reminder for the disabled person that himself had impairments and abnormality (Reeve, 2002).

Power, according to Foucault, was dynamic. Foucault denied the power in concrete terms. Power was existed in everythings. It was not surrounded but come out from everywhere. The power was not with the dominant agent but it was expanded all over through the complexity of social network. The power was carefully exercising through surveillance and recording. Such a practice was able to form the power. Foucault stated that power was something circulated. It was produced at one moment and had an effect later on. The power relation was constituted, reenactment and reproduction over time until the power has maintained.

In Foucault's perspective, there were 2 levels of the knowledge. One was the practice through the political knowledge. Another was the individual knowledge through surveillancing, accepting and recording in order to preserve self-identity by the gazed knowledgement. This individual level knowledge was significantly relating to the population level. It might be seen that the social value and the meanings of disabilities were created by various knowledge. It was practiced via political knowledge and transferred to the social members from one generation to others. This became subconscious and internationalization of people in the society. The transferring of knowledges has become grand narrative that directed people to follow without realizing themselves or having any conditions. For the knowledge at the individual level, the disabled people were trying to maintain them through the practicing of self-surveillance. At the same time, it was gazed by professional agents and kept recording. The disabled people who viewed as the useless people were excluded from social

space. This issue was accepted as the right thing, even the disabled group also suitably accepted for their impaired bodies.

The power of knowledge was able to create the negative value and meanings to the disabled people successfully. However, if there were not something to reproduce the disability discourse, the power would be decreased. Once this happened, there would be a process of normalization in order to keep the discourse exist. Foucault called it as **Technology of Normality which was one techniques of power**. Foucault emphasized that Technology of Normality was a combination of Regime of Bio-power. That meant the technology of normality was used as a tool in creation, classification, and controlling of Anomaly of the body in human society. This technology isolated the anomaly from the society by using various mechanisms (Foucault, 1981). These mechanisms were power, for example, the provision of disability meaning, restoring the capacity of disabled person, or psychotherapy, etc. This made the experts become the important center of power exercising. They exercised power of knowledge to raise awareness and create the individuals' identity.

However, once there was a power, there must always be "*the opposition*" side. The opposition occurred by the doing/acting of dominant agent in forcing the power to be stable in the future. But naturally the subordinate agent would find the way to challenge and struggle against the existence of power, or trying to destroy the covered network little by little. The opposition was existed everywhere in the power network. Once the disabled people did not accept the image or the meaning that society created for them, then they would try to re-define the new meaning through the new self-identity process in order to search for new alternatives for their lives.

The application of Self-Technology was an important technique which made the disabled people, the autistic individuals and the families had their own selfness that was unique and specific. It was not the self that returned to the truth regime as the discourse created. This technique would raise their awareness to realize that their identity occurred from the human strong belief in their created knowledges and combined them into a part of their self identity. Therefore, there were not the truth to search for and to perceive as the selfness created from knowledge and social practice. Once there was no truth about human selfness, the disabled people, the autistic individuals and the families were able to create their selfness from their

understandings in diversity. The sample of self-identity creation of autistic people is the internet community by using communication technology among the groups of autistic people without changing their self-identity to be normal (Bagatell, 2010). Moreover, the technique in using self-technology was also able to create awareness for the disabled people to be free from dominated status. The disabled people had to adjust themselves from the victims to be the actors in Self-Determination Agents. Otherwise, they become Mastery of the self by applying a process of reviewing, inspecting, and considering their previous lives. Then, they realized that their selfness was humanity, not the objects which were acted done.

In conclusion, the postmodern concept has revealed the construction of social meaning and value for the autistic people, who the society categorized as disabilities. It was the matters of exercised power and used knowledge through the process of dividing practice, normality technology, and disciplinary technology. All these technologies were working together until the negative image of disabled people became the regime of truth. Once the regime of truth was established firmly, it made the human being unable to escape from the bondage of power, since it has penetrated everywhere, and every parts of society. This has become undesirable of disabilities, and it has still existed in the society until present. Thus, the postmodern thinkers brought up the deconstruction method to challenge the apocalypse of modernist in order to open up the truth. They opened up new paradigm about the autism to the society by creating a new meaning. Thus, the autism would have their spaces in the society. Moreover, it helped the autistic people and their families to be able to create their self identity in various choices, besides what the society tried to give them. Therefore, the autistic people would be able to live with dignity. Constructioun of the new meaning for them was a new constructed knowledge as well.

2.2.1 Disability and Constructed Meaning

Disability was not only the meaning of the physical impairment such as visual impairment, hearing impairment, intellectual impairment or locomotor impairment, etc. The disabilities had many more meanings. For example, some societies defined a blind as a person with special power, who could tell the fortune. Some cultures in Africa gave a definition to a new born disabled child as a special

person whom everyone had to respect to. While in some western societies, the disabled people were viewed as the impairment and self care deficit as the encumbrance of the society. We would see that each social culture had given meanings to disability differently. That was because the disability was a matter of power, controlling, struggling in the different levels from individual, family, community, society to the country level. Therefore, in order to visualize a clear image of disability construction, I would like to present as follows;

- (1) Meaning of disability in the socioculture construction
- (2) Meaning of disability in the historical context

(1) Meaning of disability in the socioculture construction

Physical body was treated as an object in socio-cultural construction; the human body was not only real existed physically but also real existed socially and culturally. On the other hand, it might be said that the physical body was socioculturally constructed by given meanings via different discourse, image and reaction in each society. Modern society emphasized on the disability's meaning in relation with the social aspect, cultural identifying, explanation or division between normality and abnormality, or between able/disable body.

For example, in the culture of Punan Hah tribe, a small race in the Central Borneo in Malaysia, they believed that the disabled new born were caused by the parents. According to their belief, the father was the creator of a child and the mother was a fortune definer for a child. So, both of them had to take responsibility together. Except the case of a blind baby which was blamed on the mother only. It was believed that the mother had sexual intercourse with the father or with the other man while she was pregnant. As it was like a sword stabbing and affected to the baby's eyes. Besides, the disability concept was referred to the spiritual belief. The congenital disabled child was occupied by non-human spirit and not their ancestor spirit. So the child looked like devil and had no status as a human being. As well as, the children at age less than 6 months have not got a social status, which were luminal people. After 6 months old, their ancestors' spirits may come to live in the children. Their families would give those names and accept them as a new member of society. At that time, the children

would be accepted from the society as personhood and human being (Nicolaisen, 1995).

In the middle class culture in America, the disabled people were practiced as if they are invisible and shall not be talked about. The children were taught not to look at the disabled people or mention about their impairments. Therefore, it seemed like they were not existed and invisible. This meant people had the hatred of disability which unlike the racism bias, but they became afraid of those disabilities to be happened with them too (R. Murphy, 1995). For example, an 8 years old European girl in Conakry had met the disabled man who had no nose from Leprosy. That little girl stared at him in shocked and had wordless. After that she walked away with scared and touched at her nose to check if it was still there. Similar situation in the story of a man without a nose in *Stigma: Notes on the Management of Spoiled Identity* (Goffman, 1963) which shown the sufferings from having no nose and facing difficulties when meet other people, or feeling so deeply hurt everytime he saw himself in the mirror, etc.

In America, The disabled people were viewed as double self-image. First image was the person who got illness and had impairment. Another image was the person who was the citizen and having equal right as others (Benedicte Ingstad & Whyte, 1995). The disabled people felt ambiguity, especially when were invisible in society. Whereas, they had to preserve their images as equal citizen and pretend as not having impairment. This concept viewed the disabled people as deviance disavowal. They became otherness (Davis, 1961). For example, the person with spinal cord injuries lost their social status. They were viewed as a contaminated or dirty person who had been staying in wheelchair. The disabled people in America would feel devalued and were excluded from their society.

Disabled people were considered as having uncertain status or liminal people. They became marginality. Although, they attempted to join in the society, they were still outsiders. This seemed like the transition period of life from children to be adults, but still they were not became adults. They lost their roles and still did not acquire the new roles in the new society. The disabled people as well, they were fallen into the ambiguous status, and had to face with the difficulties and hardships in limited

living. They also were deprived from the economics and opportunities to be successful in their careers (R. Murphy, 1995). This social limitation was a cultural symbol.

The disabled people were deprived their human dignity all over the world. This made the disabled people looked negative at themselves and created negative identity. The groups which often have been devalued are the minority group, race group, mad people, and disabled people. They had to struggle and tried to be survived with the negative image (Goffman, 1963). They faced the difficulties in living, which was not from their impairment but from the Myth, fearness and misunderstood of the people in society towards them.

The disability, then, was socially constructed and social provided meanings. In the other word, it was the social constructed meaning. The meaning was defined without being on the logical basis but it was defined through the subjective of the majority group. Thus, disability was interpreted and various given meanings in local community. In Thai society, when the autism was categorized as disabilities, one thing that needed to find out was the meaning of “autism” whether it was disability or not. It was also necessary to find out how the disability and autism related more or less and how they were related in Thai society, what was the symbolic value of the word “autism” in Thai socio- culture, how was the myth about it, and how it affected to the livings of families with autistic children.

(2) Meaning of disability in the historical contexts

“Disability” was given meanings differently in each historical period. To investigate the history of disability in order to look into the origin of the established knowledge in each period, we found the source and complexity of meaning construction and negative value for the disabled people in each historical era. Then, the provided definition for disability was a relation between the knowledge system and exercised power. The form of power had been exercising in producing knowledge and truth. It was also practicing discourse of knowledge. Such a discourse was based on a political history of truth that linked all kinds of power together. Therefore, the knowledge, the truth and the power were related to each others and hardly to be separated (Foucault, 2006).

Ancient Greek Era

Greek Era, there was firstly using of the logics in explaining about various *phenomena*. This was a change from explaining thing based on supernatural things to humanity. The people used to believe that illness were caused from spiritual ghosts or the past ancestors rather than the natural basis or humanity basis. It was because of the fundamental of philosophy in this era turned to pay attention to individual person or to humanity rather than supernatural things. There were criticizes of original mythical power of the Gods. This era emphasised on the good merit and moral according to the theory of Excellence of Aristotle. It valued the person according to their *good deeds and moral* in the way of value as human being, subhuman or superhuman. The constructed meaning of disability, then, was linked both the original belief, moral decency in the same way as defining the beautiful people who had good shapes, image and having moral too.

The meaning of disability in Greek Era, the cause of the blind and the deaf was their sin or their ancestor's sin. The deaf and the blind, then, were looked as the person who had no moral and were banished from the society. However, in the case of become deaf or blind from the war, the meaning of disability was different. There was a value added to such people as they were respectful ones and they would be treated specially, including having an extra money support as pension and allowance. For the psychological impairment or mental disability, the Greek saw them as people who had supernatural power and gained respects from people as well as could participate in community events like other common people could. For the baby with disability or deformed infant, they were classified as useless group and would not receive any special care. Once they were nearly dead, people let them die in order to have only perfect people as the population for the security reasons of the states and the nation (Depoy & Gilson, 2004).

After Greek Era, it was Roman Era which some believes had been carried on from Greek and further transferred to Roman Kingdom. For example, any families with disabled infant, the Romans would throw away the baby into the river as they thought that these babies were useless. For the other disabilities such as dwarves, blinds, deafs were forced to fight with women or wild animals for entertainment reason of the Romans.

Middle Age Era

Middle Age Era was the period of preoccupation by religion. Paradigm of many discourses in this period was all in a moral paradigm and a moral decency according to Christianity which occupied the era more than 1,000 years (B.C. 400-1400). For example, Leprosy, a major problem, was looked as the punishment from God. As the Leprosy patients were considered the sinners, they needed to be imprisoned (Foucault, 1977). In the case of the persons with strange behaviors, spoke or thought differently from other common people, they were looked as the witches and would be burnt as they were enemies to the religion.

For the disability meaning in this era, it was still based on the norms and the religious belief and the preaching of many religions such as Judaism considered disability as a sin, no purity and was the dirtiness in the religion. So the disabled people were not allowed to join in the religious ceremonies. Same as the belief of Jewish in this era that the disabled people were sin people who did wrong to God or God punished them, etc. In the perspective of Christianity, the disabled people were devils with sins and dangerous, they deserved to be burnt in fire or dead sentence. Especially, those who had deformed body, if they were let alive they would be harmful to others as they were believed as the devil. They had to be under controlled of the priests. For the intellectual disorders or retards, they were believed as the souls and the special gifts from God, so they were able to live with other common people in the society (Depoy & Gilson, 2004). The mental illness or mad people in this era were considered as evils, scarely and dangerous. The management of the madness in this era was not in the medical way, but by the traditional practicing of putting the mad people in the ships and banished to other countries called Ship of Fools (Foucault, 1977).

The religious belief and the political contexts were important factors in defining the meaning of disability types, and considered which types of them was a sin, disgusting, had to be cursed or be flouted and looked down and which types of disability were considered poor and needed helps. In the disgusting types or scarely types, they would not be taken care of. Therefore, it was common to see that the illness or locomotor disability including blinds and deafs were often happened in the poor. As the researchers suspected that the poor people lacked of opportunities to access the information of disease and had food shortage and the family had not enough

money to take care of these disabled people in term of supporting long-term care. They tended to let go their lives with destiny. So the blinds and deafs had to be beggars for their survival (Depoy & Gilson, 2004).

Age of Enlightenment Era

Come to the era that human beings believed in their own intellectual. They would be able to know and have insights in fleasibility of existences. And they can possibly to explain all phenomena by logical thinking base on scientific knowledge. This belief affected to the social practice towards the disabilities. The practices changed from the religious belief to the medical remedy more and more as it was the rational science. Including the concept of the strange behavioral person who spoke and thought differently, looked scarely and value deducted, they need extra strict remedy in the institutes.

Giving meaning for the disability, the disabled new born with deformity were looked like the ugly demons and had to live in the poorhouse. But for those who had deformity later in their life from many other reasons, the society tended to accept and respect them. So they were able to live in the community with others. For the intellectual disabled people or retards, the society accepted them but not paying respect to them. However, this group of disability could be able interactive with others in the society (Depoy & Gilson, 2004).

For mental disability or madness, it was established as “non-rational” issue so they had no space in the rational world. Since the mid 17-18 century become the rationalism era as well as the era of economic crisis. The mechanism of confinement had been brough up. At that time, the criminals, poor people, the beggars, the unemployers, the ill people, the elderly and the mad people were all imprisoned in the same places where the government detention places were. During the year 1656-1774, there were the constructions of Hospital General in order to capture the mad people in Bicetre. At that time, Hospital General was not a normal hospital but it was mixture between a prison and workplace to control people. Controlling people in that period was not fallen into the religious discourse about sin and god’s power, but it was the discourse in related with the established value of the wealthy people who were merchants, investors, bankers. The reason for controlling or capturing of people here

was to create works and workers at the low cost. The investors would inspect, surveillance, and arrest the people who became lazy by reason of moral morking (Foucault, 1977). It might be seen that, although this era the behaviors would be considered based on rational, the disability meaning was still relied on the religious belief which adjusted the value judgement and legitimate in the society. This meant that if the people in society were difined as valued ones though they had strange behaviors, or some people were evaluated as non-dangerous people, they would be accepted and taken care from the society. If the people were called bad or mad people they would not get any assistance and need to be controlled in place so that they would do no harms to others.

Modern Era

Victoria era, all matters or phenomena were identified from the government state power at most, including how people dressed, gender status, the traditional practices, etc. The elderly was viewed in negative way, as weak and not healthy, they were often looked down from the society. The society also separated them out and put them to live in poorhouse. Whereas, the poor people, and ill ones were related to gender, race and nationality which were explained as weakness, being looked down, flauted and separated out to live in the poorhouse as well. The disabled people with deformity, since they were born or later on, were considered abnormal and put in the lower status. Espesilly, the disabled new born were looked as disgusting and had to live in the institutions. However, those with disability in later life, such as from the war, the society would pay respect and understand that they could be able to work and possible to live in the society. In case of the mad people or strange behavioral group who spoke or thought different from others, were also classified as abnormal and be in lower status, nobody paid respect to them and they were needed to get remedy from the institutes (Depoy & Gilson, 2004).

In the 19th Century, the medical science was very highly developed. The mental disability or madness became an illness. In previous era, they would be imprisoned together with the unemployed people and beggars, until this modern era the unemployed people and beggars were not jailed, only the mad people were sent to the psychiatric hospital or called Asylum. They would gain the moral remedy based

on the idea of Phillip Pinel. Foucault viewed this issue that the remedy was related to political as a form of controlling in the reasonable way. This era, the concept of individualism had highly influenced, the mad people needed to take their responsibility and to be punished from their madness. This way was pushing away the madness to the patients which Foucault identified that the moral remedy was not considered humanity or mankind at all. It was only changing a form of controlling from violent control to a daily life control system, and if they did not follow the system, they would also be punished anyway (Foucault, 1977).

In the modern era, construction of 'disability' was universally perceived and understood. This word was not used in the earlier period. The disabled people were called the name following their appearances of the characters such as blind, deaf, having leg or arm amputated for example (Depoy & Gilson, 2004). The Creation of universal meaning as such was a reflection to the practices towards the disabled people which was different depending on the religious belief, and then it became the same belief and meaning as "disability" or "impairment". These words were globally explained under the same will and led to creation of regulations and rules. The purpose of the rule was to separate the abnormal people from the normal people. The regulations of practices were different. For example, the disabled people were separated, limited to the opportunity, excluded, looked down, and be stigmatized as worthless person. Finally, these disabled people had limited space in the society.

It was obviously seen that, the constructed meaning of disability in each era had related to power and legitimization in the society. The power was hidden in ideology until became politics and culture that governed the body of the disabled people. Although there were more rational/logical thinking in the modern era, the image and meaning toward the disabled people was still in the negative way. The negative meaning was reproduced and maintained from the past until now. It had not been changed. It was only using more modern sciences in replacement of the knowledge in classical era. In the other meanings, modern society had been enlightening thought and social response toward disabled people more sophisticated, and prospered than in the past. The knowledge was constructed through sub-special sciences. With basic belief, the human had responsibility to find the truth about the nature. Human would be able to control all kinds of things following the willingness

of the knowledge creators (Foucault, 1972). Therefore, the constructed meaning of disability or the lives of disabled people was still preoccupied by ideology of majority people and still existed in the same way.

In conclusion, the postmodern concept is applied in this research study. It would help us seeing the power and knowledge over the body of the families and autistic people. The power and knowledge worked through the technology of classification, which classified autism as disability. It also worked through normalization technique, as seen in self-surveillance during pregnancy. However, once the new born baby was happened to be impairment and being called a disabled child, the families would try to struggle by searching for remedies to help their child better as much as possible. Unfortunately, they have to face with the medical system and the education system that work together for the business purposes. Moreover, the knowledge causes and remedies about autism are still in the grey area. These affected the family and autistic children became an experimenting body. Thus, it is not different from the docile body like a programmed robot following the steps of treatment. For example, they had to take their children to check their development, inspect their hearing, training speech and studying in the special program. They had to take their children to get the remedies with new technology. All these kinds of things have been done without questions as the faith for medical system and legitimization. Moreover, all discourses have been produced in supporting the medical power such as perfectness discourse, karma belief discourse, and disability discourse, etc. Therefore, the applying of the postmodern concept encourages the questioning towards what happening and turnback to look at selfhood of family. The families have struggled to negotiate the power so that the society would see their value as human being and stop excluding the autism to the marginality.

2.3 The Phenomenological Approach

The phenomenological approach is the main framework used here to access the reality of autistic individuals and their families. Hence, phenomenological epistemology and the study of experience in phenomenology (especially the concepts

of embodiment and intersubjectivity) are reviewed here to better understand the experiences and perceptions of autistic individuals and their families.

Phenomenological studies focus on how people perceive and experience the world. In this approach, it is not necessary to separate experience and cognition. In phenomenology, it is held that people do not have access to objective reality; experience is always colored by the lens through which it is observed. Phenomenologists believe that the elements of an individual's subjective reality cannot be viewed in isolation. Reality is what we learn from our experience; how they are being and meaning (Jackson, 1996). Research questions posed within this approach tend to deal with individuals' subjective experience and feelings. They tend to focus on previously unstudied areas. Phenomenological studies neither seek causal explanations nor attempt to establish relationships between variables. Rather, the research question tends to focus on "what kind of structure and essence does the phenomenon have, as experienced by the population studied?" (Chai Pothisita, 2550).

Phenomenological studies thus examine one aspect of the world without using the researcher's point of view or cultural standpoint to explain the phenomenon. The researcher will not attempt to stay outside or above the situation but to enter it. However, academics have a tendency to prioritize scientific knowledge over other kinds of knowledge. This is an important pitfall to watch out for, because the phenomenological theory rejects positioning oneself above the studied individuals' lived experience.

Phenomenology as epistemology

Phenomenology traces its roots back to the study of human consciousness by the German philosopher Edmund H. Husserl (1859-1938), who has thus been called the father of modern phenomenology. Husserl viewed that the essence of phenomenology was the focus on thoughts and feelings about the world, together forming conscious experience. He viewed that it is the human mind that creates meaning, unlike empiricism, which believes that objects by themselves create meaning and human beings merely respond to it. Husserl used the term *lifeworld* in *The Crisis of European Sciences and Transcendental Phenomenology* around 1934-1937. At this time, the crisis brought about by Nazism in Europe caused widespread disenchantment

with scientific reason; a need for something more was in the air. What was needed was an open-minded philosophy that could meet the needs of humankind. Husserl viewed that the lifeworld was above theoretical explanation and elucidated on the difference between explanatory models of empirical science and of everyday life. He asked the critical question if the practice of classical empiricists to distance themselves from the people they studied could really deliver certain and consistent knowledge (Jackson, 1996). Phenomenology took issue to critique positivism.

Alfred Schutz (1899-1959) expanded on Husserl's ideas and laid the foundations of phenomenology in the social sciences. He blended in the sociological ideas of Weber in analyzing everyday consciousness, viewing that it is not possible to separate oneself from thoughts and objects as the world of everyday life is constructed intersubjectively. Thus, he thought that objective science was an unattainable ideal. Bracketing is an important technique in helping us to understand our own consciousness and how we construct our world. Schutz's most important work, *The Phenomenology of the Social World*, was a treatise on developing the concept of lifeworld, shared perception (typification), and on the meaning of human action in society, as understood by the actor, not the researcher. Shared understandings or perceptions thus form the frame or standard by which people-in-society interpret the world around them; these interpretations become so ingrained they are taken for granted and form a part of everyday life. Schutz emphasized "unique biographical situations and stock knowledge."

Maurice Merleau-Ponty attained fame as a writer and phenomenological anthropologist. He expanded on the role of the body in the study of human perception. In a departure from Husserl, he did not believe that it is possible to access reality through the practice of bracketing; rather, he viewed that knowledge exists in a social, cultural and historical context. This argument is well-known among anthropologists and not particularly problematic. Yet, Merleau-Ponty's ultimate aim was to access pre-reflective experience to understand things as they really are (Knibbe & Versteeg, 2008). He took issue with the philosophy of positivism as espoused within science by accusing it of over-emphasis on the concrete; he also critiqued science itself by attempting to explain everything in terms of cause-and-effect mechanics. These considerations made phenomenological anthropology widespread.

Phenomenology and the study of experience

Phenomenological studies focus on the experience and subjective values of the individuals studied; it is necessary to understand the subjectivity of human beings as actors because these play a role in defining experience and interpreting “objective reality.” This is necessary for understanding how human actions are shaped, what kind of experiences individuals have, and how they interpret objective reality. The study of experience in anthropology does not only aim at capturing experience but also at giving access to the experiential meaning.

Meaning in the experience is different from symbolic interpretation. Desjarlais explained that to analyze symbol was as seeing the (Meme) therapist’s body with text and symbol. But Meme not only “has” a body, but “is” a body with feelings, tasting, expressing and memorizing. To consider the experience of ‘Meme’(therapist) would be seen ego and consciousness of the villagers and their sphere of life. These were sensory experience. Thus, Phenomenological study is not only studying about discourse, symbol, or practice, but internalizing in sense of pain (R. R. Desjarlais, 1992). With this method, the experience meaning in phenomenological sense would be attained.

To access experiential meanings, it is necessary to understand the issue of embodiment of experience. According to Csordas (2002), embodiment is an anthropological paradigm in the study of culture and the self. In this paradigm, the body is not viewed as a research object that relates to culture, but rather, it is necessary to consider the body as a subject of culture or as situated within a culture.

The term embodiment was influenced by Mauss, who believed that all human beings have both a spiritual and a corporal sense. Mauss viewed the body as the point of union between the cognitive world as envisaged by Spinoza, and the objective, material world as described by Descartes. Thereby, an important aim with the concept of embodiment is collapsing the mind/body and subject/object dualities (Csordas, 2002).

Embodiment covers both perception and practice. Perception is here defined in the sense Maurice Merleau-Ponty called “a concept of preobject”, while “practice” follows Bourdieu’s view known as “habitus concept of preobject”, which

means that in our perceiving experience, we do not have an object before we perceive it. The object is a product of our reflective thought; perceiving begins within the body, which interacts with the world. Consciousness means the body's reflection of itself on the world.

The term "habitus" in Bourdieu's sense refers to the structure of thinking needed for managing everyday life. Habitus does not emerge from society alone, because a human being interacts with external structures. Thus, there are processes of internalizing social structures as structures of one's habitus through practice. Habitus thus blends external society with the nature of the human body. Bourdieu focused on the human body as an important element in learning practice. The creation of one's habitus begins in childhood. Children's learning begins in the home where they grow up. When they continuously imitate their parents' actions for long periods of time, it internalizes the structure of external practices as a part of their body. This internalization is known as embodiment.

Habitus is not a stable structure, but rather, it is transposable. For example, children who play a musical instrument from an early age, gain acceptance within their social class, and also possess the ability to perform in other social spaces. This appears to be a natural talent, a gift, but really, it is the product of accumulated learning, whereby it is not possible to pinpoint exactly which period of the child's past the learning took place, not even for the child itself, who remains unconscious of such matters. A habitus will also change. It will accumulate based on experiences of practice, but it will retain its structure. Habitus is a structure existing within the body, based on bodily learning inscribed on the body to the point it becomes a disposition. It contains elements like emotions, feelings, beliefs, beliefs and expressions, such as gaze, facial expressions, mannerisms, the way we walk or stand, our tone of voice, the way we speak, and so on. These elements can be used to categorize individuals into distinct social classes – for example, "proper people" versus "tasteless people." One's expressions also reproduce external social structures, for example femininity, masculinity or poverty. Hence, one's habitus is also not the product of the body alone, but also of society: People under the same social structures or same social conditions will develop a similar habitus. In particular, people in the same social class will resemble each other more than people of different classes. People of the same class

practice in similar ways; they have similar shared experiences within their group, as well as similar individual experiences. For this reason, they also have similar emotions and feelings, attitudes and beliefs, as well as actions and lifestyles (Bourdieu, 1995).

Given the central place of the concept of “preobject” in perception and practice, unified in a habitus, the concept of embodiment as used by Csordas does not refer to mere absorption of experience, but when experience is absorbed or embodied, it also affects practice. Csordas has used this conceptual system to explain charismatic healing systems among Christian groups, whereby a language of control and release is used in different stages of the process of exorcism or driving out devils from the body. It is believed that when a body is not properly controlled, an evil spirit can become embodied in it. However, with the power of God, control of the body can be re-established. In this sense, faith in God involves objectification of the body. The resulting somatic image is an embodiment of the surrounding religious milieu and can involve experiences of the body feeling hot, heavy, or twitching. In another example of embodiment and subjectivity, a patient with a tumor in their brain received healing whereby a healer laid their hands on the patient’s head and imagined the tumor was shrinking. Whereas the tumor actually did not shrink, the patient’s faith made it feel like it did shrink. Csordas explained that tactile and visual modalities are conduits of embodiment and make an individual feel like they have a really existing self within their culture. The result is not just an inter-sensory constitution or interconnection between bodies through imagination, but construction of intersubjective imagination between the patient and the healer (Csordas, 2002).

The Phenomenological Epoche

The phenomenological epoche is a phenomenological method used by Husserl to access the reality of human consciousness. It is not the same thing as deconstruction, but refers to description of actual experience. As a method, it refers to placing oneself in brackets to access the reality of conscious experience.

It is not an empiricist point of view based on reduction of experience into antecedent conditions, biogenic determinations, or unconscious principles. It does not mean that human experience does not have preconditions, but that it is not completely determined by the preconditions. The phenomenological epochs entails shifting from

causes to consequences. Phenomenologist suspends inquiry into the hidden determinants of belief and action in order to explain implication, intention and effect of what people say and hold to be true. Merleau-Ponty viewed that this method explains what the surrounding world is like, what kinds of practices are engaged in, and remade with others. In this sense, the truth is seen; not as an intrinsic and static beliefs or naïve symbolic analysis; rather it's happened in the activated belief or realized in the lifeworld (Jackson, 1996: 11). For example, the notions of the Kuranko people about witchcraft do not constitute reality for people who do not use or believe in such notions. These beliefs cannot be easily understood as a product of tension in their social system, or as stereotypes. What needs detailed consideration is – what exactly do they believe? For example, a woman with terminal illness with no hope of recovery may confess that she is a witch. Such a confession is not just acceptance of one's bad luck, but it also involves imagination that being a witch means managing one's longstanding suffering or sadness. Being a witch can also mean expressing a controlled and pressured role as well as indicating that the body exists within an unjust world and that one's death means making a decision on one's destiny while concealing one's fate (Jackson, 1996; 11-12) Likewise, those who study rituals or religious healing cannot understand the meaning of the thing they study unless they have participated in the ritual or had shared experience of it (Knibbe & Versteeg, 2008).

The phenomenological turn prepares in discussing the details of what kinds of experience people have in their time, space and world. Facts in natural science constitute objective reality that is human experience, assuming the veracity of concepts like objectivity, cause, essence and authority. However, in phenomenological work these are replaced by beliefs and constituents known as “subjective reality”. Phenomenologist uses conditions belief, not logic. In fact, people intend to absolute authority and objective knowledge but when they face a crisis, beliefs are a necessary tool and existentially true; because they are able to increase the person's control of their life. For example, people still use allopathic medicine, though magical and homeopathic treatments might have an efficacy of only 25-50%. Another example, the treatment for Kuranko divination, consulting diviners and accepting the truth can help these people clarify his or her situation and reduce their anxiety (ibid: 13).

The phenomenological epoche thus consists of explaining individuals' experiential realities, or their various experiences of reality. In anthropology, this is considered practical relativism that seeks the knowledge in the objective truth of belief, tradition in order to analyze the things as experience. It is a research method adjusted from finding causes to consequences. This method focuses on finding the underlying conditions that determine beliefs and behavior to explain people's practices, intention and solutions, but not reduce to conditions or factors; such as in psychological theory that reduces experience to mere compensation and sublimation (Knibbe & Versteeg, 2008). The reality is not static belief, but reality is what happens to belief when it is activated and considered in real life. Thus, phenomenologists legitimate the people's faith, not indicate your idea as a centre. Thus, in the phenomenological view, anthropologists have to consider in detail **how beliefs are utilized.**

Intersubjectivity

Intersubjectivity is an important matter in phenomenological anthropology as it is critical for understanding the life-worlds of the studied people – how they feel and how they express themselves. Some researchers understand it straight away just by being fellow human beings, but some cannot do so. However, we can learn by becoming an insider and through participation in the research subjects' lifeworld – becoming a skilled researcher through learning and practice, as in the case of Thomas Ots, Desjerlais, or Paul Stoller. In fieldwork, researchers construct knowledge from interactions with people on the field. What is constructed is neither objective nor purely subjective, but intersubjective (Knibbe & Versteeg, 2008). In phenomenology, one must understand intersubjectivity, which more than just understands the words used to communicate, or considering them symbols and interpreting them.

“Apprenticeship” refers to coming to terms with what really happens through participating in the situation. For example, it would be better to join in a prayer than to record the contents of the prayer, even though as a cultural outsider, one would not be able to understand the practices of those in the culture being studied. This is because these things are a matter of embodied habitus. Sometimes the researcher might feel alienated, but nevertheless fieldworkers should try to learn how

to share basic experiences with those they study – how they feel, what they do and how they appreciate their life. There are no two individuals with exactly the same experiences. For example, five parents having children with disabilities would not have the same experiences. In Versteeg's work, upon joining in a ceremony at a church in Vineyard, he did not have bodily sensations as others even though he had the same background. This simply means that we can share some, but not all, things with others in the same context. This is because we cannot have experience as cultural producers of meaning. Finally, phenomenological interpretation results from shared experience – there might be conflict, but it will nevertheless be the way to understanding the meaning of “what they are” (Knibbe & Versteeg, 2008).

Using phenomenology in studying the experiences of families with autistic members will help to understand the interweaving of body, mind and social world. Although this study mainly uses postmodern anthropological perspectives in interpreting disability, to understand the realities embodied in the bodies of individuals, phenomenological approaches are necessary (Lock & Scheper-Hughes, 1990). Really, bodies cannot be divorced from social life – in other words, medical discourses, whether of diagnosis, treatment, medical technology, and sociocultural discourses, like the belief in karma or social criteria of normality of individual bodies, which determine the symbolic value of autistic individuals, they all are a part of life, all elements of a web of meanings that form a part of the experiences of families with autistic members.

Using phenomenology helps to create understanding about the meaning of present realities. Meaning here does not refer to symbolic interpretation, but to a researcher understanding the meaning of the ways in which the studied individuals perceive and behave, as an insider. By being a part of each situation, the researcher will learn and feel how others feel. By sharing their practices, the researcher will understand why the family lives the way they do, and why their life-worlds are the way they are. Understanding how they feel and express themselves constitutes intersubjectivity between the researcher and the studied families. Processes of empathy based on faith in the experience shared by both parties are also required – they help us to know how those we study feel in the situation they are in (R. R. Desjarlais, 1992).

Processes of empathy will help to understand the feelings of families about the sensory experience of person with autism, especially about those who cannot speak. For example, how will the family know if the child is ill, has headache or stomach-ache? How will they prevent temper tantrums? The expressions of families depend on how they are perceived and interpreted. For example, behaviors like wrapping oneself in a blanket or hiding in a corner are explained by physicians as signs of abnormality in a child that prefers to withdraw in its own private world rather than interact with others, while autistic individuals who are more or less able to communicate have explained that such behaviors are relaxing (Classen, 2005). Thus, by living with autistic individuals, families will gain a deep understanding about the behaviors of autistic family members – these kinds of things are the kinds of experiences that must be studied about families with autistic members.

The life experiences of families with autistic members are constructed. For example, the belief in karma and the cycle of life and death can from one angle be considered a belief that underlines disability and increases biased views about it, but some families might experience the matter differently: Accepting that one's child was born with a disability, as a matter determined by dhamma, can be cathartic – it means that the parents will not need to desperately try to find a cure but learn to live with the shortcomings of their autistic child. The ways of nurturing the autistic children are different in each family; depending on their embedded experience. The first family will be in for a struggle with social stereotypes and may join in campaigns to bring about positive change in social values. Or, the family might be caught in the whirlpool of treatments and go along with anything to rid the child of its “disability.” The other family's experience and way of life might be characterized by acceptance and the absence of “struggle” with “disability.” This acceptance might make the family happy, which the autistic family member would also perceive. The world is really perceived through a lens. That the second family does struggle does not mean that they “do not cooperate with treatment protocols” as physicians might see it, but it might be due to a dhammic reasoning embodied in the family. Thus, the lifeworlds of families with autistic members have complex sensory experience. Families' practices have different meanings, and phenomenology helps to see these concealed meanings. This perspective also enables one to understand aesthetic life, to understand the value of

complicated lives and to deeply understand their sensory perception (R. R. Desjarlais, 1992, 2003).

CHAPTER III

RESEARCH METHODOLOGY

This qualitative research study used the conceptual framework of disabilities in the postmodern as well as Phenomenology as guidance in comprehending the life experience of autism families. The purpose of the study was to answer the question that how the families with autistic children learned to live together and how they spent their lives. In particular, their lives were under the control of autistic medical care and the social value of ableism and perfection. The social myth that held negative attitudes towards being disable person had overseen these autism families. Therefore, I chose the Phenomenology method to analyse the autistic meanings through life experiences of the families with autistic children. Since the Phenomenology method gave the signifances to the construction process and given meanings to everyday life experiences through the actor's point of views. This method helps creating an understanding of the experience of reality, not only considering phenomenons as the external factors. For example, the cultural belief is not interpreted as the belief system or as the external factor, but such a belief is looked through to search for its meaning in term of knowledge. Given meaning through life experience is not relied on one or another's cultural belief as a principle.

Applying Phenomenology in studying of the experience, I emphasized on intersubjectivity with the families with autistic children. Since I have had my own experience of having an autistic child for 13 years, the advantage was that I could learn the other families' experiences as an inner person. Being the inner person helped me understood and perceived the life experience of autistic people and their family very well. However, there also might be the disadvantage that I possibly used my knowledge, thinking and feeling as principle in judging the experience meanings of others. This weak point needed to be more precaution. However, using the intersubjectivity would help me to access the phenomenons and absorb the life experiences deeply. I also realized the value of the family's experience which made me understood the families' experience with autistic children in the individual level.

Such the understanding connected with the meaning and value of “autism and disability” in Thai socioculture. Also, it related to the experiences which the families and autistic children had to face in their everyday life.

Part I: Ethnographic Settings

Ethnography is a study to understand life and culture of people in specific society. The study has been deeply focusing on fieldwork. The key tool is called Participant Observation. The researcher must be immersed themselves into the key informants' culture in order to absorb and understand their lifestyle (Chai Posithita, 2550, p. 155). Even this study is in the mainstream of scientific knowledge and I am a clinical personal. Many of informants may question whether they can disclose non scientific data or not? As the facts that some data would be regarded as non-scientific and nonsense; I has concerned about this point and do respect any idea and information from their informants. I gave them freedom to provide some information beyond the scientific reasons. I have used same principles to Scheper-Hughes (1992) who had suggested for anthropological studies as followed:

The " Enlightenment "with its universal and absolute notions of truth and reason, may be seen as a grand pretext for exploitation and violence and for the expansion of Western culture. Ideally, anthropology should try to liberate truth from its Western cultural presuppositions." (Ibid;24).

Moreover the role of Participant Observation, I had not entered to the fieldwork as an invisible or third person, but I joined some activities, discussion about conflict with the key informants. I have agreed with Scheper-Hughes, stated that Anthropologist could not get rid of themselves from their own culture (Scheper-Hughes, 1992).

“The anthropologist is an instrument of cultural translation that is necessarily flawed and biased. We cannot rid ourselves of the culture self we bring with us into the field any more than we can disown the eyes, ears, and skin through which we take in our intuitive perceptions about the new and strange world we have entered.” (ibid: 28)

Entering to the field

My fieldwork had been set at the special education school and the home of children with autism in Lopburi and Singburi provinces. It is my homeland and I have familiar with the environment, social and cultural as well. Lopburi and Singburi provinces located at the central of Thailand. There are Lopburi River and Pasak River flowing through the Lopburi Province. Sing Buri is located in the flat river plain of the Chao Phraya river. Most people are Buddhists. The villagers living in rural areas work as rice or corn farmers. Whereas, people living in urban areas, work as factorial employee and merchant. During the data collection period, there were Mega flood on Oct - Dec 2011, therefore I could not access in certain areas of the fieldwork. The special education school had been closed and converted into accommodation for the flood victims. This research period has been taken for 18 months (Jan 2011-Jun 2012).

The study has been setting in Banjongsang School (alias name) which is the special education school on 'Center of special education region 6 Lopburi' with service covering 6 provinces: Lopburi, Saraburi, Singburi, Chai Nat, Nakhon Sawan and Phetchabun. The school has been provided the students into two groups: 260 intellectually impaired students and 36 autistic students. The students with intellectual impairment usually called "Dek Punya. This group has studied from kindergarten through Grade 12. For another group, the autistic students usually called "Dek Aoo" with 4 classroom settings: 9 students in Grade1, 10 students in Grade4, 6 students in Grade5 and 7 students in Grade6. The remaining of four autistic students with better functioning has been studying with the intellectual impaired group. At the end of the school year, every autistic student is still studying in the same room but could move to the higher grade. Although an Individual Education Program (IEP) is applying, we cannot assume the student ability from their grade level. For example, some students on Grade 5 still cannot speak while student at Grade 1 may start to learn alphabet.

This school is like a second home for those students. They have spent most of their life time in school. Many of them usually stay in the school dormitory and visit their home every 2 weeks or 4 weeks. Only a few students can go back home every day. The assistant director of the school argued that students did not return back home every day because most of their families were poor and living in rural areas, lacking of transportation expense. The school had to provide reimbursement for them

200 bahts per time. In this fieldwork, I planned to use the method of participant observation with autistic students. When they returned back home, I would study their living at home in Lopburi and Singburi provinces with the methods of in-depth interview and participant observation.

On the first day, I took my son to join a queue and greeted a class teacher I previously knew. After that, I introduced myself to a school deputy director and informed him about my research objectives. I also sent a school director a letter of the Human Research Ethical Review Committee, Mahidol University to ask permission to collect data. The school deputy director formally introduced me to all teachers and staff that I was a researcher and a mother. I, therefore, had a chance to interview school executive and teachers responsible for taking care of autistic children, aiming to know principles of educating and taking care of autistic children. After that, I began creating familiarity to other school staffs, ranging from a school director, a deputy director, teachers, mentor teachers, students, and janitors. Everybody in this school called me “Khun Mae” (Mother) while students called me “Mae Boat” because my son was named Boat. I had to be careful about neutrality throughout the period of research because I did not want to make everybody feel that I had influence or sought any benefits from this school or families of these autistic children.

“Every day at 8 a.m., all children stood straight when they heard the national song. After that, children with intellectual impairment attentively exercised when they heard the exercise song while a few autistic children stood in their group and some of them exercised. However, most autistic children stood turning left and right, seeing the sky and the ground without talking to each other. Autistic children who could speak had spoken with their teachers while some autistic children cried and were moody with hot climate. Behavior of autistic children was obviously different from that of children with intellectual impairment. Children with intellectual impairment were told to lead singing the national song, enjoyed exercising when they heard the exercise song, talked to their friends like normal children, and attentively listened to their teacher’s explanation while autistic children were not interested. Some autistic children stood while some of them sat. They sweated, murmured in their throat, were moody with the hot climate, and cried with dissatisfaction. After the national song, teachers took children to classrooms. Children with intellectual

disability walked to classrooms in order and greeted the researcher while autistic children walked in group without seeing the researcher. Some autistic children ran while other autistic children did not walk so they had to be pushed to their classrooms which were on the second floor of the back building”.

The above situation could be daily seen. Autistic children were not interested in environment. At the research area, I had to first know and create familiarity to these children. I did not want to be a stranger to these children because I knew that I might not be welcomed if I went to visit their families. Creating familiarity to these children was challenging. Although I had a son with autism, this did not mean that other autistic children would immediately accept me. It took time for me to create familiarity to these children.

I created relationship with autistic children by helping teachers take care of these children. For example, I taught them to color and button. When there was an activity of training these children outside the classroom, I also accompanied these children to various places such as agricultural farms, career training building, cooking room, canteen, dishes-washing room. Principle of consistency was used in my research. I met these children every day and friendly talked to teachers and these children, making these children more considerably trust me. After creating familiarity to autistic children, I found that social skill of children with intellectual impairment was very good because these children were interested to interact with me.

Every day when I walked into school, male and female children with intellectual disability surrounded me. Some female children held my arms and hands and greeted me “Why do you come here?”. Some of these children persuaded me to jointly do an activity by saying “Today Japanese people come to see a cooking activity. Do you see me cook?”. These children were glad to talk to me. In the meantime, autistic children were not interested in me. They ran and walked past. Some autistic children stood, stared, and called my name without looking at me.

It seemed that autistic children were not interested in surroundings. In fact, they were interested and their expressive behavior was different from that of general children. For example, Games had never greeted me. When two months passed, he greeted me “Red Eyeglasses” because, on that day, I put my eyeglasses on my hair. I smiled at him but he walked past as if nothing occurred. On the following

day, I put my eyeglasses on my clothes and he greeted me “Black Eyeglasses”. This indicated that he greeted people with prominent feature without calling people’s name. When I asked him “Will your father pick you up on Friday?”. He did not answer but held my hand and took me to his mentor teachers. He wanted to tell me that if I wanted to know anything, I had to ask his teachers. To understand language of autistic children, people had to observe the surroundings because some autistic children could speak but they would not directly speak.

When these children were familiar to me, participatory observation was more efficient. Teachers did not feel that I disturbed them. I taught these children to color and helped stimulate them to thread the beads. I saw teachers take care of these children who got into convulsions. I saw teachers provide initial health care, give medicine to children, and use expertise to take care of autistic children. For example, music teachers used music therapy to attract interest of these children.

“A teacher used electronic organs to play ABC Song for children to sing. Some children loudly shouted while other children cried. Some children stood smiling while Nong Fa sang “Me Me Me Me” and smiled.

As Nong Fa spoke after the sound (Echolalia), I trained Nong Fa by picking a pink color for Nong Fa to color a rose apple and I said “Nong Fa, the rose apple was pink”. Nong Fa turned to see me and answered “Phoo Phoo Phoo Phoo”. After a year, Nong Fa could speak to answer questions without seeing any coaches. However, when Nong Fa was grown up and had menstruation, she could not wear sanitary napkins. Therefore, teachers had to teach Nong Fa how to wear sanitary napkins and had to help Nong Fa wear the sanitary napkins every time.

“Lom Hai Jai Khao, Lom Hai Jai Ork, Dang Dok Mai Ban, Phoo Pha Yai Kwang, Dang Sai Nam Lang Rin, Dang Na Pha Ar Khard, An Bang Bao” .

This is a song children tried to pronounce in the classroom. Children sat around teachers while mentor teachers tried to hold children’s hands to make gesture after the song. After that, they tried to make these children pronounce after the song. These children tried to practice singing this song. Some children only had the sound “Or” such as “Om Hai Ai Ao, Om Hai Ai Ork, Ang Ork Ai An” Some children murmured without any sound from their mouth, indicating that these children understood. After that, children introduced themselves and jointly made agreement.

If any agreement was not violated, children could go to Big C department store. Children were very excited to go to Big C. After that, children went into an exercise room. In this classroom, teachers with expertise on sensory integration used the exercise room to train children with sensory and behavioral problems. Equipment of the exercise room consisted of running machine, big balls, a pond with small balls, a big cushion for stretching muscles. For example, some children faced the problem of tiptoeing so teachers helped massage and activate legs and feet muscles of these children. Teachers compelled these children to wear specific shoes of a community hospital in Lop Buri Province. In this room, I saw "Title", an autistic child with Down syndrome practiced buttoning and belting without moving to other places. Therefore, a teacher moved the mat which was in front of the door while "Title" did not walk but tried to put the mat away because he could not stand the sight of things which were not put away.

A teacher in another classroom with adolescent children had to have skills of controlling unwanted behavior because children in this classroom began having hormone change, making their emotion easily change. They had aggressive behavior and sexual desire. One day, while I talked to a teacher about Art's health history, Jimmy unzipped his trousers and masturbated. So, the teacher loudly spoke "Jimmy, go to the toilet, don't do it here". After Jimmy heard this, he stopped doing it. While Khru Eak continued talking about almost five minutes, Jimmy lied on his back, unzipped his trousers, and held his sexual organ. Khru Eak made Jimmy stand up and told him to wear trousers and said "Go to the toilet". At a corner of the room, Bank who was a handsome autistic man lied on the stomach and slightly moved so the teacher said "Sitt", "Take Bank to the exercise room". The teacher was not frightened and said "Khun Mae, this is natural. Normal people also had this behavior". I saw Bank lie on the stomach and masturbate several times. When Bank had free time, he liked to stay at the room corner and masturbated. It was difficult to take care of autistic children entering adolescence and having sexual emotion. Therefore, it was necessary for people to understand and have positive attitudes toward this issue. Several teachers accepted that they were very worried about this issue because parents of these children did not understand and did not want to listen to what teachers informed them about their children. Moreover, some big children always cried,

urinated and defecated without going to the toilet. Teachers had to wash these children's bottoms and teach them to clean the bottoms like small children. Some children did not want to go to hairdressers but wanted their teachers to cut their hair. Children were very close to teachers as if they were the same family.

Participatory observation in each classroom helped me learn that special education teachers had to express roles of being teacher and mother to take care of autistic children. I could more considerably understand taking care of autistic children, understand sense of self of autistic children, and know basic information of these children's families.

The study of families with autistic individuals at home

Another research area was houses and places where families jointly did activities with their children. Ethnography helped me more considerably understand their livings. I learnt that autistic children and their families lived together with understanding and sensational relationship. Although these children concretely spoke or did not speak, they could communicate and make people understand them. For example, if they picked shoes, they wanted to go outside. If they said "Tired", they did not want to go anywhere. They did not directly answer "We did not go".

As for the study at autistic children's houses, I initially introduced myself to their parents at school. As for parents whose children were boarding students, I called them to introduce myself while a teacher helped advice me and gave me basic information. After these parents allowed me to collect data, I searched the routes to go to houses of the sample groups.

I called these parents to ask about the routes to go to their houses. As for remote families, I had to ask parents who came to pick their children or grandchildren up during vacation about the routes to go their houses. For example, Jimmy's family lived at Amphur Chai Ba Dan which was rather far. Before vacation, I told a school guard to inform me if anybody picked Jimmy up. The guard said "Jimmy's grandfather and aunt usually picked Jimmy up". However, this time, I saw two young men drove an old pickup to school. I remembered that these men drove to receive and send fruits at the Thai Market so I asked them and knew that they were Jimmy's cousins. As they went to Lop Buri, Jimmy's aunt asked them to pick Jimmy up,

making me know how to go to Jimmy's house. Searching the routes was very important. If I did not know how to go to Jimmy's house, I had to go to Jimmy's house in the next vacation.

I knew the way to autistic children's house due to initial help of the class teacher, an administrative teacher, and a janitor. Sometimes, I received help by word of mouth of family. Sometimes, I had to go autistic children's houses as if I had been a detective. For example, Nong Fa's house was situated at Inburi District, Sing Buri Province. An administrative teacher told me that Nong Fa's family was poor so her parents asked Pee Kwang to return home with Nong Fa. The teacher introduced me to Pee Khwang's parents so I knew how to go to Nong Fa's house. I mostly drove alone to conduct the study at autistic children's houses. If children's family was in the remote area, I would ask somebody to accompany me. I could go to Nong Fa's house by receiving help from Nong Joy's grandmother. After visiting Nong Joy's house two to three times, I felt close to Nong Joy's grandmother. As her grandmother used to live at Inburi, she volunteered to take me to Nong Fa's house. I, therefore, picked her up to go to Inburi in the morning. I saw the map, called to ask about the route, and asked villagers on the way. Finally, I found Nong Fa's house. After visiting Nong Fa's house, I persuaded Nong Joy's grandmother to find Art's house in Sing Buri Province. While having lunch, I called to ask the way to Art's house again. However, this family had already moved and did not inform teachers about new address. We, therefore, asked a hired-motorcycle driver to call Art's aunt to know about the way to Art's house. After that, I drove as I was told until I met Art and his grandmother who secretly lived in the space under a rented house. They were homeless.

The study of families with autistic individuals at home was mostly smooth. Before going to conduct the study, I would call children's families to make an appointment. I always gave these families snacks every time when I went to see them and every family willingly welcomed me. Some family wanted to talk to people who had experienced with autistic children. For example, Jimmy's grandfather and grandmother said "We considerably wanted to talk to people whose children were autistic like Jimmy". Some family invited me to eat. Sometimes, I refused due to consideration. However, sometimes, I could not refuse due to familiarity. Participatory observation during cooking and eating with autistic people helped me

more clearly see sense of self of autistic people. I learnt that autistic children used body language when they wanted food. Moreover, data collection at autistic children's houses by expressing the role of mother considerably created trust to each family. Most families called my nick name or "Khun Mae Boat" like teachers and children in school. Only Nong Joy's grandmother called me "Doctor". While I asked about Nong Joy, Nong Joy's grandmother also asked about me. When Nong Joy's grandmother knew that my work was related to health, she called me "Doctor".

I could study some families of autistic children at autistic children's houses. Some family could talk about general issues but they did not allow me to interview such as Bank's family. A teacher told me that Bank's mother did not want to disclose her son's story. Some families did not want me to go to their houses but were willing to give information at school such as Phon's family and Gap's family. Phon's mother said "It was not convenient to talk at my house because I had to send and pick three children up and I had to go somewhere. It was more convenient to talk at school because we could meet each other". Teachers told me to visit Gap's family because this family was very poor. Gap lived with his grandmother in a small hut. I had sought information from a teacher whose house was situated at Ban Mi District. However, a day before vacation, Gap's mother came to take Gap to home and said that Gap would stay with his parents at Bang Bor, Samut Prakan Province during this vacation. During the midterm vacation, I asked her again and received the same answer. The teacher told me that Gap's mother did not want anybody to see her house. However, Gap's mother was willing to give information for in-depth interview.

Some family gave information at the exercise place such as Ton's family. Ton who was an autistic man lived with his father at the police flat. I sat and waited to see Ton's father in the evening to ask permission to collect research data and ask for his phone number. Ton's father was willing to give the information. As Ton's father was a police officer who was very busy, I could not successfully make an appointment. However, a teacher of Special Education Center Region 6 informed me that Ton's father always took Ton to exercise there. About 6 p.m., I collected data of this family at the court of the Special Education Center. Ton's father simultaneously ran, talked to me, and saw his son. He said "It was not convenient to

talk at the flat because there were a lot of people. It was convenient to talk at this court because it was not crowded. If there were a lot of people, my son would not get off the car. This place was more convenient because I had to come here. I felt weak if I did not exercise”. Although I did not see way of life of this family at the flat, I had learnt their lives in the evening. I remembered questions and talked to Ton’s father who ran while Ton rode a bicycle. Then, he talked to me. When Ton was tired, his father told him to sit on the trunk. Ton could not speak. Although I asked or talked to him, he acted as if he did not see and hear me. He happily sat crushing dry leaves. I waited until Ton and his father returned home. If I wanted additional information, I had to wait at this court.

The problem of unfamiliarity to autistic children

It was very important to create familiarity and understand nature of autistic children. Once, I accepted that I was not sensitive to this issue. I went alone to the research area every time. If the research area was far, I would go with my family members. One day, I became a stranger to an autistic child again in the following event;

On that day, I planned to visit Jimmy’s family during vacation. Jimmy’s house was situated at Chai Ba Dan District which was rather far from Muang District, Lop Buri Province. Therefore, I had to take somebody to go with me. Initially, I went to this house with my husband who was a doctor. Jimmy did not show any dissatisfaction with strangers. Most conversation was smooth. Sometimes, Jimmy disturbed the conversation. But, my husband knew how to respond to various autistic behaviors. For example, sometimes Jimmy walked across a glass of water, hit our knees, and greeted us by hitting. However, we did not scold Jimmy. We shared experiences with Jimmy’s family without any tension. Sometimes, Jimmy joined our conversation to attract interest of everybody. Later, I took my friend to go with me but I forgot that my friend did not use to take care of autistic children although she was a nurse and used to go with me to study disabled people. After we arrived at Jimmy’s house, Jimmy’s grandmother and aunt greeted us. We talked to his grandmother and asked about Jimmy. Jimmy walked to see bread which I bought for this family but he did not like. I knew that Jimmy liked crisp snacks such as Lay’s but I did not buy

Lays because this snack was not useful. During our conversation, Jimmy walked to us several times and began getting moody. He ate and put our bread in a bag, gave me a bag of bread, and said “Bye Bye”. He waved us goodbye, blew us a kiss, and said “Don’t be stubborn”. I immediately knew that Jimmy did not welcome us and he wanted us to return home. Therefore, I talked and smiled at him. However, Jimmy still wanted us to return home. So I had to ask Jimmy’s grandmother to sit at the snow ice shop in the village. Jimmy still walked to us and said “Bye Bye, Don’t be stubborn” and blew us a kiss. He did not allow me to order coffee or snow ice, making Jimmy’s grandmother’s laugh. This indicated that, I and my friend became strangers to Jimmy who did not want to welcome us. This surprised me because I used to meet Jimmy at school and I and my husband used to visit Jimmy’s house but Jimmy never expressed this behavior. This situation reminded me to more considerably think of trust of autistic children and I should not take any unfamiliar people to visit autistic children’s houses.

Part II: Methodological Issues

3.1 Sample groups and Sample group selection

Sample group selection in this study, I selected the families with autistic children or family members as the sample groups. I was often asked that why I did not study the meanings and perceptions of the autistic children directly, why learnt from their families. These are the reasons as follows;

Firstly, the autistic people who could convey communication are in high Functioning autism group. While, some in the low functioning autism group could speak but they still had communication problems. To understand the abstract questions is hardly possible for the later group.

Secondly, most of the autism studies are concerning about autism in childhood. Whereas the study of young or teenage autism is very rare, there are some studies but only on the group of high Functioning autism such as transforming autistic cure to the community (Bagatell, 2010).

Thirdly, the autistic children with low functioning had the difficulties in caretaking which are different from the high functioning autism group. This meant that, besides the first group had communicational problem, they also had the social interaction problem. Some of them might have undesirable behaviors and intellectual impairments at the same time. So their families had to face with many problems such as raising problem, development problem, socially stigma problem, etc (Midence & O'Neill, 1999; Palermo, 2003). Base on the study, I found that a 17 years old child in the sample group was still having the problem of excretion. He was urinating on his pants while I was talking to his parents, or he hit his mother sometimes, etc. Such problems are different from those with high functioning autism group who have less severe of caretaking problems. But they might have the problem of self identity concealing and attempt to make them close to normal as much as possible (Humphrey & Lewis, 2008; Willey, 1999). In my opinion, the autistic people with high functioning still have space in the society and they have enough capability to reveal or express their stories to the society, for example, the life of Dr. Gradin (Grandin, 2006), the life of Donna Williams (Williams, 1992), etc.

Finally, the families with the low functioning autism group are mostly voiceless. Based on the observations on the movements of parents with autistic children in Thailand, there are movements for the inclusive education with the normal children, for a chance of higher education. These are the endeavors to increase social spaces for the autistic children. While the medical movements rather focus that the children should have received remedies and behaviors training to be normal as much as possible. I have no objection to these movements. However, there is one thing missing. That is the attempt to understand the families with the growing-up autistic children with low functioning autism. Therefore, I would like to be a voice that reflecting these families' stories so the society would perceive them. Then, they would become no longer invisible person anymore. To achieve the purpose of the study, therefore, I selected the families or grand children with low functioning autism group as the sample groups for this study. The total numbers of the verbal and non-verbal autistic group were 14 families (including my own family).

Criteria of Sample group selection: Family and Autistic children

The criteria of selection were the middle to low class family with the average to poor economic status. They must have in various occupations and educational background. All families must be in sociocultural settings in Lopburi Province and Singhburi Province. I selected the key informants who were the information-rich cases. Partly, they were from the network of autism in Lopburi Province area, which my family and I were familiar with. Thus, we were trust each others and able to reveal the indepth information. The others were from Banjongsang School, who were the middle to lower class families. Their children could not be in the inclusive education with normal children. Otherwise, some of them were necessary to get assistances from the government social welfare. The snowball sampling technique was employed in the sampling process. This technique was referred to gaining the information from one expert to another and searching for more information from one source to another on and on.

The sample group was selected from the families with either autistic boys or girls, age between 12-17 years old. This identified age range was a transition point from childhood to teenage. I might call them as “autistic person/people” instead of “autistic child/children”. In some cases, the autistic person might be grown up and bigger than a child, their name’s titles might be “Nong” (younger brother or sister) or “Pee” (older brother or sister) according to their families and teachers called them. For these autistic children or people who were in the transition point, I found that they had behavioral problems and learning difficulties which were different from normal children and teenagers. There was also a flow of “autism” definitions from the past they were called autistic children. But when they grew up with more severe autism, they were redefined as “madness” or “insane”. The reason was that the image of autistic teenagers in Thailand was seldom appeared. This was similar to the autistic study in Africa that used the word “Invisible Illness” to call it (Grinker, 2008).

Moreover, the key informants were the executives of special education school, the executives and teachers in special education center regional 6, medical doctors, and nurses who provided caretaking for autistic children. They were interviewed in order to study about the government policy and guidelines in caretaking of the autistic children.

3.2 Process and Procedure in Data Collecting

Sampling process, I selected 3 methods.

The first method was purposive sampling selection. I selected sample group from the school where was the information source. I started the process by participant observation with 23 autistic children in the school. It was a classroom for 22 autistic children and one autistic child in inclusive study with the intellectual impairment children. Then, I was looking for the autistic children with an interesting behavior. They had to live in Lopburi Province and Singburi Province. These were two selection criteria in finding 10 families with autistic children for further indepth interview with the families.

The second method was done for more variety of the data collecting. I also selected Notte's family whom I had known them before. Notte was the autistic child in the inclusive education with the normal children.

The third method was the snowball sampling technique. With this technique, I selected Mui's family who I was told by my mother's friend. Mui was the autistic child who stayed at home. She did not go to school. The last family was Joy's, which I was told about her from the teacher at the school. The teacher suggested that there was an autistic girl who used to come to school but she had not come for 3-4 years recently. The teacher could find her address for me, so I could contact her father. Therefore, the total numbers of sample group were 14 families. (Additional details about the key informants of each family, the family characters, their economic status, and data access were in the table in the Appendix.)

The sampling process was not always smooth. Sometimes, I had selected the most interesting case but the family did not agree to join the study. I had to respect to the family's decision the most. The case of Bank's family was an example. From the explanation of the teacher so I had known that Bank was a young autistic man who had high sexual desire. He did not speak to anyone. He liked to lie down at the room's corner and masturbate. His parents were teachers in a regular school. His home was about 5 kilometers from the school where he studied. But his parents would take him home only once a week. I could not approach this family since his mother kept saying that "I was not available" or "I was not in convenience". When I asked the teacher at the school, she said "Bank's mother was always acting like this. Not only with you,

but also with the duty teacher, she was not interested to talk with. She would talk with the class teacher only.” “Even with myself, sometimes I would like to tell her about Bank’s problem. She denied talking with me”. Since the family was not in convenience to give the information, I respected their decision and did not try to force them to the indepth interview. However, I still kept a good relationship with the family by greeting them when we met. For example, I met them when they came to pick up their child at school on the weekend or during the parents meeting, etc.

3.3 Data Collecting Tools

Data collecting tools in this study were;

1) Question guideline for the indepth interview was semi-structured arrangement. The questions were concerning the details of family meaning towards having an autistic child, the image of autistic children and self identity creating of the family. Cultural belief in terms of health and caretaking of the autistic children, the feeling towards the words “autistic and disability” were also in the question guideline. Moreover, the indepth interview questions were about the problems they faced when taking their children to the hospital or to school. As well as the problems from other contexts that was reflecting the absorbed experiences through body. The interview would be flexible according to the suitability of circumstances and time. Created tool was data collecting based on the literature reviews issues and relevance researches. In addition, the questions were presented to the Thesis Advisor in order to check the accuracy, correctness and coverage of various issues according to the framework and objectives of the study.

2) Participant Observation Method was the data collecting tool that I took part of the study. I learnt about the everyday life of the autistic children at school and at home by observation and recording data systemically and continuously. This was including the observation and participating in various activities related to autism remedies and educations as well as cultural belief activities.

3) Myself, as a researcher, as an important tool in data collecting (Chai Bodhisita, 2550). The researchers themselves were like the tools in collecting data which was closed to the reality of informants’ experiences. As well as I had embodied experience with autism for 13 years. I was both a researcher and a mother of autistic

child. I could use the emic views very well as I had the intersubjectivity of experiences with autistic people. Such experiences have been continued and varied range from the diagnosis and caretaking of autism, the resolving the trouble behaviors, the participating in the autistic parents meetings, the listening to the reflecting opinions on the medical and education. I had been struggling experience in practicing or refusing the medical regimens and even tried to rely on the alternative treatments. My important technique was being openness and reflection in order to understand things as they were. I was not relying on any ideas or belief systems. Moreover, I had the process of empathy by caring others based on the faith of the similar experiences. This helped me as a researcher. So I could feel and sense in each particular situation. (Desjarlais, 1992) This meant that I could access to the real information.

3.4 Data Collecting Method

This research study was employed the data collecting methods as follows:

1) Indepth Interview - After I had selected the sample group from all autistic children who I had done the participant observation with, I contacted their parents to get their permission for the interview. Also I had introduced myself officially by presenting the approval letter to conduct the research from the Human Research Ethical Review Committee, Mahidol University. During the interview, I would create the natural atmosphere as much as possible. I did not focus on asking the questions by questions, but instead I memorized the issues while talking unofficially with the informants. The interviews were flexible and exchange information. I also used the principle role of a good listener by freeing my mind and clearing my brain and be ready to get new information and meanings from the informants. Since the more we acted as knowing nothing the more we could learn about it (Chai Bodhisita, 2552). I was relying on this principle and always reminding myself that I was a learner not an expert in everything. The informants were the experts in the thing that I was studying. Thus, I had to give an honor to them and try not to put any new ideas. For the studying process, I had to keep this principle all the time. Besides, during the interview I had realized and awared of the psychological impacts that might happen anytime. Especially, when the informants had to think of their past trauma experiences and no one could possibly understand them. Therefore, I carefully reminded myself

about the sensitive questions that might stimulate their traumatic experiences. I would carefully choose the suitable words, understand and respect to the reasons of the informants. This was including the situation that the informants were not ready to share the information or crying during the interview, I would immediately stop interviewing and providing psychological supports by consoling them and expressing understanding as well as showing truly sympathy. And I would wait until they were ready to give information again without causing any impacts.

2) Participant Observation was the study of the truth by Emic view / Insider view emphasizing on deeply understanding of phenomenons and circumtances. I brought myself to immerse in the events and joined the activities related to the autistic community. Those activities were the autistic parents meeting, teaching autistic children, behavioral training and speech therapy. All sample cases, I would make connection and ask for permission to study the data at their home, their school or in other social events. I observed their everyday life activities of the family. So I could see the relations to the circumstances, and I accepted the belief and thinking system of the sample group.

3) Interview the personal staffs in the autistic works such as the executives and teachers in Lopburi Panyanukul School, the teachers in special education center regional 6, in order to study the education system for special children in Thailand. Also, I had studied the principle of autistic children caretaking, and the integrated works among medical sector, educational sector and family sector.

Data collecting would employ the tools in keeping data record as follows; myself (as a researcher), a voice recorder, and a note book for field data collecting. During the data collecting process, I would also analyze the data according to the conceptual framework of the study at the same time. I spent time almost 18 months in field data collecting (from January, 2011 to June, 2012).

3.5 Data Analysis and Results Interpretation

I have had the data analysis process since the beginning of data collection. I have done the analysis during data collection in order to get the basic information for decision making in the operation planning and data collecting in the next phase. Then, I inspected the information from the indepth interview and from participant

observation during the activities of the autistic families to learn their everyday life. I also checked the information from the interview of relevance personal staffs in the autistic works in order to look through the coverage and coherent of the whole data. After that I planned and collected the additional data in the cases of incomplete data in every dataset collecting phase. I analyzed the collected data and interpreted data according to Postmodern and Phenomenological concept. During the analysis, I had been neutral, no bias and never put my own belief in the data analysis. I avoided jumping into the conclusion. Moreover, I always opened up for relevance data to reveal the truth from the appeared facts.

Data analysis, I used the postmodern concept about the disability. I analyzed the representative image of autism and meanings of autism in the social level. I emphasized and analyzed the autism discourses and the discourses of disability in Thai social culture. I also focused on the medical autistic discourses e.g. the political policy of the government, medical service system and education system which acted towards the body of the families and autistic children. Therefore, the results of interpretation would be related from autistic family, medical autistic discourses, and the autistic discourses in Thai socioculture.

Data analysis in terms of Phenomenological concept was revealing all beings and meanings of those things. In this study, I used the Phenomenological perspective in analysis of being in the nature of autism. In particular, the issues were concerning about the specific senses in order to understand the living experience with the autistic families in the individual and social level. I could not analyze and interpret such the meanings if I did not have the mutual experiences with the families. Same goes to the acceptance and realization of the human value could not be possible in the analysis unless we had shared the living experience together. Therefore, I realized the significance of learning through emic / insider views and taking part of the lifeworld of the families. Then I could interpret the results; what was the experience of the autistic family, how they felt, how they expressed it and how they sensed the world. This was not only the interpretation at the verbal level or symbolic interpretation. Sometimes, the interpretation of results might be conflict but it was the way that made researchers as me to understand the meanings of “what they were” (Knibbe & Versteeg, 2008).

Moreover, according to the principle of Phenomenological research, it was believed that every research methods were contaminated with bias, value and being on subject, not object; especially the study of human and social aspects. Therefore, my previous experiences might already have affected to the study and made the study findings had different perspectives. Although it was the same issue of the study, the ways to get data, the data interpretation, and the presentation of each study result were definitely different. Eventhough I had medical knowledge as a basis, I had always become aware of and never let all these obstructed the study of the real being. I had used my own consideration in making decision in order to harmonize with the situation and result of the data that might be happening in various forms.

The most difficulty of data collecting and analysis was the senses of the autistic people. Since most of sample cases were unable to communicate verbally. Some cases could communicate but only with the easy short and concrete words. They could not communicate deeply so the data from the interview/conversation was not effective. Then, I used the way of reading the books written by the autistic people in the high Functioning autism group both Thai and foreign writers. Some books needed to be ordered from abroad and it took quite a long time. Thus, this part of data collection was much time consumed. I spent a certain period of time in analysis the results on how the behavior characteristic and feeling of these autistic people were, and on which issues they had specific senses. Then I applied the knowledge gain to do the participant observation with the sample group. Thus, this kind of information was not able to gain at the beginning phase of the study. Most of such information gained when I did the follow up and monitoring period in almost a year or a year and a half later.

3.6 Credibility of the Data

Credibility refers to the inspection of data harmonized and my interpretation towards the real being in different level. Being in the research field for one and a half year, I emphasized on the participant observation with the autistic children in the school area during the first 6 months. So the children would become accustomed to me before I went to study at their home. Then, I had got to know and made acquaintance with the key informants in the families for the indepth interview as

the prepared questions. During one year later, I made the follow up and monitoring visits to the key informants of each family. I also made the observation and follow up the progress of each autistic child both in school and at home. I had kept the field data record periodically, and done the data rechecking in the triangulation way, which were as follows;

The triangulation data in this study, I had collected data from the key informants who were the families of the autistic children. The secondary informants were the teachers who are taking care of the children at present. The past information of each child, I had inspected with the teachers in the special education center regional 6 who used to take care of these children in pre-school period. Also, the data was inspected with the network of autistic parents group in order to check the coherence and accuracy of the data.

The inspection of the data collecting methods was done by studying the same issue with at least two different methods. I used the observation, the written recording, and the indepth interview in this study. Sometimes I also used the unofficial conversation group. When I met the parents during the meeting, we would sit together and exchange some general information about our lives.

The inspection of result interpretation, I checked with the key informants who held the first hand experience. Also, I rechecked with the theories whether my interpretation was coherence with or contrast to them and how. In addition, checking with the teachers who have the working experience with the autistic children is crucial too. Finally, I looked through over all results interpretation with the advisors who are the experts and keen on qualitative research.

Theory inspection was done by the experts who assisted me in considering and analyzing the data. I requested for advices from the advisors who are the experts in qualitative research. They also assessed the accuracy of this qualitative research methodology during I was collecting and analysis data as well as presenting the interim data in the analysis. The presentation was in the *Friday Meeting of the Social and Health Research Institution*, which benefited for me in having variety views covering the study issues.

3.7 Ethical Aspects Consideration

I have relied on the ethical consideration for all research participants as follows;

Building trusts between the key informants and a researcher (me) was a crucial thing for the study of autistic family. Informing the objectives and benefits of the study seemed insufficiency to build such reliability. I must be sincere and keep good relations with all of them. I greeted them everytime we have met. For the autistic children, I made the acquaintance with the teachers and became as a part of the school. So the children would not think that I was a stranger. Then, they would be alright when I talked to their parents or teachers.

Confidentiality of the data, since I am is an instructor in psychiatric and mental health nursing. I have more experiences in the patients interviewing and consulting. So I could understand and be aware of the importance of the data confidentiality. I prepared the questions guideline for the key informants from the beginning. The recorded data was by alias name instead of the real name. The field data would be kept carefully in the cabinet with the lock. Then, all the field data documents and recording sheets would be destroyed immediately after finishing the analysis.

Privacy consideration, the places for the interview would be selected suitably and convenient for the informants. It must be a private place and not crowded in order to keep data confidentially. In case that the informants choose the school for interviewing, I took them to the coffee room as it is the glass room, quiet and no others disturbing, etc.

Concerning benefit and reciprocity, I would provide assistance and support for both physical and mental to the informants. Everytime I visited them at home I always brought some snacks with me. In the poor cases, I would help them as possible by giving them rice and other food, installing the television satellite and cable line for them to receive news and informations, etc. If there is the useful information for them, I am willing to share with them. For example, contacting with the assisting organizations for social welfare for the disability, providing them health concerning information, taking my mother to share and exchange experience with the same age informants, etc.

In this research study, I tried to take away my role as a nurse while collecting data. I would use this role again when the informants needed the medical consulting only. This helped me having true intersubjectivity experience with the families. More importantly, I provided psychological supports the ones who were suffering and disappointed. Sharing experiences of being the mother's role helped them felt that there were someone understood them truly. This could reduce the severity of mental impacts. Besides, it made the informants trust me more until they could ask me for helps. Such a case of Jack, about 10 o'clock at night I received the phone call from Jack's mother. She told me that her son hit on her head hardly by hand, and she felt dizzy and numb. She sounds like crying with scared, and did not know what to do. She asked me to drive Jack to a teacher's house as she could not drive. But I could not do as she asked since she had not made an appointment with the teacher to take care of Jack. So I tried to calm her down and solve the problem at the right point. I tried to find out what happened and what made Jack so upset. I found that Jack was asking her a question but she did not hear so she did not reply. Then Jack hit her head and she could not control him at all. Thus, I told her to be patient and talked to him nicely to find out what he wanted. Give him what he likes or take him to colour the pictures to calm him down. Finally, everything was alright that night. It is obviously that the moral principle should be realized all the time of field data collecting and it helps me reach in the phenomenons deeply.

CHAPTER IV

AUTISTIC CULTURAL MEANING AND CONTESTATION FOR THE NAME

In mainstream concept, “autism” means a person who has behavioral, communicative, social interactive impairments. Such a meaning is the medical explanation. Very few people could think of autism in other contexts, especially the cultural meaning. This chapter, I argue that autism has various different meanings. They are range from the explanation set of local people that looking at the autistic children as the madness to the definition of autism based on the medical explanation set. If the children did not have the symptoms as in the *representative* autistic images which the society perceived and understood, they would be in an unstable status and be given new meaning as the madness. The madness *meaning* holds negative value, their families have to face with suffering and struggle to deny it. They accept to be called “autistic” rather than “mad”. Many families try to deconstruct that meaning and reconstruct the new meaning by relying on Buddhist principle. They try to look at it as a natural phenomenon, and karma retributions attached to all beings. Then, they try to accept all beings. This view is a transition point from a disabled status to a person status. Whereas some families are not paying attention at impairment or disability, they look at it as the aesthetic differences. They give the new meaning as a high spirit (Thep or God). This kind of view is a transition point from a disabled status to a higher spiritual status. Thus, the autistic meaning is a matter of construction and variety as the following details:

4.1 Naming as exclusion: Autism as madness

The word “autism” has been known in Thai society for only 2 decades. From the experiences of sampling families, they had never seen the autistic children before. They would call the children who are different from normal as their symptoms

such as the children who did not speak were called “dumb/muteness”, and called the children with no legs as “limbless”.

“In the past, I had never seen the autistic children. If they could not speak, we called them “dumb / muteness”, or they looked like Down syndrome, they were called a retard or an idiot. If they were handicaps with no arms, no legs or some obviously seen impairment, we named them as they were.” “If the children were chaotic and not stay still, shouting, and running around that meant they were normal and we thought that they were just naughty. It was not necessary to take them to get a cure from doctors. Some children did not play or interact with others; we thought that it was good as they were decent children. I knew the term “autism” from the television and Khun Poom, son of the oldest princess”.

Grandmother, 72, of an autistic granddaughter

This grandmother’s word reflected that a child with hyperactivity was normal. Even the children with Asperger who had a social interaction problem, they were not considered impairment as in the present. All constructed illness was belonging to the medical explanation. The more medical sciences are advanced the more new naming of diseases are given. The word “autism” is a new naming disease.

Another grandmother shared her experience that

“In the past, I remember that there was a boy who had similar symptoms as an autistic child. He was about 15-16 years old; his name was Prasan (Alias name). He liked going outside from home, wandered around and could not come back home. He did not speak. When he was a little boy he was very naughty but he was good looking. He just sat and smiled all day. Everyone met him would take him home or bought him some food. He had very short life about 30 years old only. He died because of a fever. At that time, we did not call this an autistic child but called “witless”, “imbecile”, and “imperfect brain”. He was not a dumb as the dumb could not speak but able to understand. Just like the dumb girl, she could not speak a word but she could take care herself, and she was able to ask for money to buy things. They had different symptoms. He was not quite a retard / an idiot. But surely he was not crippled, feeble, or a malformed boy. In case of my nephew, when he was a little boy and did not speak, I understood that he was a tight-lipped (reticent). So we tried many

ways to make him speak such as hitting his mouth by a frog with holding our breath while hitting, or made him eat a boiled sexual organ of a pig. We did these according to the belief, not over 4 years old the children would be able to speak. At present, when we knew that our nephew is an autistic child, it makes us think of that boy and we understand that actually he was an autistic child, too”

The story of grandmother’s experience clarified that the children with similar symptoms as autism would be called “witless”, “imbecile”, and “imperfect brain”. These were the terms used to call autism in the past. Same as the novel by n.M.R. Kukrit Pramoj called “Lai Chivit” (Many Lives) in the episode “Life of Linjong”, having a name called the children with the similar symptoms to autism as “madness” or “dottiness” as well (n.M.R. Kukrit Pramoj, 2543) The novel said that....

“...Linjong’s new born child was a boy, he cried very loud on his first day. This was a sign that the boy would grow up strongly. On the day, Linjong’s son was born her beloved husband just passed away. She was overwhelming with sorrow but she had to try to go over it as she was afraid that her breast milk would be rotten and poisoned to her child. She had never accepted that Daeng, her son, was her gain through suffering. On the other hand, she believed that he was the result of good karma (or her luck). He was born during the most suffering time of her life. Deang was the name of her son, he became a center of her life. To Linjong, he was like a precious treasure with invaluable and unable to be replaced. Deang was easy to raise as an infancy, he had normal development as when it was time to turn, he could turn, when it was to crawl, he could, and it was time to stand and start walking, he could. Nothing was different from other children. Linjong observed that her child was not quite normal for the first time when it was time to speak. Deang did not speak like others, though she tried to play with him by using children babbling words, teaching him to call “mom” but there was no single word out of his mouth. There was still a hope of Linjong as a mother to hear his son speaking. One day, when Deang was about 5 years old. He was naughty than usual he climbed up and down all the time. Linjong shouted at him but she was stunt when she saw his naïve eyes not just like 5 years old boy. He could not perceive that he did something wrong. Linjong’s shouting scared him and he jumped to hold her who is his mother.

Time passed by day after day, Deang was about 9-10 years old, but he was still eating, sleeping, speaking, urinating and excreting like a three years old boy. Sometimes he just bursted laughs without any reasons. When he was in a group with other children he did not understand what the others played. He became as a toy for others. He was being mocked, bullied, and teased without mercy, not different from animals. Finally, Linjong decided to keep her son in the house but still the children shouted and teased at him, used a piece of wood, and a rock throwing at the house to make him scared and laughed with fun. All neighbours knew that Deang was abnormal, as madness or dottiness. They all gossiped about Linjong and her son, someone pretended to visit her in order to see if she had a mad son really. Linjong tried to think about which karma (bad action) she had done to cause this, but she could not think of any. It was even made her become more stressful. She only hoped that one day her son would become normal. When she knew that there were any good doctors no matter the medical doctor, magician, or a sacred holy water monk she would take her son to get treatments. However, nothing was better. Lately, she heard about a sacred monk who could cure this symptom, living in Nontaburi Province. She decided to take Deang to meet him. On the way, the ship was sunk. Deang was so scared he held the bar tightly. Linjong pulled him as hard as possible until he let his hand and turned back to hold her and cried out "mom". It was the word that Linjong has been longing to hear for whole life. Then, both were sunk deep down to the bottom of the river.

Some parts of the novel "Lai Chivit"(Many lives), 2543: 188-205.

The word "madness" in the explanation of local villagers is based on their experiences which represent the cultural belief in their livings. The explanation of "madness" or other similar words such as dottiness, imperfect brain, or witless are holding the negative meanings. Such meanings show that the person is not conciousness, disability, and inability to self control. As in the following story of Jimmy;

A Story of Jimmy: My grandson wasn't Mad

Jimmy was a 14 years old boy half Thai-half Nepalis with white complexion, and pale face. He was very thin though he ate a lot because of his hyperactive behaviors. He rarely remained still so he was rather skinny. Jimmy was hardly smiling. He always ran around in the house area which had surrounded by a barb wire and the steel gate to prevent him from going outside. Jimmy was living with his grandparents and his aunt's family in a rural area of Lopburi province. Their living compound was consisted of a main two storey house, and there were sleeping house as many rooms in connection. The front area, there was an old wood opened room with three side walls with windows for good wind flow. A hammock was hanging between the trees in front of the room. This room was for receiving guests and visitors. Neighbourhood area was Thai style rural community, houses were built closed to each others and there was no concrete fence, only middle size trees grow in a row as a fence e.g. Chaba flowers, Kratin or Carn trees. The house style was a wooden house with two storeys with opened ground floor which was used for relaxing.

Jimmy had a sign of autism since he was infancy. His grandmother observed that he did not make any baby sound, no eye contact while another grandchild at the same age as Jimmy was making a baby sound, smiling and responding to others. Grandmother tried to tell his mother about this, but nobody believed her. Until Jimmy became 2 years old, he still did not speak but grandmother had no idea what happened with him. They did not know about autism. They thought that their grandson was only tight-lipped. When Jimmy was 3 years old, he liked watching commercials on the television. And he did not respond to his name when he was called. He liked to raise his hands in the air, though he had no seizures. They took him to Yuwaprasartvaitayopratum Hospital in Samutprakarn Province, and here the doctor told them that Jimmy was an autistic child.

Aunt was the one who had a duty to take Jimmy to get treatments. They spent 3 hours travelling by Bangkok-Chaibadan bus. The whole journey Jimmy had never sit still, he made a loud noise all the time because of the hot and humid weather in the bus uncomforted him. Aunt had to control him to sit still all the time. They arrived at the hospital quite late and had to wait for a long queue, and Jimmy was getting fussier. They had to go to the hospital every month for a full year. They

decided to find a school near the hospital for Jimmy to study like other autistic children, and no need to take a long travel to the hospital. However, it was not easy to find the schools nearby, every school refused Jimmy as the reason that he was not remaining still. Later, Saraburi hospital opened the Child-Psychiatry clinic, the family decided to transfer him to this hospital.

After that the family heard about Special Education Center Regional 6 would be established in Lopburi Province to teach the autistic children, so they took Jimmy to get training here. They took Lopburi-Chaibadan bus in the morning about 1-2 hours to reach the school in Lopburi town and went back home in the evening. They travelled everyday for 2 months, and felt very exhausted both of them. So they decided to rent a town-house in the city though the family economic status was not very good. They had to spend their savings to rent the house and live in the city. However they could not stay there very long and had to move back home in the rural as Jimmy was in tumult and making a loud noise even at night time. The neighbours could not stand him, so the land owner asked them to leave finally.

Jimmy doesn't like narrow space or crowded places. He would be fidgety. There was once that the family took him to Wang Kan Luang waterfall, he was running around and lost somewhere. Jimmy likes running away; sometimes he runs out to the road and intercepts the cars. Once he could ride a bicycle, he just carelessly rides everywhere without noticing cars on the road. One day, while his grandfather was bending down his face and collecting some vegetable, Jimmy was disappeared. Everyone in the family was worried and anxious, they tried every ways by walking, riding bicycle and motorbike and driving a pick up car to find him throughout the village but they still did not find him. All felt exhausted, it was about 6 P.M. then they heard the national anthem sound. Suddenly, his aunt recalled that Jimmy likes watching the national flag. She rushed to the school where about 3 K.M. far and found Jimmy was standing there with abstracted looking at the flag down the pole. Grandfather asked him that "Jimmy, why did you run away from me?" He replied "Why run away from me". Once grandfather heard that he felt very sympathy on him and could not blame him anymore.

Jimmy can speak when he was 5 years old by the speech therapist only one time. Aunt gave the reason that "Going to the training session spent more money

including the travel cost, besides to get the queue was very difficult. **We could train him by ourselves as we live together, every family members help talking to Jimmy and teaching him to speak in our local way** “We raise him so we **undertand him better than the doctors.** We knew what he likes and dislikes. How do doctors know better than us?” Through a year of my field work, I monitored Jimmy and found that he was a smart boy. At the school, he could play computer games. The first time I met him, he could not read but the last time I met (one year and a half), he could read the text from Karaoke song. Nobody taught him how to read but he could read by himself. At present, he could read some sub-titles on television and read the text on the medicine bags.

“Honda Toyota vios fino.....” “Shokuyasu Monokatari, sunsilk,....” All these words came from Jimmy while he was running to me on the first day that I visited him at home. His words were about the T.V. commercials. Jimmy looked at me and said the same things, and mostly ran back and forth. On that day, he ran to eat jackfruit and ran away, and then he ran back to his aunt as he felt toothache and opened up his mouth for her to get the fruit out off his teeth. Then, he jumped over the glass of drinking water, walked through the group of us who are talking to each other. He walked across to grandmother and patted on the visitor and tried to push the visitor’s legs not to sit with legs crossed. Then, he put his face on legs, and patted the leg by his hand many times for greeting until he was satisfied. For a while he ran back, waving his hand, snapping his fingers near ear, raising his hand in the air, smiling and laughing. Another while, he went to lie back in the hammock, unzipped his pants and played his sexual organ. Grandmother and aunt had to tell him to stop. Then he ran away.

Once he backed again, he went to the DVD player behind grandfather and knocked it. Everyone turned to him at once and said “Don’t knock”. Grandfather pointed to many DVD players that were out of order because of Jimmy. Then for a while, Jimmy lay down and unzipped then played his sexual organ again. Grandmother turned to him and asked “Jimmy, what are you doing?” Jimmy stopped and ran. Later on, when Jimmy could speak he replied grandmother that “Jimmy play kite” (Thai slang for masturbation). Grandmother complained that she did not know who taught him.

Jimmy's behaviors made many problems to the family. Aunt shared that during the semester breaks, she cannot do any works she had to take care of him as grandparents were too old and could not catch him. He liked running to buy crispy snacks all day. If the ice-cream selling car passed by, he would run out to buy it. It must be the chocolate ice cream only; he did not eat other flavors. Grandmother added that he did not know how to spend money, he just picked up what he wanted and we had to follow him and paid to the shops. We used to give him money to spend, but when he met something else more interesting he would throw away the money. It seemed like he totally forgot what he was going to buy. If Jimmy asked for something, but he did not get it, he would destroy all stuff, hit the doors, sometimes he hit himself. Recently, he just threw away aunt's mobile phone somewhere, or someone might get it already. His aunt tried to ask him about the phone but he did not reply.

One day, the front gate was opened, Jimmy ran out. I observed that the opposite house there was an old lady lying on the second floor corridor she used a birch hitting on the floor periodically. Jimmy was going to go up that old lady's house, but he stopped abruptly and ran away. Raising the birch was a signal, meant that you should not come in, otherwise you would be hit. Jimmy's behavior was known widely in the village. If he ran out and it was almost evening, the villagers met him. They would tell him "Jimmy, go home, your grandmother will be worried". Someone came to tell the family where Jimmy was. Everyone helped to look after him for the family.

However, the rural life was not always beautiful. When Jimmy becomes adolescent, some of his behaviors created the conflicts with other teenagers in the village such as Jimmy caught the girl's chest made her boyfriend got angry and punched on his face. Many times Jimmy were bullied in every forms both physical attack and verbal condemns like "jerk, bastard, sicko" Grandmother said with tears in her eyes, she continued "sometimes I heard they said that "here comes the mad man" when they saw Jimmy. People in this area see Jimmy as an abnormal, a mad, or a retard boy, someone thought that he had brain problem, as when he was screaming and closing his ears. He often raised his hand in the air and left like that, nobody understood him. He made some people felt annoyed and condemned him. Grandmother tried to explain that "Nobody wants to be born like this; he cannot choose what born to be. Even our own relatives do not understand how I can make

others understand. When they asked me about Jimmy I would tell them that **my grandson wasn't mad, he was an autistic child**". While grandfather added that "How could we make them understand that he was an autistic boy as **our grandson was not like those in TV. They looked nicer but ours was weird**. Nobody was like ours, wasn't it?"

The Spectrum of Autism

"I told them that my grandson isn't mad; he is an autistic child" "How could we make them understand that he is an autistic boy as our grandson was not like those in T.V. They looked nicer but ours is weird. Nobody is like ours, isn't it?"

From those sentences of grandmother and grandfather, it means that the representative image of autism is different from the actual behaviors of Jimmy who is also an autistic child. In technical term, "autistic" has wide definitions in English used the term Autistic Spectrum Disorder (ASD) which covers the children with social impairment to other severe autism comorbid with seizure or retardation. However, the widely definition provided is not always good, the children in group of Asperger syndrome have to struggle to be out of this definition (Bagatell, 2010) in order to reduce being stigmatized and expressing their self identity to the society. However, for the severe autism as Jimmy, the family would prefer their grandson to be called as autism rather than a mad boy. What would be the reasons?

This study finding showed that the term "autism" was firstly known in Thai medical science in B.E. 2510. However, general people have known autism around B.E. 2540 or about 10 years ago. In the same time as Khun Phum Jansen, son of Princess Ubonratchakalyasiriwattanpannawadee, came back to Thailand. Khun Phoom was in the royal family which Thai people respect. He was diagnosed with autism and had special abilities such as memorizing calendar dates. Physically, he had not got any deficits or impairment to be seen from outside. Khun Phoom became the representative image of autistic person at that time. Then, more people knew about autism, for example, the case of Por's father, he said that

"Right now, Por is 17 years old. He has first symptom when he was 2 years old. At that time, no ones knew about the autism, even staff in the hospital I took him to. We had to find the books about autism to read by ourseleves since there was no

internet connection as in the present. We had to drive our son to Yuwaprasart hospital. There was no information about autistic children on television. Most people knew about it when Khun Phoom came back.”

In my experience, when my child was diagnosed as an autistic child in B.E. 2544, everyone asked that “Is that the same as Khun Phoom?” Vision of the image of Khun Phoom is a wide media tool that makes people know about the autism. Since then the autism is not only in the text books or in the medical treatment institutes only.

Image of Khun Phoom was an autistic person with capability and efficiency. He could do activities with his mother and there were several project activities they organized. This image had fulfilled the parents’ hopes that one day their children or grandchildren would become normal and possible to work. The autistic image was in the positive side, as well as in the past decade, there have been wider media, and more knowledge about autism. The displayed image was a trend that autism is a person with special ability and occurred with a group of high education and good economic background. For example, children of doctors and nurses tend to be autistic than others’. It became a belief that this symptom happens with high society and high educated people only. This helped the family easily accept the autistic children. Later, in year B.E. 2545 Thailand had operated the Health Care Security System, which enhanced people’s opportunities to access to health care service more. There was a screening project for autistic children. Every child has to be screened according to the slogan that “No eye contact, No social interact, No hand gesture (pointed finger)” The autistic children have more chances to be diagnosed, so the number of autistic children become incredibly high. Among those autistic children, they are from several economic status; poor and wealthy. Therefore, the belief that autism happened to the high education and economic family had to be dropped and changed. It turned out that autism could happen to every socio-economic class. However, the presentation of the positive image of autistic people is still continued such as the media presents the story of autistic children with special ability and able to be in the inclusive education with normal students, for example, the story of Ton, Nutch’s Story, etc. (Jittirat Pookjinda, 2545; Nutch’s writing, 2544) Including the presentations of special activities which showing the intelligent of autistic children in

manywebsites(www.autismthai.com/;www.khunpoom.org/index;www.musicstation.kapook.com/view42205.html;www.youtube.com/watch?v=AsLSI9ffU-Q). These presentations aimed to raise awareness of the family and made them realize the early treatments as soon as the children were diagnosed. The parents carried the hope that their children would become just like normal one day.

Presenting the representative image of autistic people as above mentioned was only one sided revealing. The image of autistic children who grew up in the negative way had often been perceived as persons who were dependent, messy defecating, unable to control themselves or even expressed inappropriate sexual behaviors. This group of autistic people seemed like non-visible illness. The meaning definition was then unclear and there was no specific name for them. It was impossible to call them “autism” as it was outside the perception of local people. Therefore, their perception and interpretation about Jimmy’s symptoms was different from the general symptoms of autistic people in the media, no matters on radio, television or internet.

Autism became Madness

“My grandson wasn’t Mad” were the words from grandmother that hurt her so much and she did not want anyone to call her grandson like that. Mad person has the negative meaning since the past to present. Official language calls this group of people as “Mental illness /disability /impairment”. It is a beautiful term for avoiding the creation of negative meanings. The image of mad person refers to a person who was not in the real world, not able to control him/herself, harmful, and scarily. Especially, during Middle Age in the western society, mad people were caught and let them go with the ship into the sea without any destination. They were excluded from the society, which Foucault called ‘ship of fool’. Whereas in the enlighten era, mad people were non-logical ones, dangerous, and needed to be imprisoned. Later, in modern era when the medical science was more advanced, mad people were given definition as mental illness and they needed to get treatments and take care by the experts intensively. Mad people would be controlled as well but in the institutions instead of prisons and they would be taken care by the medical knowledge to docile body (Foucault, 1977; Foucault, 2006).

In Thai society, the image of mad people is not different from those in the west. In the past, mad people were taken care adrift at home, in community and strayed as beggars. Mad people had just been managed concretely in the year B.E. 2484 in the period of Field Marshall Por Phiboonsongkram by the issued law to control mad people in Measure 7 said that “Based on the investigation process, a person became a beggar and was old or mental illness or having severe disease. So the person could not work or feed oneself by other way, including no relatives or cousins to take care. The officers shall send him to the poor house” This group of people then was seen as a burden of society, no value, and being excluded from the society. Moreover, mad people in the public places as well as in the soap operas, films, novel or even on the road, they always like talking to themselves, unable to help or control themselves, messy, do harm to others, etc. They become dangerous and need to get treatments and put in the institutions. Society lacks of presenting the pictures/images of the capability and efficiency of mad people. Thus, the image of mad people is only in the negative way and being excluded from the society.

Jimmy’s obvious symptoms are poor eye contact, abstracted eyes, smiling, playing hands near his ears, crying out without meanings, being able to speak but only the words in T.V. commercials, running around sometimes run up to neighbours’ house without knowing his territory, and he did not know the social rules. Once he grew up, his sexual hormone was changed; he started playing his sexual organ, catching up other girl’s breast until the boys in the village were upset. So then people call Jimmy a mad man, nobody understands that he is autistic. Since Jimmy is different from the representative image of autistic person but close to the image of mad person according to the experience of local villagers. The definition of autism is slipped away from an autistic person to a mad person. Therefore, Jimmy’s life is excluded and pushed to the new world, which is not the autistic world but the mad world, that is stigmatized firmly and it is difficult to be erased.

A story of Tiger: Being less human after naming as madness

During this field data collecting, I had a chance to meet Tiger, a young autistic man at a hospital. I had observed him for 4 months and I did the follow up a year later. Although Tiger is not in the studied field areas, his story is reflecting the

issue of naming autistic person as madness. Therefore, he has been excluded from the society and even their family still cannot accept him.

At a psychiatric hospital, a clean boy with a fair complexion age about 14-15 years old. He was sitting face down on the wheelchair with the two arms are tied up with the blue cloth. His hands were covered with the plastic barrel of saline solution. He was trying to move his arms out from the bondage. The head nurse of the psychiatric unit reported that this young man was left behind the hospital. He was found by the hospital guard by chance when during inspecting the area around at early nightfall. There was no any evidence at all to let us know his name. There was only a T-shirt and a pair of jeans he was wearing with a tiger logo tag. So I would like to call him "Tiger" as his name.

Tiger stayed at the hospital for more than a month. His everyday life was sitting on the wheelchair with his face down all the time. There was no smiling on his face. He did not make an eye contact with anyone. The nurses helped taking care of him by washing him, putting disposable diapers for him, placing him on the wheelchair and then moving him to the balcony. He was feeding food at the meal time. On the first day I met him, I said "Hello Tiger". He still did not look at me. I had tried to greet him every day for a week, so he started looking at me with a quite understandable face. But he still did not say anything. Actually, Tiger cannot speak, so it is difficult for the nurses to understand him in the only one month time.

Tiger might have to end up his life in a nursing home. But at this moment he had to be in the hospital as he still could not take care of himself. The doctor diagnosed that Tiger was a psychosis while the head of nurses and all staff identified that he was autistic. They provided the additional information that in their working experiences with the autistic people who come to the hospital to get treatment mostly they come with their families. It is different from Tiger who was left alone. Tiger has the same behaviors as other autistic persons which are food selecting, prefer eating crispy snacks and they dislike taking medicines. At the beginning, it was very difficult to force him to take medicine. The nurses had to find another way to give him drugs by putting every kind of food on the tray, and then observed what kind of food he chose to eat. Later, the nurses would mix some medicines which were possible to eat with food into his food. This way he was possible to take the medicines. Sometimes, the staff

bought his favorite chocolate milk for him to take the medicines. They had trained him like this until he can take the medicine finally.

Tiger was becoming adolescence, he started having sexual desire. This was the reason why the nurses had to tie him up otherwise he would put his finger into his ass until bleeding. I had a question that why they summarized that such a behavior means masturbation. The nurses explained that “This behavior was not happened with Tiger only. There were some autistic girls like playing both their sex organs and asses to smell. They also made a sound like they were orgasm. The problem was they were bleeding and we had to give them antibiotics medication.”

Although Tiger cannot speak, he had all kinds of feelings just like other human beings. Living his life alone, Tiger was afraid of being lonely. One day, there was a quarrel in the psychiatric unit. The aggressive patients were making a loud noise. Tiger ran into middle of a patient group as if there was a safe place for him. Tiger’s eyes are vacant but there was a hidden scare in his eyes. He hardly made eye contact with other people. He looked at everyone with his watched over eyes. This kind of eyes was similar to those autistic people rather than the psychotic people. In the second month, Tiger started making eye contact with me sometimes after I bought some Chinese buns for him. He often got some snacks and milk from the nurses as they were fond of him.

Some days I and the nurses tried to take him for a walking exercise together with other patients. We had not much succeeded as his knee bones were stuck together so he could not straight his legs. So he could not walk properly and he needed someone to help him walking. Tiger had not got used to the new places, he often acted with fully scare. When he entered the exercise hall, he tried to run quickly into the crowd where many patients were doing exercise. When the exercise finished, the patients walked to the ward. Tiger knew the time well; he would quickly walk to the middle of the row without anyone telling him to do so.

All hands tied, Tiger feels uncomfortable. There were bruises around his wrists. He tried to untie himself by biting the tied cloth. He started having a weird behavior such as when he was sitting next to the cement polar he was trying to bite it. The nurses understood well and tried to tie him up in a new position such as tied up his two arms together, tied him up with a wheelchair or a chair, or with the steel

behind the building. Being tied up like this made Tiger felt dissatisfaction very much. One day I heard him cried out when I went to see him outside. I found him was tied up with the steel behind the building. He was crying out with a groan and trying to bang his head with the steel. The staff rushed to untie him and changed the tighten position. He still could not let free from bandage as every time he was untied he would pick his ass for masturbation. Taking care of Tiger was not an easy thing as he still cannot take care of his defecating. If he was not wearing diapers, he would be messy with his piss and shit all the time. The staff had to clean him all the time. The assistant staff told me that "The autistic children when they grew up they would be like this mostly. Perhaps, when they were young their training might be to stress. I was not sure that too much training would be good for them. But the sure thing was when they grew up they had to come in and out this hospital all the time. Their parents took them here." This staff's words reflected uncertainty and unconfident with the results of the strict behaviors therapy which was affecting the life of autistic persons.

This was another reflection of the autistic persons who were abandoned, and deducted value of human beings. Nobody wanted them even their own family. In the life experience of Jimmy and Tiger both reflected the wounds from their families and society. The society that defied the human value by the sameness idea, for those who were different or deviated from the normal standard would become abnormal. They were definitely devalued human being according to their level of differences or deviations. Both Jimmy and Tiger are autism and they both were given the meanings of madness in the local word. Tiger's family could not accept his beings and they could not stand with the negative image towards the psychotic people. This was different from the case of Jimmy's family, although they were suffering from the flow meanings of autism as well; they tried to struggle and fight back in order to escape from the frightening and dangerous image of psychotic people.

Tiger's life, therefore, was unlike Jimmy's. While others were trying to run away from the image of mental disability, but Tiger was unable to do so. His family already gave him such an image of psychotic people by leaving him at the psychiatric hospital. Tiger was diagnosed as psychosis, although the explanation from the nurses insisted that he was only an autistic person. However, Tiger had to spend his life in a psychiatric institution which meant that his life had been excluded from

social life. He was not being accepted in term of capability, either having a chance to prove himself that he was able to live with the others in the society. He had to be captured in the hospital. His case was considered a severe discrimination of disabilities from the society. The captured person could not spend his life together with others in the society. Capturing then meant the limitation of social status (R. Murphy, 1995; R. F. Murphy, Scheer, Murphy, & Mack, 1988). It also meant devalued individual by being gazed all around the clock, the patients were having no chance to be themselves. The only thing they could do, was to show that they can follow the staff's orders only (Goffman, 1961). Tiger's life in the hospital seemed to be taken a good care from the experts, but in the depth, his life was being devalued of individual seriously. Moreover, he attempted to be able to live in this institution though he was fearful. He had no family to accept and understand his sense of insecurity and fearfulness. He may have no chance to begin his new life. The best situation for him was to start his new life in the new institution. That was all.

4.2 Naming is natural: Autism as Karma

Having ending in the poor house was cruel. Nobody was a living life as tiger that was excluded from the family and community. The families with autistic individuals had to find the best ways for living with, eventhough they had to face the crisis situation, for example:

A Story of Jimmy: redouble suffering

Providing care for Jimmy was not only behavioral therapy as other autistic children. When Jimmy became adolescent, his family had to force him to behave in the social norms, such as he should not play with his sexual organ in front of others or in public and should not touch the women, etc. If Jimmy could not adjust his behaviors to gain social acception, the definition of "madness" would be surged at him and the family. Thus, the family had to struggle against this unstable definition. Jimmy's life then was so fragile and having many chances to be abused all the time.

While the local villagers thought that Jimmy was mad as he always ran around, never remained still or knew anything. But every family's members did not

think so. They knew that Jimmy had feeling and he was sensitive too. **The more society looked at him in the negative way, or denied him, the more he suffered, but he could not explain it in speech.** Jimmy had experienced of being abused from his family member. This adverse event was happened when Jimmy was about 9-10 years old. His mother got married with a new western man. Jimmy and his younger brother moved to live with his new family in Phuket. Jimmy was assaulted from his step-father seriously and his younger brother was killed. His mother knew everything well as she was in the crime scene, but she had never revealed it. Everyone assumed that the step father could not stand Jimmy's weird behaviors, so he hit him. His mother and younger brother might try to stop him, so the tragedy was happened. After that the step father ran away. His mother took him to live with grandparents and then she was disappeared too. Grandmother could not contact her. She said that "I thought his mother blamed herself as the cause of the death of her child. If she was still arrived, one day she would come back again". At present, the legal case might be expired. After the tragedy, Jimmy had psychic trauma, he cried at night everyday. The dorm caretaking teacher observed that Jimmy covered his head to toe with blanket when he was sleeping and sounded like weeping. So the teacher opened the blanket and found that he was crying and full of tears. Later, Jimmy had messy behaviors though before living in Phuket he was trained to remain still. He missed his younger brother, and was drawing a picture of his brother. On the day, I went to visit them at home. Jimmy's aunt brought the photo album when he was young, while we were looking at the picture of Jimmy sitting on his father's lap, Jimmy ran to us and took the photo of his mother and ran away. Aunt told me that "When we talked about his mother, I thought he could remember, he used to ask for her but did not look at her photo. I don't know why, but he might have bad impression. He kept all his mother's photos and when he went to bed he cried." Although, the event was 5 years ago, aunt thought that her nephew has never forgotten. Sometimes at night he was crying and calling for his mother and younger brother. Aunt only consoled him that his brother was already in the heaven.

Such redouble suffering like this, according to Buddhism which was referred to explain the happening events including karma, bedeviled, cycle of birth and death, heaven and hell, etc. Everyone in the family believed that what were happening

to Jimmy range from being an autistic child, being hatred from society, being abused until he lost his brother, were all about Karma retributions. Even, his aunt used to blame herself “What’s karma of mine”. Once she thought about the Karma’s Rules in the previous life, she and Jimmy might be related and then this present life they had to take care one another and became mother and son. She accepted that taking care of Jimmy was very exhausted both physically and mentally. Everyday Jimmy went to sleep about 1 or 2 o’clock in the morning, and then she had to wash all dishes as Jimmy ate all day. Since Jimmy never remains still, she was afraid that he would be in danger. She was worried about him very much. In the beginning, she was very stressed and used to get angry with her sisters and her brothers in law. She was crying every night. She had 6 brothers and sisters, but why her who had to take care Jimmy. Her sister was a nurse and got married with a doctor, they were wealthy but they never seemed to care about Jimmy. On the other hand, aunt was not wealthy as she delivered fruits in the market but she must be the one who takes care of Jimmy. However, once she realized about karma she changed her attitudes and tried to make a merit and consigned good merit to her own bedeviled, practices according to dharma, and offer food to the monks every morning. If there were any suggestions about sacred monks or items, she would try to go and pray for Jimmy to be recovered from autism. At least, he should be able to remain still. Aunt believed that all these things help lift up her mind, as it concerned about karma and pay back karma debt. Recently, when I visited her, she was dressed in white with happy face. She smiled and said that “I have to make merit a lot, do meditation, merit results could help us. I went to the fortune teller he said that my previous life I left my child for others to take care, so that was why in this present life I had to take care this nephew. Even the animals liked cats, dogs or pigs we could feed them, why cannot we feed a human being to be good.”

Karma’s Rules and Dhamma Principles were the best way of sufferings management according to grandmother’s belief. They insisted that they were grandparents of Jimmy; it was not possible to leave their grandson. No matters how their grandson would be, they would raise him as the nature principles. They raised him with true heart and real mercy. A boy like Jimmy was very hard to find caretakers. Although, his grandmother was willing to pay for caretakers 400 Bahts a day not including his pocket money to buy snacks, she still could not find one. So they decided

no matters what happened they would take care of Jimmy by themselves to repay for their karma in the previous life. Moreover, in grandmother's experience such a boy will not live long. Their neighbor was also abnormal he could live only 19 years and passed away without reasons. Right now, the only things grandparents could do is dhamma practicing at the temple, making a merit, chanting or praying for a good merit would be for Jimmy. "We only need him to be able to speak, remain still but all is up to karma retributions"

Jimmy's family is one of the samples that looked at the autism as a matter of Karma in order to release from the problems. This is same as many other families that used karma as a motivation to help the family to be able to accept and ready to move forwards such as Pol's mother. She told me that since she got the first child she was interested in reading Dharma books such as the books of Luang Por Jaran (the great monk) from Wat Ampawan temple, general dharma books, etc. She even read upto 34,000 Dhamma teaching topics in Tripitaka. She realized that every single life had both happiness and sufferings. In case of her son, Pol, she understood that it was a matter of karma. She did not blame anyone as it was the results of previous life karma action and this present life she would take care of her son as much as possible.

Applying the explanation set of Karma is able to use with people in every socioeconomic classes. Including the case of Nott's mother who is a nurse which considered a modern person in the circumstance of the medical sciences, she still believes very much in Karma issues as she said "I really believe in Karma, it is the result of our action from past life. We all have been grown up with the belief to make merit, to free birds and fish to extend lives, to pay respect to nature like trees. All these actions make us feel relaxed and comfortable in mind, but this is not credulous belief" "At first, when I knew that Nott was an autistic boy, I felt so stressed. It was suffering, my heart hurts. I read a book of a nun named Tossaporn, so I wrote a letter to her telling her about my sufferings, my autistic son and his symptoms. She kindly phoned me and told me that she would extend kindness to us through metta chanting. She asked me to maintain and practice as 5 Buddhism precepts and Buddhism chanting then my son would get better. My life has a hope since then. At that time, Nott was about 4 years old" The mother had also consulted the fortune tellers and they told that her son would be able to speak and study as normal. It was right Nott was able to write

before he could speak. Although he could voice when he was 3-4 years old, then he could speak word by word such as Thai alphabet, Kor-Kai. Then he developed little by little. His mother believed in Karma as she insisted that “Karma is a matter of relations, we paid back for him, when he gets better we also get better”.

Autism as Karma, this belief helps the families reconsidered what had happened as a nature and they could live with a hope, and have motivation to be survival. The belief of Karma according to Buddhism becomes the explanation in every situation. In particular, the unstable event as autism because it still could not find its medical causes and specific treatments.

A story of Joy: not Autism but Excitement stage

The story from grandmother who takes care of her granddaughter “Nong Joy” without caring about the term “autism” as her parents who are modern people do. Grandmother used her own belief about ghost and local culture remedies such as fortune telling, curing by monks, and spiritual oracle. Such a belief is still based on Buddhist way, grandmother is practicing her daily life routines of merit making, and going to the temple same as Jimmy’s grandparents. Joy’s grandmother has never thought that Joy is abnormal or mad but Joy is different from others as she was in the excitement stage when she was young. So she refused to speak since then. This explanation set helps grandmother has a positive view on her granddaughter and it is obviously seen from the name that she called her granddaughter as “My little angel”.

It was happened when Joy was 1 year and 3 months old, grandmother told me “at that time we rented a house in Yanawa area. It was the old house and looked scarely. I thought the land owner feed a ghost. The ghost made Nong Joy jumped and so scared. On that day, I was in a house and Nong Joy was bathing and playing water a bath. Suddenly, Joy was screaming, shaking when I ran to her, she was in excitement stage. Then, again when she was eating a corn, a few days after that day, she was screaming and lost conscious.” Grandmother totally believed that these both events made Joy was so excited and refused to speak since then. She added that “After that I went to many fortune tellers, most of the times I did not take her with me, but only took her fortune. A blind teacher suggested a fortune teller from the south from PP Land village, he was very good. He said that soon Joy would be able to speak, at

present a young ghost was taking care of her. It was a good ghost. Then, he asked whether Joy has been in excitement stage. Thing that he asked was exactly right.”

Grandmother explained more that “I believed in what he asked, I was not credulous.” Many fortune tellers said the same thing including a nun in Inburi district, Singburi province. Also, a blind fortune teller at Prabuddhabatr said that her granddaughter had high prestige. There was a sacred thing protecting her. She would be alright. Grandmother said that “It is true. In the past, Nong Joy could call Grandpa and Grandma when she was about one and a half years old, while she was eating corn, she screamed. I believed that house has fed the ghost as there was a spirit house of Mali Spirit, there was a hut to keep stuff. My granddaughter might see something otherwise she would not scream suddenly like that.”

“My granddaughter has the excitement disease, the fortune teller used to tell me that and they said when she becomes 15 years old, she will be able to speak. This coming January, she will be 15”. She was smiling with hope. When I asked her about autism, she replied that “what’s autism I don’t understand. In the past, there were children who had the same symptom as Nong Joy; they were fed as usual, no training as in the present. It was called the excitement disease. It was not madness”.

Grandmother explained that the excitement disease caused by seeing a ghost. The belief about spirits or ghosts is being with Thai people, especially, those who live in the rural area. They hardly go out of the villages and they used to see ghost. So they tried to convince everyone to believe that there is a real ghost. For people who do not believe in ghost might be the ones who have higher education or used to be monks, some might apply Dharma as a tool to get rid of spirits. Ghosts in Thai belief are so variety such as a house spirit, Ka ghost, Land ghost, Master ghost, Spirit living in the trees, Takien tree spirit, Tani-banana tree spirit, Pop (a dracular like) ghost, Ancestor ghost, Phudhi or demon, Pred or lower spirits, etc. All these ghosts and spirits, some are good while some are bad. However, general people believed that ghost has more power than human. In case, they are good ghosts or Thep (high spirits), they will be respected and fed with good food. If they are bad, they will be got rid off otherwise they will go into a human. Thai people believed that once the bad spirit lives in a person, the person will become psychic or mad (Nopporn Suwanpanich, 2551:110-111).

Mae Mali spirit that grandmother mentioned was a wild ghost which she explained that the house owner fed this spirit by building a spirit house for her. Grandmother believed that this ghost must be appeared in front of her granddaughter and made her scared and did not speak since then. While the fortune teller told her that the ghost that protected her granddaughter might be a house or land spirit. The house spirits are often living in the area of the house; they often make family members happy. They are mostly ancestor spirits. In Isan (north east part of Thailand) called Phi Dae Phi Jum, Thai Yai called Phi Lum. People believed that grandparents who passed away, after death their spirits were still at home to help protecting their children and grandchildren. House spirits are sacred and family members have to pay respect to them regularly. Normally, they would not scare family members. Thai people in the central part believed that this spirits are at the main pillar of the house. For Land spirits, the people in the past often asked them to protect them, so when Thai people travel anywhere they are taught to tell Land house, so they will travel safely.

Grandmother tried to make me understand that her granddaughter's symptom was the excitement disease, not madness as well as a man named Tawil who she knew in the past.

“My neighbor named Tawil, he was not mad. At that time, he was about 13-14 years old; he was always sitting naked on the second floor of the house. His house had opened space on ground floor, the second floor was made of bamboo and the roof was grass. He was very worried about his stuff. If someone pretended to steal something from him, he would take it back immediately. He was become like this because when he was 3 years old he was being *hopp* (*hopp is dialect means to fool or scare someone with gesture and verbally*). Grandmother explained by showing body gesture lifting her arms up and down and cried out that the mad man comes! This was the way that made that boy extremely scared and he ran upstairs of his house and never came down again. His family was very poor. His mother and father had to work in the rice field and left him alone at home. I saw him sitting there with no clothes. He looked normal not frustrating but he could not speak, sometimes he laughed with himself alone. Until he became 20 years old, and he had to enlist in the soldier selection process, but he took the black card. So he did not have to join the army. After that I saw him dressing and working as a normal man.”

Based on grandmother's experience, she believed that Nong Joy has to be able to speak as Nong Joy and Mr. Tawil both have the excitement disease. The way to tease or scare children is often done by adults or teenagers to fool young children. When grandmother was a child, she was teased like this too. She said that

“At that time, I was about 3 years old; I walked behind the temple with my brother. There was an old man who liked teasing children, he ran after us and pretended like a mad man. My brother ran away with extremely frightening, he then had severe fever. The doctor injected medicine for him, but he could not walk after that. His bone was destroyed. Later, he was cured by supporting the bone with steel so he could walk again. That's why teasing or fooling children should be avoided. My brother became like 'sunnibat' (that's meant neurological diseases; i.e. Parkinson's disease, cerebral palsy, chorea, spastic muscles, ect.) stammered speaking since then. But he could study and when he had to enlist in the soldier selection process. He got red card and had to be a soldier in Prochaubkririkan camp. My mom was so sad and worried, so she asked the Chief to take my brother to work at home to help him in the pig farm”

The excitement disease in the understanding of grandmother was possible to be cured and the patients would get better when they grow up. The cause of disease was from a ghost, and one of solutions was consulting with the fortune teller, the oracle who could solve the problems. So grandmother told me about the solution that “Mostly I went to the fortune tellers, to get sacred water from temples, and do oracle. I used to do that myself, I did not take Nong Joy with me. I did meet an oracle with Mae Lek Issarangkul Na Ayuttha in Mahasarakarm 3, in front of Chii Pa temple. Right now she was passed away, but nobody continued her works. The best fortune teller is Chalor, the successor of Luang Por Prae, Singhburi Province. At present, he is not a fortune teller anymore. I used to take Joy's fate (birth date and time) to him; he called for the spirit of “Por Poo” who was very accurate. He said about Nong Joy in the same way as others did before”

In my direct experience, I used to take my son to the oracle ceremony, at least it was an alternative way with nothing to loose. But if I insisted not to take him to, all my cousins and relatives would blame me for not respecting it. At that time, my son was 3 years old, he was attending the speech therapy session in Bangkok, but it

had no progress. When a friend of my mother suggested and explained all details about the ceremony and its successful results. She said there was a child who had the same symptom, he did not speak but after attended the ceremony he became talkative. My mother then decided to take her nephew to this ceremony in Nongkhae, Saraburi Province in the morning of a day that was not a Buddhist Sabbath day.

The house of the medium was reflecting her ability to connect with spirits and supernatural things. It was a two storey wooden house; upstairs was used for the ceremony. There was a table set of Buddha image, flowers, candlesticks, a joss-stick pot, and a sacred water basin. There also are many pictures for worship including the photo of King Rama V. The overall atmosphere was magical and horrific. I could not remember well that which ghost or *Jao* (a higher spirit) was invited to the medium. Neither, I could remember the medium's dressing, whether it was white dress or old traditional Thai costume with golden belt. The oracle ceremony by inviting a higher spirit to the medium who is a human called Demon (ghost) and Angel (high spirit; *Jao*) Possession which meant that both ghost and *Jao* were in the medium at the same time. The ghost meant the ancestor spirits, a child ghost, or a local traditional spirits e.g. *Jao Mae Taptim*, *Jao Po Khaotok*. Sometimes, they were the heroins in the past, *Pan Tai Norasingh* or the Great Kings in the past such as *Pra Jao Thaksin*, *Prapiyanaharaj* (Rama V), *Krom Luang Chumphornkheetudomsak*, or even the great monks like *Somdej Buddhajarn To* (To Promrangsri) or the high spirits for country or city guardian such as *Theparaksa Lakmuang*. Sometime, the Hindu gods were invited such as *Uma Dhevi*, *Prohma* god and *Siva* god, etc (Nopporn Suwanpanich, 2551: 38-51).

The ceremony was started in the morning in the parade in house of the medium, and there was an assistant which I remembered that *Ajarn Nopporn Suwanpanich* called "Mae Tung" a lady who helped setting up things, lighting up the joss sticks to pay respect to the Buddha images, to a tray with pedestrian for teachers, or a bowl set of high class spirits. Then, after the respecting, the medium was shaken the whole body, he became drowsy and spoke faster with different tone of voice, the language used was unable to understand. The villagers said that it was God's language so there must be a translator of the medium too. Then, the medium was blowing at the head of my son and splashing sacred water. When finished, the medium had yawned

and slept, with the frightening jerky body and then calm down. After a while he sat up and spoke normally again.

The oracle is a ceremony according to the belief, the people employed this method often had problems or had the questions about their illness, spouse, career, and dangerous events. So it is not surprised that the families with autistic children would consult the oracle. As the oracle ceremony would help fulfilling the missing part from the medical regimens. The medical perspective, the autistic children are abnormal, they need to be cured and trained for changing their behaviours but some cases are nothing better. This could be discouraged, frustrated and no solution to the problems. The belief, according to Buddhism, was related to the action of previous life and karma retributions, so the solution was at resolving or erasing the previous karma. All these could possibly be done by fortune tellers consulting, taking sacred water, praying to the sacred items, and making merit and doing oracle ceremony.

A story of Nong Fha Twin: Karma and Local wisdom

Nong Fha's family live in the rural society in the area of Indraburi District, Singhburi Province. The information I gained at that moment, Nong Fha is an autistic girl. She has a twin named Nong Fhon who is Cerebral palsy. Once I arrived at their house, I found that their parents do not take care only the disabled twin daughters but they have to take care of their grandmother who has cancer with severe staging and their aunt who has convulsion too. The parents are farmers. In the past, they worked in the rice field together but since they had this twin, the father had to work alone and the mother had to take care of all family members who mostly are disability.

Nong Fha's house was located among three houses in the same fence, which all belong to their relatives but they were only at home for sometimes. The entrance way was wet as it was in the rainy season when I visited them. Nong Fha's house was in the far most behind. It was an old style two storey wooden house with opened ground floor. There were many bamboo beds for sitting and lying down during the day time. All family activities were done in this area from cooking, relaxing to receiving guests. Nong Fha is the elder twin, she is autism with slightly heart problem (Patent ductus arteriosus; PDA), while the younger twin is "brain less" according to her

father's calling. So she has to stay home. The special education center did not allow her to school because she could not take care of herself.

Their father told me that once the doctor told us we had twin daughters, we were very glad at first but when we knew that they both were disabilities we could not accept that. It was very terrible. "Even the doctor said one disabled child was bad but two were even worse". However, we could finally make up our mind to accept that. The grieving process was taken more than 6 years. They were seeking for the remedies which were different from other families who usually searched for speech therapy. This family started the treatment of Nong Fha's diarrhea. At that time, she was 11 months old, the doctor in Indraburi Hospital suspected that she might have Down's syndrome. So, she was referred to the Children Hospital in Bangkok. The doctor there diagnosed that she has PDA and explained that she had unclosed heart wall and the hole in between heart chambers. They had to take her to examine the Echocardiogram once a year. The last time was in February B.E.2554, during treatment process Nong Fha and Nong Fhon were sent to the development center. They were trained for a while, and then the expert informed that Nong Fha was not Down's Syndrome, but was autism. The parents were confused because they never heard of it before. After that, they had never taken her to any training, including the speech therapy. They took her to the hospital when the doctor made appointment only.

Taking care of disabled family members is a tough work for a caretaker. Grandmother became hardly possible to help herself while the younger twin, Nong Fhon who is Cerebral palsy plus deaf. The doctor gave her a hearing tool but she did not wear it. She pulled it off all the time and her parents did not know how to do. Before the doctor adjusted the medicine for her, she did not sleep for 3 days and 3 nights. In the morning she was still awake. Right now, she is getting better. She is skinny, and walking like a limp. She had drooling. Her hair was messy. She was wearing T-shirt and old shorts. Walking with her bare feet on the dirt ground, she was carrying the rice bowl and asking for her mother to fry an egg for her. Although, she cannot speak she would point at things to tell what she wants. Her mother understands her very well. On that day of the visiting, she ate three fried eggs already. Her mother talked to me and fried her egg at the same time. When she finished eating one, she asked for another one by hitting her mother and point at the egg to tell her. While Nong

Fha just was sitting there, smiling and hugging her bear doll without interested in anyone. This is her everyday routine. During the big flood event, at first their houses were not flooded much. The water had not reached the second floor yet Nong Fhon was walking and falling into the water. Fortunately, her mother saw that and helped her in time. When the water reached the second floor, the whole family had to move to live in the temporary camps provided by the government. The situation was even worse as the camp ground was limited, the room was small and the weather was very hot. The behaviors of the twin were hardly taken care; they would walk around with no destination. They could not play with other children in the camp.

The suffering was increased when the society did not try to understand. The parents told me about their difficulty period when they had to take the twin to the hospital in Bangkok. At that time, they did not have money. They had to sell their saving gold for cash to take their daughters to get remedy. The family did not have their own car, but to hire the car to Bangkok was so expensive. So they took the ordinary bus, the father said that “At that time Fha and Fhon were very young, we hold them sitting on our laps. From Indraburi to Bangkok it took many hours. When my daughters stood up, they grasped the hair of a person who was sitting in front of us. I had to make apologize to them so many times. Then they made a strange noise very loud. The passengers in the whole bus turned to look at us”. The mother added that “That was right. They cried and felt frustrated. They cried on the way go and the way back. When we were going to get off, the passengers asked “oh, the crying girls will get off, won’t they?” It was humorous. Our daughters did not remain still like other children. They made the disturbing noises all the time. It was good that they were young and small we could still hold them at that time. When they grew up and became bigger we could not hold them, we had to find money to rent a car for curing their daughters in Bangkok. Sometimes we met the doctors, but sometimes we did not. Later the father went alone to see the doctor to tell their symptoms and get the medicines without taking them to. At the time we travelled by bus was extremely exhausted “The most tired period was when they had to pull off their decayed teeth. Her father had to carry one daughter on his shoulder, and I had to carry another one on mine. Their blood was bleeding out and mess on our clothes. Everyone looked at us. It was horrible time the whole way home.”

Since the daughters were not same as other children, the parents had to tolerate with people who did not understand. “When we went to the temple for making a merit, everyone turned to look at us. We were very ashamed because they did not understand our daughters” “Another time, when we took them to the market near our house, they made very loud weird noise. Everyone turned to look at us both daughters and parents in the same time. We tried to take them to the market often as we had no choice. Then the shop sellers were getting used to us. They knew that our daughter was not normal” “She likes buying milk bottle and cloth, I did not know why every time we went to the market she had to buy these things. The seller could remember this girl, so she allowed her to carry the bottle and cloth for a while and get them back later. At present, she just had new favorite bear doll. She really loves it and holds it all day” Nong Fha is autism with the repetitive behaviors. When she went to the market she would buy a milk bottle every time. Once she got a doll she quit the old behavior, and started a new relation to the new thing. Her parents understand this behavior very well. Then their neighbors begin to understand this more and more. There are cousin’s friends to play with her now, but still she cannot play with the same age friends. As the autistic children cannot play with others, Nong Fha often pulls other hair, and Nong Fhon always bites others. Nobody wants to play with them. While we were talking both father and mother looked happy, they were talking and smiling all the time. Their faces looked fresh and bright. So I asked them what was the reason, they said that *“All emotions are extreme. There is nothing worse than this. We had faced every situation. Most sufferings had just passed.”*

The family had to face with sufferings and being in the unstable situations. They had suffered from the most exhausted care taking and from the hopeless in the uncertain remedy. They had never been sure that their children would be able to speak, including the uncertainty of the future of their children and other unstable situations. Nong Fha’s parents had relied on the Buddhism and had the belief in the heaven and hell, Karma, cycle of birth and death, magic, the Karma owners, swearing to the sacred items, chanting and meditating, etc. All religious principles they relied on to help them releasing from the sufferings, these things also helped them changing their attitudes and behaviors. They became more accepting their fates and destiny and the individual value of their both daughters.

Since they did not have enough money to get the remedies, the family turned to the local wisdom. Finally they were successful the twelve years of waiting had come true. Nong Fha could speak although it was rather late than normal age of 5 years old according to the medical knowledge. On the first day I met Nong Fha, I found that her speak style was Echolalia. For example, I taught her about colors “Nong Fha, A rose apple is See Chompoo (pink color). Nong Fha repeated the last word “Poo Poo Poo Poo”. When the trainer sang a song “A B C ...Z” or a Do Re Mi song, she would make a sound according to the rhythm of the song and sang “Mi Mi Mi Mi...” until the end of the song. One year later, Nong Fha could reply my questions although she had never trained with any experts before. Her parents proudly told me that “*We did all the old local ways such hitting her mouth with frog, boiling the female pig sex organ for her to eat, or stealing the rice from Chinese play for her to eat, in the morning we collected the water on the lotus leaves for her to drink. Also, eating the duck’s tongue, they said it was good. Everything local wisdom say, we did all.*” Together with praying to all sacred items, then the conditions of both daughters would be better.

The parents take care of their daughters with love and care; they have tried to speak with them regularly according to their understandings. Together with the local wisdom practices could help their daughters getting better. All the suffering in their minds starts to be released. The autistic care providing of this family did not employ the mainstream medical practices but using the knowledge from their experiences. It was the knowledge outside the medical textbooks but able to use with the real everyday life.

4.3 Reassigning naming: Autism as Thep (God)

“Autistic child, according to my understanding, often do not speak but they make a weird noise like ho-oh-ho as an alien. I have to guess what they want. Other people look at my younger brother as a weirdo and confused. But if you asked me that which Thep (God) that my brother is like, I think he is similar to Ganesha. Ganesha is plum or chubby, in the ceremony, he will get fruits and desserts. He doesn’t want anything but he is ready to give happiness to all just like my brother. He enjoys eating.

He doesn't do anything by himself. Everyone is ready to take care of him from taking a baht, brushing his teeth and even washing his ass."

Boat's older brother, 14 years old.

The belief in reincarnation of Thep or God was influenced from Hindu religious including the belief in Thep (Gods) e.g. Siva God, Vishanu God, Phromma God, Indra God. For *Ganesha* God, most people believe as the land protector, as they will put the picture or statue on the floor near the entrance. *Ganesha* is considered Threshold god, people who passed by the door will get the protection. Some people put *Ganesha* on the intersection or curve road for worship in order to prevent the road accidents. Merchants worship *Ganesha* for good fortune and good business. Teachers and artists also pay respect to *Ganesha* as a father of Arts, including Silpakorn University, students and staffs pay respect to *Ganesha* and worship as a university's symbol. *Ganesha* god had a human body but his head is an elephant head. This god is a symbol of prosperity and abundant. According to the Myth, *Ganesha* is quite greedy and fond of sweet desserts. He was born from Parvadhi Dhevi, and she asked him to be her guard at the gate. The reason that he had an elephant head because on day Siva God who was Parvadhi Dhevi's husband came to visit her, but *Ganesha* did not allow him to pass the gate. They fought and *Ganesha*'s head was cut off. Parvadhi Dhevi was so deeply sorrow. Then, Siva God and other Gods had given new life to *Ganesha* and replaced his head with the elephant head. His mother, Parvadhi Dhevi, was very delighted and the three worlds were in peace together (Micheal Right, 2550: 28-43). From the *Ganesha*'s Myth, the older brother thinks that his autistic brother behaves like Thep (God) as he is always happy, smiling all the time. When it is the time for meals he will go to the dining table, the food must be delicious and he eats about 3-5 meals a day. For the whole day, he stays at home, he does not like going out. Although, his younger brother is strange and different from other children, the positive attitude helps the older brother accepting and understanding the younger brother better.

In Thai people's belief about God reincarnation and the belief in karma as making a good karma deed will go to heavens after death, which is opposite to making bad karma action will go to hell. These all ideas are based on Trai Bhum (or the Three

Worlds, a Thai Buddhist cosmology) which has been believed widely from the ancient time. It is obviously seen from the mural painting on the temple's wall such as on the wall of Wat Prasiratanasartsadaram. Trai Bhum means three worlds which are Kamabhumi, Rupabhumi and Arupabhumi. Kamabhumi (*the sensuous world*) was related to kamatanha or desires: greedy, angry and confusing, the animals are reborn as human beings in the human world, as hell animals in the hells, as yaksa (demons) in the Asurakaya world. If they were reborn as Dheva (higher spirits) in the heavens where there are 6 realms of heaven. One of the six heaven realm is daowadueng. Rupabhumi (*The form/fine material world*) was the world/land of brahma which was an absolute happiness without Kama (desires). Arupabhumi (*The formless/immaterial world*) was the world /land of non-formed body, there are only minds. The narrations about heavens and hells are the indirect teaching of religious to the common people in order to encourage them to do the good action, making merits, being sacrificed, so when they died they would go to heaven. Trai Bhum, then was the source of ideas, inspirations for poetry and writers. The story in Thai literatures such as Khun Chang-Khun Paen, is teaching all these things as a basis (Sathien Koset, 2544:5-13). Most Thai people have absorbed such teaching from literatures, books, mural pictures on the temple wall and parents' teaching. As it might be seen from the case of Mui's family, which the family members believed that Mui was a rebirth of god. In Mui's thinkings all are related to doing a good thing, sin and merit, hell and heaven which convinced the family members that Mui is Thep (God) reincarnation, not an abnormal boy or a boy with impairments as in the medical explanations.

A story of Mui: Autism as Thep (God)

The story of Mui is about a family with an autistic child, which the family's members meet the beauty of the differences. Mui has been newly defined as "Thep" (God) which is the explanation of his family who has strong faith in Buddhism, plus with the view of Trai Bhum (*three worlds where all beings take cycle of rebirth*) which refers to Thep or Brahma Bhumi (or heaven), Human Bhumi (human world) and Abaya Bhumi (or hell). This family looks at the possibility of all beings differently from the mainstream discourses. They do not care about the medical diagnosis or suggestions. They are not interested in taking their child to get treatments

or going to schools. The meaning of Thep (God) is in the higher status than general people. It is a transition from the disabled status to the high spiritual status.

Mui was born in B.E. 2542, his father is an attorney working in another province, and his mother is a housewife. He has 1 younger brother. The family is an extended one as they are living together with the cousin's families around their house in the same area. Mui's house is a two storey wooden house. His father will come home every weekend. Everyone looks at Mui as a Thep or God rather than an autistic boy. Their practices toward Mui are in the way of adorable kisses on his cheeks, saying lovely with him. There are no the behavioral therapy for an autistic child as in other families.

The first autistic symptoms of Mui were turning around himself, turning the fans and a bicycle wheel for a long time like a half day. He liked watching the logos and knew all logos such as Macro, Siam Commercial Bank, Lotus supermarket, etc. His parents took him to the doctor in Pra Buddhabaht Hospital in Saraburi Province. The therapist trained Mui's development, but his mother took to the training session only 1-2 times as she thought that he was not much abnormal, and he might only has physical problem as he was often sick. Since she was pregnant, she observed that a baby did not quite move, but he was delivered normally at Kasemrat Hospital, Saraburi Province. Mui had different development from other babies as he did not crawl or stand before walking. When he was 1 year and three months old he could walk. Mui was very hard to be raised, he often cried for milk many times at night. He drank milk all the time. His mother thought he was tight-lipped as when he was 2 years old, he did not speak at all. So she hit his mouth with a frog as the belief. He could speak normally when he became 3 years old. At present, he is 12 years old; he still has a problem of defecating. He still defecates while he is standing. His mother has to take a bath for him to clean up.

The term "autism" is not producing any anxiety for this family. I have never heard the word "autistic" in Mui's family. Everyone thinks that he is a reborned Thep (God). Here is the story from his mother, *"During my pregnancy about 2-3 months, I had a dream about a girl in Thai traditional green dress, she had big forehead. She was standing in front of the hotel and smiling to me. When Mui was born, I could not recall that. When he grew up, he looked alike that girl in my dream."*

They have the same big forehead. But when I carefully think he looks like Jao Por Prakarn (a Thep)” Then she picks up the photos of Mui when he was young to insist her thinking. She continues that “A Chinese foretune teller said that he is HengJia, the Chief of all monkeys. He was passed away and rebirth. If Mui went to any places where there were ghosts, all ghosts would run away” “When Mui was 6-7 years old, he climbed and stepped over the spirit house. No children could do that. The fortune teller said that there were no Thep (God) in the spirit house anymore. They all ran away. The otherside land, there are many ghosts and if Mui steps his feet on the land, all the ghosts will be disappeared”. Anyway, she does not believe much, until the year B.E. 2550; she would like to sell the land in Bangkok. The fortune teller suggested that she should let her son steps on the land title document, and made a wish to be able to sell the land. She did that, about 1 week later she could possibly sell the piece of land. It was like a miracle as there was only one person phoned her, and agreed to buy easily. My sister who owned a piece of land also sold her land and got money too.”

Being Thep or God is emphasized by the expression and language usage, while I was having conversation with his mother and his aunt, there was a woman came in the house area and took a broom to sweep the floor. His mother whispered to me that this woman came for borrowing money or asked for food. Then the old woman said “Madame, do you have food for me?” Mui heard that and immediately replied before his mother that “You are the beggar or what? So you come to ask for free” The old woman was frightened a bit. His mother is smilingly then prepared the food for the old woman.

Two weeks later, I had a chance to meet Mui’s aunt. She talked proudly about Mui that about the year B.E 2547. Mui was about 5 years old. Aunt took his fate to a fortune teller called Mor Haew, at Sopa Village II who is the medium of Chinese Thep (God). His procrastination was very accuracy. He said that when Mui grew up, he would become a great monk who will be famous. When Mui is getting older, his action and the way of talking is more like a monk which same as the fortune teller said. This emphasized the belief of his family that Mui was a reborned Thep, which is not a medium. Many words or sentences came out from him though he has never been taught before. For example the word “beggar”, nobody told him before so how did he know. His mother added that he learnt by himself, he has never been used as a

medium. This meant that he is not a medium linkage between the spirit worlds and the human world. Therefore, I asked about his language used whether he used the Thep languages as other medium did. His mother replied that in the past sometime before he went to sleep he would say something like AmmUmm HmmOmm and in the middle of the night after we slept.”

Mui’s language usage is always surprised everyone in the family as he does not use the language as the children at the same age, and it is not Echolalia as other autistic children. His speaking language confirms the belief that he is a reborned Thep. For example, when he was asked about going to school, he would reply that “I have graduated, let my brother goes to school”. When he saw his aunt drinking or smoking, he will warn her by saying that “It is your karma, I do not blame you”. Sometimes, he said “You did too much bad karma, be careful you will be fell into the 6 realm of hell” When his aunt wanted to park her car, he turned and said that “It is not a public place, not illegal, you can park”. Sometimes, he taught his brother that “It is wasting money. You’d better keep the money for making merit. It is too expensive the stuff is not good quality”. When he wants his family to make a merit, he would say “Auntie, you are so stingy, you have to make some merit” All these words of Mui made his aunt laugh with funny, differently for the children would call an adult.

In the year, B.E. 2551, when Mui was about 9 years old, his great grandmother was become ill in ICU. All cousins on his mother side were arguing for treasures and they could not agree with each others and made a loud noise. Mui then interrupted and said that “You all are speaking too much” Everyone was shocked and looked at each other and stopped their arguments. He continued that “Why do you fight each others, it is a bad. We have to love each other” After that there was no argument or fighting among the cousins. This is another reason that his mother believed that “It is good to have such a son. He made the cousins love each others more. So everyone loves him, and thinks he is a god. He is the center of our whole family”.

This family’s way of life is very faithful to Buddhist principles, everyone believes in sin, merit, conducting good deeds would get good in returns but committing bad actions would get bad karma in returns. Even Mui himself had deep concerning about heaven and hell. His mother believed that Mui has pure mind, he

does not attaché to materials and not like luxury. This might be a good merit from his grandmother who liked making merits, doing good things to increase her good deeds. Mui offers food to the monks every morning, and he will say to his mother that “Mom... I bring a merit for you”. Mui loves his grandmother very much, when he was asked about his grandmother he said that “Grandmother is in the Daowadueng heaven, there is a royal cart to pick her, and now she is an angel”. When he was asked about the money that he is collecting, he replied that “I care much about my money as I will use it for increasing fulfillment” When his mother asked him that “Mui, why were you born?” He replied that “I was born to create fulfillment”. Whole day, Mui sits in front of the computer, plays games, watches website and YouTube, and besides him it is something that he cannot miss, the television turn on Channel of Dhammakai Temple. The television must be turned on all the time. This might cause him to absorb all Dhamma teaching of this temple as he watches it everyday until he learnt to speak like the monk’s preaching. Mui turned on the You Tube website for me to watch, and then he clicked at DMC and pointed to each monk and said their names “Pra Maha Veerachai, Pra Raj....., Pra doctor, Pra Somchai, Pra Ubek....., This one is Pra Suthichai. He teaches Laung Por’s biography, this one is Pra Mae Lek, a good teacher” Mui seems very happy when he talks about the monks. When he goes to the market he will rent Buddhist amulets every time. Although he does not study and cannot read, but he has very good memory, he can remember various Buddha images, Buddha image for birthdate, and images around him “Pra Buddhachinnarat, Pra Kaew Morakot (Imerald Buddha), Luang Por To, Luang Pu Tuad, Pra Sothorn, Nang Kwak.....” Someone came to visit and saw him and said that he is pathetic. Mui would reply immediate that “You don’t need to feel sympathy on me”.

The reason why the family thought that Mui was a reborned Thep (God) as he also has *special mind ability*, he could tell something in advance. For example, he said that his mother would win a lottery, though he did not know that his mother had bought one before. Then it was right, his mother won a lottery as he said. Sometimes he said that his father would come home though it was not during the weekend when he always back home. Then about half an hour, his father arrived home. Mui has a special ability in language using which is similar to Autistic Savant but still has some autistic symptoms such as the defecating problems. For the first time that I visited his

home, I found him defecated on the chair and computer desk. However, 7 months later he could tell his mother that he wants to pee pee. When I asked him for taking his photo, he would not reply directly but instead he used his hand touching the yaksa-servant of the Buddha image and said “Yaksa would get angry”. His reply is so much different from others. He did not refuse directly that he did not allow me to take his photo. I had to persuade him for a while then he would allow me to. His mother is very proud of him, everytime I visited and talked to her, she would praise him with true smiling and laughing happily, which was different from other mothers with autistic child.

It might be seen that this family did not look at the individuals with autism as the development impairment, behavioral problem, language used deficit, and social interaction problem. On the other hand, they look at the child as a reborned Thep (God) as this explanation helps the family realize value in the child and accepts him as higher spirit, not normal person or disabled person. They provide love and pride in the prominent point of the autistic child; such as his good memory about monks. They feel truly that the child is an expert in this issue or even the ability in memorizing symbols or logos. The differences of an autistic child, thus, are not a problem at all. Viewing the autistic child as Thep or God had turned out to be a good thing for the family as a center for connecting cousins and relatives and bringing lucks to the family.

4.4 Autism as Constructed Meaning

In this Chapter, it is obviously seen that the constructed meanings of Autism are diversity. In the local villagers’ explanation, they have tried to contend and make negotiation with the given meaning in order to be free from being viewed in the negative way. **Naming is exclusion**, it is about the struggling with the requests or the local villager’s meaning of “madness” and being chased, cursed and condemned. Nobody wants to associate with. ‘Being mad’ means being exclusion from the society. Therefore, the family tried to explain that their nephew is autism, he is not mad. So the society would accept him. At least applying the term “autism” still has a better representative reference to the royal family and being more accepted in the society rather than “madness”.

Naming is natural; it is a search for the way to liberate from sufferings or bitterness in life. The life of Jimmy had been redouble suffered from inside and outside the family. Outside he was called a mad boy while inside his family he was being abused from his step-father until he was serious injured and lost his younger brother. Moreover, his mother ran away from him after the tragedies. To view all these things as the matters of karma, it helps Jimmy's grandparents and aunt found the truth of life that everything goes as natural. Autism in this natural view is concerning about nature. Some research studies analysed that viewing the disability as a matter of karma or destiny was the emphasis of the family's sufferings and it would be the cause to increase more suffers to the family (Jittima Juethai, 2551). However, in this study, the family point of view, karma is both positive cause and effect in order to encourage them to take care of their children.

The idea about karma emphasized the feeling of the family with autistic children. In the first phase, the family viewed autism in the negative way, and hardly possible to accept what happened. The family's distress is even more when other villagers said that "it must be your bad karma retribution from previous life" or "it is the previous karma results from the past". All these were looking at the previous life karma retributions as the causes that why this family is poor, their children are autism because of their own karma, so they were born to pay back their karma. People who viewed this could not helped anything, they only look and keep quiet. However, this action is wrong according to the Buddhist teaching.

To view things as the retributions of the previous life karma or the destiny was in the outcast cult which was different from karma in Buddhism. Such the outcast cult made people having no will to do things. They would lack of attempts to improve everything as all things went on without rules, which was an external factors that we could not control. These things were not up to our actions. Buddhism emphasized on present actions rather than previous action. However, it did not mean that the previous karma have no effects. On the other hand, it was the factor creating result in the present which meant that we have to do good thing to improve our life in order to have a better fruitful in the future (Prathamapitika, 2540:55).

Most people looked that karma was a result of an action such as the phrase mentioning that we have to surrender the karma retributions when we are suffering by

misfortune or illness. All bad events were related to karma. This karma had a negative meaning. It was about suffers, dangers, disaster as well as all bad results in the past. People tended to look at the past karma, not at the present action. Actually, karma means action, its neutral word. It can be referred to good things called “merit or good karma”. It also can be referred to bad things called “sin or bad karma”. Looking at the past karma retribution of local villagers is considered the negative view at the beginning, but once they can accept it and understand that everything belongs to natural rules, the family will try to find the survival way out of the sufferings. Just like in the case of Jimmy’s aunt, at first time I met her she looked terrible, her face was so tired including her talks and tone of voice seemed like in the deep sorrow and suffers from her own karma. One year later, she looked fresh and happier as she could accept everything that happened, and view that Jimmy and her self had somethings in related from the past lives. Then, she turned to follow the way of Buddhism as well as Jimmy’s grandparents.

Villagers have applied the Buddhism way of live they practice Buddhist activities such as offering food to the monks, giving and helping others as well as believing the Dhamma preaching such as “Doing good things will get good thing in returns and doing bad things will also get bad things in returns” “Ones have to collect and increase their merits for the better in the future life”. All these Dhamma words were inserted and attached in the children stories, legends, Buddhism literatures e.g. Mahachadok, Pra Vesundorn, etc including the sculptures and Arts concerning about heavens and hells which all found in the temple chapel’s and hall’s wall. Buddhist principles have been embedded in the experiences of villagers. Once their children were born disabled, they often looked at it as a matter of karma and do not blame anyone or even the social unfairness they received, they did not blame the society.

Naming is Natural - it is another point of view through the story of Joy’s grandmother who used the explanation of villagers in the past without concerning the modern medical explanation at all. She believed that autism happened because of ghosts, or spirits that made her granddaughter felt excited and stopped speaking. Autism to her is not an abnormal, but it is something happened naturally. Her acceptance of her granddaughter as a person reflects her opposition to the constructed meaning of autism in the negative way.

“My little angel” had a metaphoric meaning reflecting the opposition to the constructed meaning of disability in the negative way and fighting with the mainstream discourse. The little angel of grandmother helped her seeing the beauty of her granddaughter. Joy has a beautiful face but does not speak, she just sits and smiles. She often turns her neck from one side to another, sometimes jumps and turns around. She likes looking at the mirror. All her life, she has been with her grandmother 24 hours a day. Except on Sundays, grandmother goes to temple to make a merit and meet with her cousins and friends. Grandmother has living her life in the Buddhist way so she tried to find the medical pluralism, such as consulting fortune tellers, getting a healing from monks, taking sacred water and attending the oracle ceremony. Medical pluralism are based on one views of the world rooted from mixed cultures among spirits belief, Bhamin and Buddhist. They are also controlling the health behaviors according to their own cultural belief (Komatra Chuengsatiansup & Yongsak Tuntipidok, 2550). Once grandmother believed that her granddaughter does not speak because of the house spirit made her scared and excited, so the treatments according to the belief seemed logical for her. Moreover, the oracle ceremony was negotiating with the spirit that living inside the person’s body or some oracle place has a ceremony to open up the karma contract which the contract partners were bedeviled. The oracle ceremony helped an individual to remove his/her own past karma and ready to create good karma at the present and future life. In the case that the oracle ceremony could not fix the past means that the conflict point in the individual’s mind could not be solved, it created more sufferings and discouraged them to live their lives further (Tawach Maneepong, 2548, p.44). Thus, the solution of conflict points in the past is similar to attending ‘Freud’ Psychoanalysis in the modern medical practices. Levi-Strauss (1963) explained that comparison of Shamanistic cure and Psychoanalytic therapy. The Psychoanalytic therapy would deeply explore to the unconscious level and take out the thoughts, which might be the childhood conflicts, in order to get treatment. This theory believed that every behavior is a result of working in structure of mind in the unconscious level. Whereas the Shaman cure will bring the patients into the ceremony or inductive process in myth by using the Poetic metaphor in the concept of manipulation. The manipulating will be done through the symbols that have meanings in the actual world, which the structure of mind during

the curing process will be in the unconscious level as well. He had explained more that:

“The modern version of shamanistic technique called psychoanalysis thus derives its specific characteristics from the fact that in industrial civilization there is no longer any room for mythical time, except within the man himself. From this observation, psychoanalysis can draw confirmation of its validity, as well as hope of strengthening its theoretical foundations and understanding better reasons for its effectiveness, by comparing its methods and goals with those of its precursors, the shamans and sorcerers”. (Levi-Strauss, 1963, pp. 200-204)

Reassigning naming: Autism as Thep (God) – the story of Mui showing the new defined meaning of the family has been used without considering the autism as impairment or disability. Mui has not been registered as a disabled person. There is not any searching for the remedies either in the modern medicine or alternative treatment. Mui has been respected from the family members as a god (Thep) which has a special meaning. Therefore, Mui is not in the disabled status but he could possibly jump over to the high spiritual status.

If considering the diagnosis of Mui’s behaviors, he might be categorized as Schizotypal personality disorder. Such a personality is related to the symptom of schizophrenia and often found in families with mental illness. A person with this personality often becomes a medium in the oracle ceremony. Based on Psychoanalytic theory, the person needs being respected since he/she did not gain respects and he must be cured to be normal.

However, Mui’s family has no applied the medical remedies; they used Buddhist vision which applying faiths of Trai Bhum (three worlds) in reassigning naming. His family is an extended family. There are 3-4 houses of his mother side cousins living together in the same fence. The belief of Mui as the reborned Thep (God) has strong influences to his family, everyone loves and adores him. Although, Mui is different from other children, they could be seeing the aesthetic on the differences. Such a world vision is not necessary in the mainstream so it makes his family is happy. Such a belief about autism is not only in Mui’s family, but also in other country like Srilanka. The family can accept the autistic children as they believed that in the previous lives they were warriors. They had been injured and lost

hearing sense until they died and they rebirth as autistic persons in the present life (Leonard, 1985). Same as in the autism study in Isreal, they believed that the autistic children were in higher spiritual status so they possible conducted religious ceremony. (Bilu & Goodman, 1997)

Therefore, it might be seen that the autism meanings are various. Each word that used for calling the children with autistic symptoms is related and meant to their living lives. If the construed meaning is negative, there are not any families accept it with suffering and sorrow. Thus, the families will try to struggle and make negotiation in order to escape from being looked negatively. Including, they will avoid using the word “autistic” and try to reassign name and meaning such as being a reborned Thep (God), etc. The new meanings are all positive to the experiences in caretaking of the autistic children. Moreover, applying the view of Buddhism, it helps creating motivation and supporting the family in taking care of the children. Although, the modern medicine has been more influenced over the other health systems more than 100 years, as long as the modern medicine could not provide the solutions, the Buddhist view and the medical pluralism still have their significant roles in taking care and curing autism.

CHAPTER V

SENSORY EXPERIENCE IN THE WORLD OF FAMILIARITY

“One day, I took my son to go to his aunt’s food shop in Bangkok. When my son entered the food shop, there were a lot of customers. I was worried that he would greet other people by hitting the table, coming close to them, and speaking loudly. As I feared that these people would be frightened, I tried to make him walk upstairs. I felt that these people stared at us and doubted that where my son went and what my son did. Some people pretended to be uninterested in my son but they took a glance. Grandmother told me that my son was glad so he hit the table and made a loud noise, making all people in the food shop look at him. Grandmother thought that people here were very disgusting because they looked at her nephew who walked to the table and touched the table. She knew that her nephew wanted to eat that kind of food and tried to tell her to order that kind of food for him. However, customers did not understand and expressed disgust for her nephew. While eating, these customers always looked at her nephew. However, some good people tried to recommend a good hospital which could treat her nephew. Most people felt disgust for her nephew. When my son was bigger, other people more considerably did not understand by looking at my son. I did not care what these people thought because I only cared about my son, making me think that autistic children did not want to interact with other people because people in some society did not understand them”.

This was real experience of my family. I immediately perceived that other people considered autism as abnormal. My son tried to inform people about his need by touching, knocking, making loud noise, and expressing gestures so that people could meet his need. Natures of autistic individuals are different from others. Most of them usually like revolving themselves, tiptoeing, laughing, rocking their body, looking symbols, and staying in their fantasy world. They could not behave in accordance with social norm. Therefore, they are classified as abnormal in binary opposition discourse; which are classifying normal people/disabled people, normal

people/mad people, normal children/special children, normal children/autistic children, and normal children/problematic children.

In fact, autistic people with speech impairment have sense of attachment like others. They use various senses for communication, the same as blind people have good senses of sound and touch. Deaf people can develop sign language and visual skill. Rarely, people think about senses of autistic people, especially in non-verbal case. The Experts have tried to develop various programs for autistic children with speech impairment; such as using 'picture exchange communication system' (PEC), developing programs in Ipad. However, several autistic people could not access these programs. Living with autistic children, people have to understand self of autistic people and perceive through feeling rather than seeing them as abnormal people. Therefore, I wanted to study self of autistic people through family's perspective aiming to indicate that how families understand and share feeling with autistic people.

5.1 Anthropology of the Sense: World of Senses

Visual sense was mainly used in the scientific world so sight was an outstanding sense of mankind, bringing about innovation. Visual Sense was very important in the western society and was more reasonable than other senses (Classen, 2012). Moreover, the meaning of sense was associated with gender, condition, and social classes. For example, the meaning of high class people and men was associated with senses of seeing and hearing while women and labors were compared as senses of touch, smell, and taste. The lower classes were compared as smell (Orwell 1937: 160; cited in Howes, 2005). Stoller (1989) suggested sense in ethnography that researchers should avoid sensual bias.

“Sense data, especially visual, became all-important to the emerging scientific culture. Empiricism eclipsed rationalism. The emphasis on empirical observation raised sight to a privileged position, soon replacing the bias of the “lower senses” (especially smell and touch) (Stoller, 1989, pp. 7-8).

Stoller argued that although sight was the main sense of the western world, the study in Songhay found that taste, smell, and hearing were more important than sight. Anthropological study had been scientific since the period of Malinowski who

mainly observed and considered visual-acquired information but ignored non-visual acquired information. The ethnographers mostly talked each other instead of talking with people in the field. Stoller suggested that ethnographical work of anthropologists had to beware of sensual bias and should open their senses for the world where they were going to study (ibid: 7). Stoller accepted that several multi-cultural researches were influenced by Kant's visual orientation. His research showed that other senses consisting of taste, smell, hearing were as important as visual sense but ethnographical study had to be more vivid, accessible and use fieldwork data with scientific principles (ibid: 9).

As for 'McLuhan in the Rainforest' Classen (1993) presented the story about native people who lived with the nature, had sensory experience, and were aware of social values. For example, senses of taste, hearing, touch had the meaning and social values. Values of sense were what humans perceived as experience and complied with culture. The sensory order, in fact, is not just something one sees or hears about; it is something in one lives (Classen, 1993; Geurts, 2002).

Social value system did not have to use language although language was a communication medium. However, sense could also be a communication medium (Howes, 2005). For example, people in Andaman Island attached importance to smell (Classen, 2005). Mental visualization was used by blind people to be familiar with place (sense of place) (O. Sacks, 2005). Woodsmen "Kaluli" in Papua New Guinea Island perceived time, season, and area through sensual sound in the forest (Feld, 2005). In this research, I did not aim to indicate that other senses would replace visual sense but wanted to indicate that autistic people used several senses to learn and understand their environment and used senses to communicate and have intersubjectivity with other people.

5.2 Sensing and Living in the world of familiarity

Several people thought that autistic people liked to be in their fantasy world. In fact, their senses were different from those of general people. People could understand sense of self of autistic people if they were living with autistic children,

bringing about attachment and shared feeling in the form of intersubjectivity embedded in the experience, as following:

“One day, a family came to eat food at the shop. A boy was very polite like other children. When entering the toilet, a boy shouted “Ho Ho Ho..After hearing, we looked each other, smiled, and immediately knew that this boy was autistic”.

My family perceived self of autistic people by interpreting sound. I was familiar with sound of autistic child “Ho Ho Ho” in the toilet indicating their independence without having to try to be quiet. This autistic child was well trained until his behavior was similar to that of normal people. Nobody knew that he was autistic because he could hide his secret or difference. However, his sense of self was still the same when living in their familiar world.

Sense of attachment with familiar people

Autistic people seemed to be absent-minded and sat smiling in their private world. These behaviors were interpreted that they did not perceive or have feeling, and did not have attachment with other people. In fact, autistic people had sense of attachment with other people like general people. They expressed differently sense of attachment with familiar people in school as follows;

When Teacher Ekkachai walked to a registration room or an administrative room, I often saw a big group of children followed him. At lunch time, Teacher Ekkachai told these children to first walk but they waited to walk with him. He said “These children were innocent and frankly expressed what they thought. All teachers in school knew this issue. If other people wanted to see me, they could find these children”.

Autistic children interacted with familiar people. When they saw unfamiliar people, they were frightened and pretended not to see these people. Autistic children considerably expressed reaction against these unfamiliar people. If these people looked at autistic people with doubtful eyesight, some autistic people would not walk or get off the car. If familiar people greeted or played with autistic children, these children were shy and bit their collars. These children were moody and

expressed dissatisfaction if unfamiliar people interacted with them. This showed that it was rather difficult for autistic people to build relationship with other people.

Autistic people had emotion and feeling although they could not speak but their family perceived that how autistic people felt.

Por was a 17-year old autistic man who was speech-impaired but murmured in his throat at all times, walked around, was not aggressive but he sometimes hurt his mother when he was hungry at night. He urinated and defecated on his trousers. When he was adolescent, he had sexual desire by prostrating on the floor, smelling girls' shoes, and masturbating until his trousers were wet. He was like a man with clouding conscious so his mother said "He could not be trained because he was not conscious. If he was conscious, I might tell him something". It was not easy to take care of him because he was not a small child. Nobody wanted to specifically train him. Therefore, his father and mother were very sad and distressed despite their best care. Moreover, they were criticized that their child was mad". Nobody understood. When his father and mother took Por to anywhere, other people liked to stare at Por's behavior, causing his family to be insulted. "We felt that other people thought that our son was abnormal. However, we did not care about what these people thought. It was difficult for us to explain about this issue". Although other people thought that Por was abnormal, his mother believed and perceived that he had sense of self, emotion, and feeling. "We could perceive. For example, if you smiled and greeted him, he knew and satisfactorily greeted you. If your facial expression was not good, he showed dissatisfaction".

Por's reaction indicated perception of autistic children. Autistic children were able to perceive although other people did not think that these children subtly observed other people at all times. This indicated that while people observed autistic children, these children also observed these people. These children knew that what other people thought about them. For example, when I wrote information on a piece of paper, Por would grab a piece of paper and a pen, smiling and writing several circles to show that he could write. Moreover, Por's mother understood her son's self through interpreting her son's sign language and sound. During eating time, I observed that Por called "Mama" and walked around. Por's mother prepared food and Por ate rice, curry, and fried pork with murmuring and satisfactorily smiling. Although

it looked messy, Por's mother did not scold him. He did not sit on a toilet but stood urinating and defecating. When he stooped, his mother knew that he wanted her to clean his bottom. She understood her son's manner. Although nobody saw her son's self, she saw values of his son.

Sense of place

People usually had sense of place. For example, Thai people went to stay in foreign countries. They were familiar with their houses in Thailand where they used to live, play, have neighbors and there were trees, canals, shops, and communities. The term "sense of place" meant not only living but also owning that place which had social roles and was acceptable to people (Kahn, 1996). Autistic people considerably had sense of place. Every morning, Games who was a 17-year old autistic man woke up when he heard hens' crowing. After that, he ran to urinate at the same tree every day. Jack who was a 15-year old autistic man did not go outside. When I persuaded to go outside, he asked if it was tired, indicating that he did not want to go outside. Several autistic people were happy when returning home. These children had specific area in their house. For example, they had to sit on the same corner when entering the bedroom. While eating, they had to sit on the same table and chair despite rain or sunlight. Although they had new bedrooms, they always sat and played in the old room and slept on the old bed because they were familiar with old place.

To live with autistic children, people had to understand sense of place. According to the law, all Thai children aged 7-14 had to make identity card to prevent aliens from making identity cards. The problem was that autistic children did not like crowded places. Therefore, it was difficult to take these children to make identity cards. Boss's family took him to go to remote district office where people seldom went. "I slowly drove to Nong Doan District, Sara Buri Province. When I saw that nobody made identity card, I immediately took Boss to make identity card". Por's mother said "I could not do like that. When I parked the car, I feared that I could not find him anymore because he could easily get off the car and walk around."

As for my experience in taking my son to make an identity card, on that day, I and my husband took all evidences to the district office in the early morning and informed officers that we would take our autistic son to make the identity card and he

had a problem of strange place. We needed them to provide document and available time. When returning home, we told my son that he had to make the identity card and take a photo. At 2 p.m. I, my husband, three children, and two private soldiers got on the car because my autistic child was familiar with people at home and school only. We had to create familiarity. When we arrived the district office, my husband parked the car while I contacted the officers. Everybody had to get off the car but my husband did not get off the car because he had to park the car, causing Boat not to get off the car. Therefore, my husband had to stop the engine to show that everybody would stay here. I and my youngest child walked ahead of Boat and opened the door for him. Boat took two steps and stopped walking to see us. A responsible officer asked me “Did he use to go out of the house? I answered “If he was not familiar with that place, he would not get off the car”. This showed that he did not have sense of place with the district office. Everybody understood and had to let him walk and periodically stopped walking. We had to allow other people to finish making identity cards. I noticed that Boat saw what they did. After that, he took two steps and stopped walking. Everybody tried to inform him about each step of making the identity card. His siblings did as an example by standing taking a photo, scanning fingers until he was confident and complied with his siblings. The officers at the district office considerably gave cooperation by providing convenience in scanning fingers and taking several photos. Finally, he could successfully make the identity card.

Most of these children did not go to unfamiliar places so it was very difficult to take care of these children who would scream and wriggle on the floor (temper tantrum) in the unfamiliar place. To deal with this behavior of general children, people should walk to other places to make these children know that this was unsuitable behavior. This practice was different for autistic children. The parents with autistic children had to examine whether that place would stimulate their child's senses such as too loud noise, very bright light, crowdedness. They had to reduce those stimuli or take their child out of that place. After that, they had to train their child to be familiar with the place.

Sense of hearing and aggressive behavior

Mark who was a 15-year old autistic boy could fluently read, write, and speak with familiar people. He was aggressive and could not wait so his mother had to adjust his behavior so that he could wait and stay in the society. Most children liked classical music but Mark was annoyed. He was very sensitive to the sound. One day, my son cried loudly so Mark clawed at my son's face. He could not tolerate with the sound of children's crying. He needed to stop that sound by scratching the children's faces. If other people separated Mark from the crying children, he would claw himself so his face was full of scratches, making other people think that he was an aggressive boy.

Sense of hearing influenced a daily life. Patients with post-traumatic stress disorder were very sensitive to the sound. For example, soldiers who got battle operation heard the gun's sound. Their memory would come out and interrupt their sleep cycles. The villagers living in the landslide heard the rain sound. When they were in heavy rain, their recall memory would appear. The sound stimulated their memory. As for Mark with autism, he was sensitive to the sound of children's crying. He would not escape but had to stop that noise. That sound stimulated him to be aggressive. That sound became powerful and made his family face several criticisms. For example, they were blamed as a broken family with aggressive children. The sound of children's crying was considered as sensory overloading for him. This situation was very difficult to handle because there was the sound of children's crying in school all the times. The autistic individuals responded to that sound differently. Most of them acted as if they did not hear and they were absent-minded. Being silent in their private world would reduce stimulation on disturbed environment. For example, Ton, a non-verbal autism, stood among very loud music after lunch time. I greeted him; he smiled without looking at me. He did not have eye contact, even though I came very close to him about a foot. He was able to create the boundary for soundscape and be happy with his imagination. For Phon, he had better perception than Ton. He did not usually spend his time with his imagination. He could not create the boundary to desensitize the sound of children's crying. Nobody understood and interpreted as a problematic child, excepting his mother and the teachers did. The

teacher tried to separate him from his sensitivity. They provided him to study in the classroom where far from the sound of children's crying.

The sound was powerful and caused temper tantrum. This could be managed by using suitable senses of autistic individuals to distract attention as follows;

My autistic son was very sensitive to the loud noise. He would comply with people who gently spoke with him. He was also sensitive to the sound of electric motor. Battery sound considerably sensitized his hearing. Every time he had his hair cut, he would cry loudly and wriggled until people in the market knew that who made such a loud noise. Two to four people had to hold him during having hair cut. A hairdresser should be the same person with considerable skills because Boat would be revolving his head all the times. This was more difficult, when he had been growing up. Finally, his grandmother got an idea; she noticed that he could not tolerate seeing people with incompletely buttoned clothes. She told the hairdresser to put on clothes with buttons. When he saw that the hairdresser did not button up his clothes, he would completely button up clothes. As he paid attention to buttoning, the hairdresser could completely cut his hair. He could use sense of touch to tolerate the sound sensitivity.

Sense of touch

Autistic individuals learnt new things and environments by touching. They use sense of touch by knocking, touching like the blind people who used sticks and touching instead of seeing (Grandin, 2006; O. W. Sacks, 1995). As my experience;

My autistic son learnt things through fingers. When we bought new things, he would touch and knock. He would walk around the room and knock various things if we changed the surroundings. My family and I tried to teach him to use a computer as learning assisting tools. But he knocked the keyboard almost broken. He knocked the new TV, the new notebook, the new smart phone, etc. Many things were broken. This habit was not always terrible. He was able to train his inappropriate behaviors by using sense of touch. For example, he had a problem of uncontrollable urine and feces. He always urinated on his pants. So, my family and I trained him by knocking. When he wanted to defecate, we would knock the toilet and tell him to sit on the toilet. When he wanted to urinate, we would knock a urinating bowl and tell him to urinate

there. So surprised, he was able to more considerably respond to knocking than telling. Moreover, he used sense of touch to communicate. Like most autistic children, he would hold and put his close relatives' hand on the object that he wanted. When he had fever, he would hold and place his close relative's hand on his head. Once he had asthma, he would hold and place his grandmother's hand on his breast to show his symptom. Therefore, his grandmother took him to hospital to receive treatment. And he considerably surprised family members by correctly bringing a bottle of anti-histamine drug on his personal dining table to tell anybody to give him medicine. This indicated that he could learn and communicate without using speech.

Autistic individuals had normal eyes and ears but the process of acquiring information through seeing and hearing could not efficient function. Therefore, some autistic people learnt through touching before seeing. For example, they did not know that whether they wore shoes correctly. If somebody touched autistic people's legs and feet, they knew which shoe side was right or left. Some autistic people perceived through pain by hitting themselves and biting themselves when they were angry and glad. Moreover, excessively tactile stimulation was the problem of autistic people. If they were hugged, it took time for them to adjust themselves. Some felt uneasy and rejected hugging. For example, when I hugged my son, he would laugh, bend himself, and push me. As some autistic individuals perceived through sense organs which were very sensitive to stimulation, they could not accept any changes so they liked repeating their action. For example, Joy did not like new clothes so she cut brand of clothes. When she stayed home, she did not wear bras. She liked wearing drawstring cotton shorts and t-shirts. She did not like wearing trousers and did not like using sanitary pads when she had menstruation. While some autistic individuals felt relaxed after touching delicate objects, as following;

Ton was a 17-year old autistic man with height of 190 centimeters. His father was a police officer while his mother passed away. Therefore, his father took care of Ton. Ton could not speak. His daily routine was to cycle with his father around the field of Special Education Center. Ton exercised here almost every day because he had been familiar with this place since childhood and this place was not crowded. "He felt happy and relaxed". "If he did not exercise, he would be very tense. He had considerable power so I could not fight with him". When Ton was too

tired to cycle, I would tell him to sit on the trunk. After I gave him two dried leaves, he would crush the leaves.” Ton’s father explained “I knew that this was not correct but he liked. This method helped him relax. He liked playing with sand and removing fish meat from fishbone”. After his father gave him two leaves, Ton sat without going anywhere. He did not show any strange behaviors. Touching sand and dried leaves were desensitization. Sense of touch helped him calm and relaxes.

Senses of taste and smell: familiar smell and taste

Autistic individuals considerably faced the problem of repetitively eating behavior. Familiarity with smell and taste caused considerable difficulty to family. For example, Tiger only drank chocolate milk. Boss liked eating vegetables. Joy liked eating fried rice. Jimmy always ran to buy sweets in front of the house all day. His favorite foods were chocolate and spicy food. He could eat very salty food, such as a bowl of fish sauce.

In my experience, my autistic son had repetitively eating behavior. When he was a baby, he was addicted to baby bottles until the time to stop using it. I had to try several methods to stop this behavior, such as providing half-strength milk, putting bitter substance around nipple of baby bottle. But this was unsuccessful. Finally, I kept a baby bottle away from his vision so he cried for seven days. He tried to tell me by knocking on the table where milk was prepared. I prepared three meals, sweets, and sweet drink. I told my family members “don’t be sympathized” nonetheless he would use baby bottles until growing up. During 7 days, he did not eat anything except sweet drink. My mom cried in front of the house several times. Finally, he began to eat food but still had problems with repetitive foods. For example, he had sunny-side up eggs with medium rare for several months. He ate Phad Kraphao (pork or chicken fried with Thai herb and chili) for two years and drank Yomost milk only. He has taken only “Sara” antipyretic in strawberry flavor till the present time. Noodle had to be bought from the same shop. He had never tasted food but smelt it. He used sense of smell to indicate where the food prepared from. Maybe he would be a gourmet in the future. To let him eat several kinds of food, we tried to persuade him but did not work. Finally, we could change his repetitively eating habit by preparing the foods which had good smelling.

Sense of movement (Vestibular sense)

Autistic children with hyperactive or tiptoeing did not easily stumble although they did not look at the floor. I observed Joy's behaviors. She usually opened karaoke in her personal room, revolving, and smiling happily. Like, Donna Williams was happy when revolving with her younger brother and lying on the floor seeing the world revolving (Williams, 1992). People tried to stop such a behavior but who knew that revolving and rocking body helped autistic children calm down. They were happy and always revolving similar to people who were addicted to drugs (Grandin, 2006). As my autistic son, he would laugh, revolving his head and rocking his body when he was grad. He liked swinging a swing to the very high level and would laugh happily. When he was 5-6 years old, I used to buy kids motorcycle for him because he did not ride a bicycle. While riding the motorcycle, he looked at the sky with absent-mindedness. He never fell down from the road. He could ride for several meters beside the edge of road at all times.

Visual Sense and the familiar world

Autistic children learnt through visual sense. For example, Notte learnt reading before speaking. He had to first see and understand. Jimmy and Boss could read by watching karaoke. Games could read since he studied in a kindergarten without being taught by other people. Games saw and remembered until he could read. He beautifully wrote and correctly arranged documents for teachers. Several families remembered how intelligence of Games during his childhood. He was the cleverest child in the Special Education Center, Region 6. Ford a non-verbal autistic child was 8-9 years old. He began writing Thai alphabets Kor – Hor. Every time he saw a piece of paper, he would happily draw only Thai traditional cartoons on the piece of paper. As Ford could not speak, he could not tell anyone why



Ford's
drawing
about Thai
traditional
cartoon

he liked drawing these cartoons. Maybe, he remembered from watching Thai traditional story every weekend.

Grandin (2006) explained that autistic people thought and remembered through seeing. Some of them could remember routes around the city and could easily play jigsaw. Some remembered details of each page of the book. She could image and design the intervention in the livestock farms. However, visual sense and memory caused problems because autistic people could not change pictures in their memory. So, their habits were limited which could not be changed like only living in the familiar world. For example, some would put the shoes in the shelf if these shoes were in the wrong place. The paper should keep in the paper container. If paper was placed on the cupboard, it would be thrown at the back of the cupboard. Clothes which were used to put in the basket only, even it was wet or dirty with feces. Visual memory, thus, was the issue of familiar world and correlated with sense of place, people, and things of autistic people.

Nong's story

Nong was a genius drawer but his intelligence did not make him have a good life. He suffered from misunderstanding of his teachers and friends when he studied with normal children. He was called "Deg Auo" (meant autistic child) and was dismissed from inclusive education system. I did not have opportunity to visit his family but only greeted his mother in the parent meeting. His story was told by his teacher at the special school.

Nong with autism was 15 years old and presently studied with the intellectual impaired children in Grade 9. He could speak well. His special capability was portraits drawing. He began studying in Grade 7 at a special education school. Before that, he studied in an inclusive education school. When he was very young, he did not have any autistic symptoms. When he studied in the higher level, he had a learning problem. So, the teacher sent him to evaluate at the medical clinic. His diagnosis was autism.

After being diagnosed as an autistic person, he received a pink tag fixed on his clothes while other children received yellow tags. With the reasons that different symbols indicated that Nong was autistic who should be specially treated. After that,

he was teased, causing quarrel and punishment. Since then, he disliked anyone calling him as autism. The school had disseminated knowledge on autistic people, which negatively affected Nong who had to face the social problem in school.

The teacher committee evaluated that he could not study with normal students anymore. One teacher recommended he should receive treatment and study in the special school. At the beginning at a special school, he was easily irritated and angry. He had a repetitively eating behavior. He only drank chocolate milk. He liked eating noodles with torn chicken. Now, he practices to eat several kinds of food and fruits. But he still disliked anyone calling him as “an autistic person”. Therefore, the teacher used this reason to control and adjust his inappropriate behaviors. If he did not want others call him as autism, he had to control himself, keep calm and could wait.



Ananta Samakhom Throne Hall

Nong's Portrait: Drawing from his memory

One day, teachers took children to field trip at Vimanmek Mansion and Ananta Samakhom Throne Hall in Bangkok. They were so excited traveling by a sky train. After returning to school, students were assigned to draw pictures as they remembered. Nong presented his ability at portrait drawing. This was beginning of his genius.

As Nong could not considerably create relationship, he could not learn with art teachers, making his drawing potential unable to be developed. His class teacher said that his art works both drawing and molding were excellent, but learning results on other subjects were not good. For example, he had not skills on calculation in mathematics. As for writing class, when he was ordered to write after his teacher wrote on a blackboard, he would write from right to left while other people wrote from left to right, making people unable to understand that meaning. If the teachers wrote

on a piece of paper and gave this paper for him to closely see, he could write as the example. His capability on drawing was acceptable to his teachers and friends. At present, he is very proud and happy.

Nong's story indicated labeling through misunderstanding self of autistic individuals. If people understood senses of autistic individuals, they could create potential and confidence and would be well acceptable in the society.

5.3 Sense of self of autistic people: Learning Experience of their families

Autistic people could learn and develop themselves. I noticed my son, he used to have temper tantrum when he met unfamiliar people or went to unfamiliar places. When he was 11-12 years old, he had more considerably observed others was doing, which ways made others like him. When staying with his father, he would be polite and run to the toilet for urinating and defecating without making a mess. When guests came to his house, he would be shy, smile, take a glance. When teachers greeted him, he was shy and could raise hands to respect teachers. He learnt that these behaviors made adults like him. If people doubtfully looked at him, he would not get off the car.

Autistic people learnt through their experience and interpreted others' reaction. As for Joy who was 4-5 years old at that time, when her parents took her to the funeral at the temple where there was very loud sound of Thai musical instruments, she was screaming so their parents had to take her to return home. When she was 12-13 years old, her parents took her to ordination ceremony. She could quietly sit with appropriate manners in a chapel. Her mother said "she observed us how she should do, when I told her to quietly sit, she could do it". In case of Jimmy, at first time I met him, he wore shorts and old t-shirts. One year later, he changed to wear trousers and shirts like adolescents near his house. This indicated that Jimmy perceived and observed the surroundings. He could develop himself into adolescence.

The self of autistic people had special senses. For example, Games perceived and learnt through visual sense. This helped him remember the details of reading and electronic equipment. He learnt to read and set electronic equipment

without coaching. Ton was a scary big guy but his father knew how to control him and release his tension. He liked touching delicate things and crushing leaves, which induced him out of reality from expert's explanation. However, his father did not stop this behavior. He accepted and believed touching desensitized his son to be gentle, not aggressive.

Whereas, some special senses affected the interpersonal relationship, such as sense of place, sense of attachment with familiar people, hearing sense or sensitivity to sound. As for this research, these autistic people did not request to go to unfamiliar places. They liked staying home and schools. Wherever they went, their family members or their teachers would accompany them. They had repetitive activities. Changing their surroundings and daily routine created fear and anxiety. They would be in a panic state (Grandin, 2006). It was very difficult for them to make relationship with others.

Autistic people seldom interacted with others. This did not indicate that they could not perceive or learn anything. They perceived others' thought but they lacked experiences of how to make interpersonal relationship. Especially, if they lived in the surroundings with negative attitude toward autism, this would be more difficult for them. They were not accepted, devalued and labeled as abnormal. Similarly, most disabled people seldom interacted with people in the society despite more facilities because they did not want to be insulted in the society (R. Murphy, 1995). If people in the society still expressed disgust, feared, or insulted autistic people, they could perceive and absorb the labeling process. They were not quite sure how they should behave and interact with other. Being in their world of imagination might make them feel safer.

In conclusion, senses of autistic individuals were special, not disorder. Each autistic individual differently had special senses. Although visual sense was special for autistic individuals, this did not mean that all of them had this sense. Senses of autistic individuals were specific, not universal. To living with them, it was necessary to understand sense of self of autistic individuals. For example, Joy had oversensitivity to touch so her family had to select soft clothes. Ton had sense of touch. Touching as relaxing technique made him calm. He could create his boundary when he wanted to escape from loud noise. Some autistic individuals might like

classical music while Mark considerably felt annoyed. He was oversensitive to the sound of children's crying. Boat could not speak so he tried to use several senses to communicate. He would select mode of attention, such as using sense of touch to tolerate the sound of motor equipments. According to principles of taking care of people with sensory/perceptual alteration, the providers need to stimulate them to speak and discourage non verbal manners. However, this study indicated that the families with autistic individuals understood sense of self of their children. They considered their children did not alter perception. They understood their communication through interpreting either verbal or non-verbal manner. They accepted their children as they were.

CHAPTER VI

CONTESTATION FOR NORMALCY: BEING AND LIVING IN NORMATIVE WORLD

To understand the experience of being and living with the autistic person, it was necessary to comprehend power and knowledge in medical discourses. This Chapter was presenting the stories of autistic families who struggled in the normative world. The families were controlled, monitored and gazed by medical practices in terms of power and knowledge. Such knowledge had been absorbed in the individual bodies and forced them to follow the autistic regimens which considered as successful methods. As they strived for normalcy, some families could push their children to inclusive education, while the others were disappointed. They doubted and questioned about the medical treatment which claimed its effectiveness and rightness. They also faced stigmas such as the judgment of person with autism as abnormal, problematic and inability to learn. Finally, their autistic children were excluded from mainstream school.

6.1 Value System of Normal

‘Normality’, not disability, is considered as worthy of expectation. Every family needs their children to be perfect physically and mentally. None of them want their children to be impaired and seen as valueless person and social burden. To have normal children is an important indicator of the family’s success. Also, the successes of children in learning, careers and being respected by other people are considered the success of the parents. Therefore, the success of children increases the self esteem and self actualization of the parents according to the Hierarchy of Need by Maslow.

Be living in a society, the issue of family’s life is a common topic to chat among friends. If you have a child, the common questions would focus on the success of your child. They would share the secrets of raising successful children. Most of

them give the significance to the preparation of their children into the tutorial school system since they are in kindergarten. They expect their children have opportunities to study at the national famous universities and get jobs with high salary and high position, accordingly. Society values the normalcy and ableism of a person. Once any families have disabled children, a group of friends would gossip, or not mention about. Having disabled children becomes the sensitive subject. Since it means that the families are failure as they have disabled children with incapability; such as my own experience and Jack's mother experience:

"I have not joined many social activities as before, there are only few close friends whom I interact with. I don't want being asked. Every time when someone asks me about Jack, I don't know how to say. I feel like to cry. He looks like normal boy. He's smart"

Jack's mother

"In conversation with groups of friends, everyone is appreciating with the success of children; nobody dares to ask me about my middle son. If they asked they would ask me as quiet as possible like whispering. Before they asked they would say something like it is natural no one wants this to be happened to me. It seemed like they tested me that how much I could tolerate it"

I, as a researcher

Value system of normal is very important. The families have to try every method to prevent having disabled children. High advanced medical technology has become the alternatives for many families such as ultrasound inspecting, checking of the membranes in amniotic fluid to find abnormal chromosome. However, since the autism is not being detected during pregnancy as other genetic diseases, the parents are still asked from the society; such as drinking alcohol, tobacco smoking, or working too hard during pregnancy. The sensitive questions are the insufficient love and poor providing care the autistic children.

Normalization by the medical practices would answer all questions for the families. Medical intervention could solve the impairments so that their children become close to normalcy as much as possible. While the education system is

supporting the medical knowledge by restoring the capability, stimulating the development, adjusting behaviors as well as training the autistic children to have social skills to study with normal children in mainstream school.

6.2 To be normal: A Typical Autism

Medical institution has created the knowledge in providing care for autistic person. This knowledge claims the effectiveness and the rightness. Most families should follow this regimen, starting from screening, investigating, diagnosing, and providing treatments. If they practice following this protocol, the children would become less impairment and improve their development and behaviors. They become close to normal children. However, all processes have to be done within the 5 years.

The Case of Notte

Notte was 13 years old boy, his parents were a doctor and a nurse who were wealthy. He was one of the typical autistic children in the medical definition. He was diagnosed and received treatments from the specialist of Child-Psychiatry department and all kinds of treatments available at that time e.g. pharmacotherapy to control undesired behaviors, speech therapy, sensory integration, behavior therapy, Hemoencephalogram (HEG) or even Acupuncture in the traditional treatment. His mother told us 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” (increasing graph). I had to take him to practice with trainers as much as possible. We had to be patient. I had to surrender everything to have my boy being trained, no matters how much I had to pay.” The term “graph shoot” was the medical knowledge that was deep rooted in his mother mind and thought. Since everyone in the family was explained by the professionals that if the autistic children could be trained before 5 years of age, they would have more chances to be close to normal. If the autistic child were more than 5 years old and could not speak, there would be less chance to be normal accordingly. This knowledge had influences over the mother in trying to search for treatments and education for the child. She told us more that after she was running around to meet with the specialists, she turned to go shopping for trainers

instead whether it might take her a lot of budget. When Notte was a little boy, his mother hired the teacher from a foundation who worked extra time in a famous private hospital. Then, after he was a little bit grow up, his mother hired the teacher to take care of him one by one and made a reservation for a new teacher who was going to finish taking care of her friend's child. Since she believed that the teacher was skillful and had more experience in training the special children of primary level. His mother was willing to pay to every kind of educational institutions. Every evening after school, she prepared the extra exercises for her child to do. Notte had been training harder even during the semester breaks which he had to prepare himself for the next terms. When he could not do the exercises or felt bored he would twist his personal rope to release stress but he was not allowed to stop doing the exercise until he finished all. His life was being programmed as the pattern of autism which followed his mother's will and her hope that "Notte had to be in the inclusive education. If he was in the special school his development would be regressed just like other autistic children".

In case of Notte's family, it was obviously seen that power of medical knowledge and negative representation of the special education which these two things worked together in the process of normalization.

In the point of view of Michel Foucault the term "power" was not enslaved or using violence but it was controlling through norm by using disciplinary as a crucial tool of power in taking control of people in the social norm as well as control all micro detail in everyday life throughout human physical body. (Foucault, 1981, 2006)

The medical knowledge stated that if the autistic children had been diagnosed and received treatment as early as possible it would help the children had better prognosis and high possibility to be normal. (Pongsak Noipayak, 2009) This was the medical text that relying the treatment and capacity restoration with this knowledge had more unconsciously influencing towards the family's thoughts. The family had never known that they were controlled by this text, as it was seen from the case of Notte's family. They tried to search for treatments and therapists, though they had to face with medical process and commercial education system. Moreover, the efforts in training their autistic children were to correct the impairment and increase

the chances for their children to be in the inclusive education. Finally, the behaviors training became internalized in everyday life. There was the training time table started from the waking up to sleeping time and the exhortation from parents in order to be ready for studying in mainstream school.

6.3 Autism in a ‘disease cure’ framework

The autistic families are governed by the medical knowledge. They accept the diagnosis and treatment process. They think that the autistic children will get better in medical intervention as other diseases. The families’ perspectives are in ‘a disease cure framework’. With the faithful and believe in the medical science, the autistic disease could be cured. In fact, children with autism have symptoms in impairments of communicative development, social interaction, and repetitive behaviors so it could not be cured by medicines directly as other diseases.

The autistic treatment is still in the Experimental Era. There are several new researches happened all the time such as pharmaceutical intervention, Hyperbaric Oxygen Treatment, using HEG, Nutrition remedy, Stem Cell, and Acupuncture, etc. All these new knowledge could be retrieved from the medical journal, internet, and there are also the workshops to provide knowledge for the parents. For example the director of the Special Education, Region 6 and Autistic Parents Network will invite the parents to seminar in advanced autistic caring. During my field data collection phase, I had a chance to participate in the training workshop on How to solve the autistic children behavioral problems by Visual Strategy and Floor Time Technique on 20th March, B.E. 2554, etc.

The autistic cure in Thailand is mostly derived from the western countries, but there are some developed in Thai context such as Animal Therapy. In the west, there is the animal selected and trained to use in the treatment program such as dolphin, pony and dog while in Thailand, the chosen animals are horse, elephant in the north and water buffalo in Lopburi Province, etc. Every treatment claimed its effectiveness and efficiency without revealing its criticism data.

The western countries have more criticism about the autistic treatments such as the Facilitated Communication method. This treatment method is done by

developing communication among the groups of verbal development problem e.g. autistic children and intellectual impaired children. The children are asked to point at the letters or pictures on the board or type the letter on the key board, while the training assistants help supporting their hands, wrists, elbows or shoulders. This Facilitated Communication method has been popular in the United States of America since 1980. This treatment claimed that it could help curing autism effectively even the severe cases. Later, there are many criticizes that this claim is not always true, and there are no reliable research findings, no accuracy or any generalization with any groups of children. Once the method was conducted double blind experiment the findings were not as it claimed. Moreover, there was a problem of sexual abuse to the children from the training assistants, caretakers, and special teachers. (Erevelles, 2005, pp. 43-63).

The findings of this study found that the families have been influenced from the meanings, practices and treatment frameworks to be their guidance. The current problem of the families is that they do not know the negative information about the autistic treatment. Moreover, the treatment information is still lacking of criticizing in reliability, accuracy and generalization aspects. The families are willing to take all efforts and resources in receiving treatments with the faithful in the medical institution. They hope their children would get better and be able to live with other normal children. Even though it might not result as their expectation; as seen in many life experiences of Joy, Por, Jimmy, Mark, Jack and my own son.

The Case of Por

Por is a 17 years old autistic adolescence. He is another one who could not attain the expected outcome of medical treatment. Day by day he is getting older, but his behaviors are regressed. He used to be able to speak then turned to not speak. He only makes sound in his throat. Also, he used to be able to write his name, now he only draws a circle repeatedly until the paper almost torn.

Por is the second son. He has one older brother aged 24 years old who works in a private company. Por is tall man about 160+ centimeters. He has clean cut hair style with neat and clean face with a bit mustache. His weight is about 70+ kilograms. His father is 54 years old. He got a heart disease, and was operated

coronary artery bypass surgery 4-5 years ago. His father works in a state enterprise company and his mother works in a government office. Their household income per month is about a hundred thousand baht a month; they have also a building for rent where their house is located behind.

Por's mother told me that when he was young, he was very naughty and unable to speak. They took him to the mainstream school from Kindergarten 1-2, he still could not speak. His mother and grandmother thought he was "tight lip", so they solved the problem with the traditional way. That was hitting his mouth with a frog but it did not work. So they took him to inspect hearing examination at the clinic in Lopburi Province, the result was normal. Then, they took his child to investigate at Saraburi Hospital. Por was diagnosed as autism. They felt shocked as at that time there was not much information about autistic. To get second opinion, they took him to investigate again at the Child and Adolescent Mental Health Rajanagarindra Institute (CAMRI). Later his grandmother transferred him to receive treatment at Saraburi Hospital. He got speech therapy and applied behavioral therapy. Until he was 13 years old, his grandmother was passed away by the car accident. His parents then took him to receive treatment at Yuwaprasart Hospital, Samutprakarn Province. They believed their son would be better, if he received treatment with the experts. His mother told me that;

"The remedy is essential for the autistic children, I did not believe in the oracle, magic process, or the traditional sacred watering. I thought that my child was getting better when he was trained. However, I had never thought that when he grown up he would become like this"

Por has never been better he could not remain still and did not sleep. When he was irritated and unsatisfied, he hurt people around him. He used to bite his mother about 3 years ago. He did not wear clothing and made loud noise and rampaged. So the family took him to the hospital. The medical team admitted him to get behavioral therapy and psycho-medication to control his undesired behaviors for 2 months. He did not back home during the weekend since the first week he was crying and shouting, although he was wearing any clothes as the hospital trained him to do so and he was trained to eat properly too. The second admission, he was wakening up and hunger at night, and then he tried to hurt his mother.

“He cried out “mama mama” but not very clear. If we did not give him foods he was very angry. So I went hiding in another room so that he could not see. If he saw me he would get upset and hurt me. So we had to take him to the hospital. The nurse explained that the medicine was not effective because we grinded the medicine tablets for him. The medicine supposed to be melting in the stomach.

The nursing team taught his mother to pour tablets into his throat orally by using the fingers pushing the medicine into his cheek bulge so he had to swallow. There must be 2 persons to do this. At present, Por is able to take tablets. When I asked his mother about the reason of taking him to get treatment at Yuwaprasart Hospital, she replied that

“We used to go Saraburi Hospital. Other people looked at him like a weirdo. He could not wait as there were so many patients and many people walking around. And we had to wait for the medicine. That was not convenience as they did not have space for special children.

She explained more about “being a weirdo” that *“his son was not remaining still, he was making a noise. By eyes of the passersby made I felt so. But at the Yuwaprasart Hospital, all were autistic children, they were the same”*

His father added that *“In the past, he could write his name, identify colors I don’t know why these abilities have gone. We expected that he would get better, but the more he gets older the worse he becomes. Only his body is grown up, but his brain is still young.”*“Autism is a matter of slow development, but it is possible to be developed up. In case of Por, he was taught but he did not get, he did not follow. This is the learning obstacle. He might be able to get a little but he did not want to express it. He became like this might because of us did not provide him more chances. We tried to take him to get curing many places but we could not do it continuously or gave him more time than others.”

His parents has still taken him to get remedy all the time, at present, every morning his father takes him to school. In the evening, his mother will pick him up and take him to the Special Education Center for one and half hour in training session then they go home. During the semester break, they hire the teacher to train him at home during the day time. They always blamed themselves when their son would not get better, as follow;

“I think we did not do the whole process. We did not train him all the time; we had to ask other to do (means his grandmother who took him to the training sessions when he was young). When he got training, the caretaker must be with him and focused all the time. But we could not do that as we have to work otherwise how we could earn for living”

At present, teachers are not available for training him because they have difficulty to manage and control his physical and emotional problems. His mother clarified more that next year he will be 18 years old, he could not continue studying in the special education system. He needs someone to take care during day time at home. His parents get worried as Por hardly communicate; he speaks only “uh ah” in his throat. He still urinates on his pants. He could not use that toilet. He moves all the time when they take him anywhere he got of the car and not return. When he was sick, the parents had to buy medicine from the drugstore as it was difficult to take him to the hospital. His father seemed to be disappointed and said ***“What shall we do, we have to accept the truth. We think we do our best, his mother puts her most efforts”***

This story indicated that his parents knew he was autistic when he was 3 years old; they took him to receive treatments continuously since then until he is now 17 years old. However, his symptoms get worse from able to speak some words became murmur in his throat all the time. He could not take care himself. His parents believed providing insufficient time as the limitation of autistic curing. If the patients get treatments, they must be recovered. If they were not better, there might be a mistake in the curing process. Such a mistake was fallen to them. They blamed themselves. The medical knowledge has a hidden power in the individuals. Every time that I visited them at home, I found that the parents have been faithful to the medical treatment. They have tried to have their son trained with the experts. When I returned to ask the teacher, the answer was that “He is too old, it is difficult to train”. Despite the fact that this child has been trained since he was young but nobody seems to realize this actual point.

The Case of Joy: Autistic girl who does not response to the medical intervention

Joy's parents usually seek for new medical knowledge. They try to take Joy to be cured but there is no progress. Joy is still the same; she does not speak just sits and smiles and often absent-minded. She loves turning around and laughing. Joy is about 15 years old. She has one sister, 4 years old. She lives with her parents, sister and grandmother. Their house is a housing estate style. There are 2 bed rooms, 2 bathrooms and 1 kitchen. She lives with her grandmother in one room. There are also 2 rooms for relaxation, next to the kitchen. She often spends day time to listen to music and play. Her house is neat and clean, there is a fish pond in front of the house. Everyone in the family loves and take care Joy very well.

The first day I met Joy's father and her grandmother. Her father called her to greet me. Her appearance is good with smiley face. She is about 160 centimeters tall with white complexion and curly hair. She did not speak a word, raised her hands to "wai" to pay respect in Thai, she was shy and ran away into her room. Her parents have good education background. They work in the factory with income about fifty-sixty thousand Baht per month.

Joy's medical history, she was delivered in normal. Her autistic symptoms were appeared when she was 9 months old. She did not respond to her name calling until 1 ½ years old. At that time, the family thought that she was deaf. So they took her to test hearing at Anantamahidol Hospital, the result was normal. When she was two and a half years old, she still did not speak. So they took her to investigate at Children Hospital but her symptoms were not clear since she could sit still for a long time and play toy normally. She practiced riding a 3 wheel bike when she was 3 years old. She was not frantic. The only problem was she did not speak and sometimes she was absent-minded. The doctor said that she was Delayed Speech. During that time, a few medical professionals knew about autism. She was transferred to investigate at the Child and Adolescent Mental Health Rajanagarindra Institute (CAMRI). She was diagnosed as "autism". She had been trained in the intensive course for a month, which emphasized fine motors practices, such as using cloth hanging clip, but still she had the communication problem.

When Joy was 3-5 years old, she joined the inclusive education at a private school in Lopburi Province. During this time, she received the behavioral therapy and speech therapy in Bangkok once a week for almost 2 years. Morning session was behavioral training for 1 hour and then practiced with speech therapist for 1 hour. They travelled forth and back between Bangkok and Lopburi Province but her symptom was still the same.

“We knew that the autistic children should be trained before at the age of 5 so that they would have a chance to be recovered. The nurses, trainers, and speech therapists tried to tell us. That was the reason why we tried to take our child to get treatments many places”

At the age of 6, she was checked up Electroencephalography (EEG) and the result was normal. She had also practiced her speech at Yuwaprasart Hospital once a month for one year. The doctor prescribed some medicine for her. Her father did not know what kind of medicine but the tablet was white, taken half a tablet each time. From my experience, it might be *Thorazine* or *Haloperidol* because Joy was sleepy after taking medicine and sometimes got oculogyric crisis, which characteristically described extreme and sustained upward deviation of the eyes, and the eyes may converge, deviate upward and laterally, or deviate downward. She was inert, unhappy and not smiling and laughing as usual. After taking medicine for 5 months, their parents decided to stop any medicine for her daughter.

“We did our best. Most of mothers with autistic children had to quit their jobs. We could not do that as our family is not that rich. We had to be satisfied with what we could do. We felt sad. Other children are more severe than our daughter, they screamed and hurt themselves but they get better and recovered and able to speak finally. But our daughter was not that serious symptoms but there was nothing better”

Joy's family was under the circumstantial of medical discourses same as Nott's and Por's family. The medical knowledge that indicated “if the autistic children had been treated in medical regimen before 5 years old, their prognosis would be good” had strong influence towards families' thoughts. Although the families struggled to find the most effective treatments for their children, the result was not their expected outcome. Por, for example, has regression, while Joy's symptoms were not better but even worse. The families who were faithful in medicine must be

disappointed and hopeless; “A disease cure framework” seemed to be meaningless to these families.

6.4 Power in Autistic Treatment

In the experience of family and autistic children found that the therapists including doctors, nurses, psychiatrists, and child development specialist, are the authority people who can use power since they have knowledge and be expertise. They also have the professional license legally. While, the families were supposed to have less medical knowledge; they are in the position of receivers could not dare to dispute or to question the treatment process. They try to be good clients who surrender to the knowledge’s power.

*“Anywhere that provides the treatment for autistic children, but it seemed that the speech therapists do not care, and understand children. They are not friendly. No matters how the children cry, they force them to do. **It really hurts me.** But I have to allow them to train my child as they are more expertise than us. Later, we have to train her ourselves. We are more flexible. Then our child could act as follow the order”*

Joy’s mother

Power exercising through the knowledge is so complicated, not a power of an individual. The power is distributed, shifted and transferred. The power also has network and capacity. The medical power has been in hierarchy. Medical doctor on the top level is a head of power exercising and has obligation in creating knowledge and power. Then the created knowledge and power has been transferred to the next level which are the nurses and other specialists. Foucault called this “the pyramidal organization of supervisory observation”. In Foucault’s perspective, power was not in term of violence but it was the power exercising based on the unequal power. It was the game that used in controlling and it seemed reasonable. (Foucault, 2006)

Unbalanced power has a network which here refers to the specialists participating in the autistic treatment as a strategy in supporting power. When the families take their children to the treatment process, they often meet with the power

exercising from the authority of the staff in every level in form of blaming the family and dominating with their higher knowledge.

“I used to be blamed by the speech specialist. Our daughter had not progressed in speech even blow her mouth, so they blamed us that we did not train her at home. Finally, they told us that our daughter is in the retard level. Every time I went back home and got headache and full with stress. They said in the neutral tone but hidden with the blamed words all the time. This made me feel even stressed I tried to think back and forth in my head, so I don’t want to go to the therapy. I attempted to do and was blamed for 8 years. After that, I could not stand still anymore. I had already stopped training for 4 years. Nothing is better”

Joy’s mother

In the autistic discourse practice, the appeared power is not balance. The specialists often are in the higher position than the clients. The specialists have authorized power as they are knowledgeable which Foucault pointed out that “Power all on one side”. This means that the knowledge power has created a state of docility to the clients. They have to accept the medical orders which are considered necessity to the treatment. This power exercising 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 autistic family are situated in the medical discourse unavoidably.

The contestation with the power here becomes negotiation with power’s techniques as the experiences of Joy’s and Mark’s families. They had to accept sufferings from being blamed or surrendered to the power for a while. After that they would be ignored and refused the treatment finally. However, some families realized the necessity of the treatment due to their expectation about normalcy. So they would negotiate with the power by changing the form of relationship to be more equal. They presented themselves as they have knowledge and been in the same level as the therapists in order to reduce the overlapped power.

“I have been blamed all the time that I did not do the homework. We trained my nephew all the time but he did not follow. But they blamed us with strong words I did not know what to say. So I told them that his mother was a nurse too. Then, everything changed, they talked to us nicely.”

Boat’s grandmother

“Normally my son would get a queue for training once a month. I had to try to contact the staff directly, sometimes bind them and bring them stuff every time. I did do everything to get training 3 times a month. If there were someone did not come to the training, the nurse would phone me. They might feel considerate us too as I was a doctor’s wife. When there were someone cancelled the training, I would drive my son to get replace them. No matter how far it was.”

Notte’s mother

Presenting one’s identity as in the therapists’ level can help at least to neutralize power. However, many families cannot do as such. They were still looked down and blamed as if all were their faults, such as

“As a mother, when I met the bad events, I had to accept them. Some staffs spoke nicely but many were opposite. Mostly the nursing assistants in yellow uniforms spoke to use badly. I did not want his father to hear this, so I contacted them myself. I rather took that as I did not want him to feel bad. The words I often faced with like “Why didn’t you do it?” “Why was the child getting worse?”. As a mother I had to take that, only replied them in my mind that this was the reason why I took my son to get treatment here. How could I cure him at home, and if my son was good why did I have to take him here”

Por’s mother

“Why didn’t you do it?” “Why was the child getting worse?” all these sentences are from the providers which mean that if the children had continuously trained they would get better definitely. On the other hand, if the children were not better because the families did not believed and followed the medical orders. These words emphasized the mistakes of the families, though the therapists have to help the

families and children with intentionally and sincerely. They should have capability to understand the children progression. Their role is not supposed to exercise knowledge/power to dominant the families. **In reality, the therapists are the ones who suppress, refuse to listen to the problems and judge the families with only medical perspective.** The families then have to accept their sufferings within medical power exercising. They also have medical knowledge to provoke their minds all the time.

“ I, myself, have been thinking and reviewing all the time whether I had put fully efforts in training for my son as such the knowledge that says if the children are trained extremely, the autistic children must be better. Until my son was 5 years old, my hope was decreased since the knowledge in my own self emphasized and reminded me all the time. I realized if my son become older than 5, the prognosis will be bad. My knowledge about autism would come in my mind all the time. So it was not wonder that why many families viewed the cause of mistakes at themselves”

I, as a researcher

Power and Morality in Behavioral Therapy

Behavioral therapy is a psychiatric treatment focusing on controlling behaviors and adjusting undesired behaviors based on the principle of learning. Behaviorism believed that “Deviant behavior is learned so it can be unlearned” (Wilson & Kneisl, 1996, pp. 65-67) Therefore, taking care of the autistic children with deviant behaviors could apply the behavioral therapy to correct the undesired behaviors by encouraging the children to learn new things.

To implement the behavioral therapy, it must be based on the moral treatment which accepted worldwide. The behavioral therapy was adopted in Thailand in B.E. 2488. However, the therapists seemed to ignore the moral principle. This study found that the treatment process of autism emphasized on changing behaviors which was very intensive, not flexible. This method was sensitive for the parents especially it was against the nature of the children with autism. The autistic children would be forced and controlled, sometimes be quarantined and punished so that they would learn the undesired behaviors. At this point, it has become an empty room for misunderstanding between the therapists and the families. The families felt that the

therapists are lacking of understanding their minds and the nature of their autistic children.

“Our son was not better. At the beginning, he ran around and the hospital staff locked him in the room. I heard him cried and screamed. The next day, we took the taxi from Dindeang when arrived at the Aerawan elephant museum, he screamed and jumped to the front seat to force the taxi driver to go back. After that I observed that he was afraid of being alone in the room. The door must be kept opened as he was afraid of closing the door which seemed as we caged him. Later, I tried to train him myself. I looked for the books and found several techniques to train him. While training him, I was also crying. Once he could speak I was very delighted. Then I started looking for Thai alphabets writing book to train him to write. He looked at it and I train him to write little by little such as how to write the first alphabet, how we draw the line from here to here, something’s like that”

Mark’s mother

Behavioral therapy becomes traditional practice in the institution. The therapists looked at the autistic person as a robot without considering their minds, feelings and emotions. In medical perspective, the autistic person had personal problems as robot-like behaviors which described by repetitive behaviors, apathy, lack of emotions or feeling, and not playing with other children. Such behaviors made the therapists focused on correcting impairment rather than dealing with a person. These practices were the strictly intensive training, lacking of flexibility and focusing on the training outcome. These practices were contrasted with the moral treatment. With reductionism perspective, the therapists ignored the individuals being (Hendriks, 1998).

Is it necessary to do the strictly intensive training? Is it possible that the behavioral therapy should only focus at learning new behaviors? The therapists must understand sense of self and the nature of autism. The training should be concerned the nature of autism and their family’s feelings. The therapists should also show their empathy and closely contact with the families. These will be the moral treatment.

Exclusion by therapists' Judgment

This study also found that in the autistic children treatment therapy there is still the power of medical personnel hidden all the time. The therapists use the power in making judgment that which children have the deviant and problematic behaviors. Such the judgment is considered exclusion the children out of the treatment programs.

“When Mark was 6 years old, he started being flurried. No one could displease him otherwise he would get angry. At that time, we took him to meet the psychiatrist at Saraburi Province twice a month. But it did not quite work as he went there and cried a lot. The staff told me that “He could not be trained as he did not participate in the training” I also observed that the trainer looked frustrated, it seemed like they preferred training only the neat children. They did not think to train the hyperactive children or severe children, why?”

Mark's mother

Such the judgment is related to the politics. The problems happened because of lacking of the ethical neutrality. Handling the children's deviant behaviors had not considered the autistic children as a problematic child but should focus at the behavior itself that needs to be corrected. The principle of behavioral therapy is to correct the undesired behaviors, why do they exclude the children with such behavior from treatment?

Morality in Pharmaceutical therapy

The pharmaceutical therapy is in a disease cure framework. It might be right with the other diseases but not with the autism. The main autistic treatments are stimulations of development, behavioral therapy, speech therapy and other learning assistant. Therefore, the pharmaceutical treatment is not the solution for the autism directly. Medicines will be prescribed in case of the deviant behaviors controlling, as well as in the cases which have seizures history, attention deficit hyperactivity disorder (ADHD), sleep disturbances, aggressive behaviors, emotional problems and self harm.

Using medication coexists with the life of autistic children at Special education schools. Most of them are severe functioning and need the medication to control their behavioral problems. The teachers told me that almost every student here have their own medicines with them. They show me the medicine bags and water bottles. Most of the drugs are Thioridazine, Haloperidal, Risperidone, and Depakin. Every day I observed that the teachers call the students to take their medicine at the same time. It is necessary for the teachers to know about the drugs. So the teachers have the roles of the teacher, the parents and the nurses. Providing cares for severe autistic children or the children with convulsion are not easy. For example,

The Case of Korn

One day while I was talking with the teacher, I observed that a boy lay down on the cushion, his eyes were vacant and his body did not move. The teacher hurried to catch him to lie and turn his face to left side. He told me that "*I guess he has seizure as his eyes were vacant. He must be turned this position otherwise his tongue would be blocked his breathing.*" For a while that boy looked relaxing and slept. Nong Korn (Alias) is 13 years old. He is skinny. He was diagnosed as autism with convulsion, and might have severe mental retardation. He has taken Depakin drug and another one which the teacher could not remember. His grandmother was the one who meet the doctor and told them about her nephew's symptoms but she did not take him with her. Then she brings these drugs to the teacher. The teacher also tried to tell her that Korn still has convulsion once a week, so that the doctor would change the drug for him. The doses of medicine were never changed because nobody saw him with convulsion at home. In the beginning, he came to school he had unstable emotions, drooling, and excretion sloppy. At present, he is better, but still needs to be trained his fine motor such as by tearing the paper, arranging beads. He can put on his PE suit by himself but cannot fasten the buttons or zipped nor arranged beads.

The Case of Nan

Nan is the 4-5 years old autistic girl. She always sits with no eye contact and her hands are moving all the time. She has white, clean and neat complexion. The teacher told me that when her mother got pregnant about 5 months, she was bleeding

but still had complete period of pregnancy. When Nan was 2 years old, her family told that she was sick and had been suction but they did not know what it was. After that she was frustrated and had repetitive behaviors, hyperactive, and self abuse. She was diagnosed as autism and mild mental retardation. She has been prescribed by Deparkin (0.25) in the morning and (0.5) in the evening. At the first time, she went to this school she was very moody and self biting. At present, she still does not speak but can follow some orders. She has 2 sisters, the elder sister is learning disorder and her younger sister is hyperactive child, and she is the middle child. While we were talking, I taught Nan to separate colors of the clips from the basket. She could do that which means she has concentration at some point. Her life is being at the boarding school with teachers and will go back home once a month.

From the case study of Korn and Nan, the drugs treatment is necessary for controlling their behavioral problems. However, some autistic children have been used psychomedications for a long time. These become over-reliance and inappropriate drug administration. For example,

The case of Nat

Nat is a 9 year old boy. He is autism with attention deficit and hyperactivity disorder (ADHD). He has repetitive behaviors sometimes. His autistic symptom is only at level 1. His aunt told me that *“when he was 7 years old, the teacher at the Child Day Care Center came to visit and told me that Nat is hyperactive child and suggested that he should see the doctor and study at a special education school. He is talkative which a symptom of autism from the doctor’s explanation. He could not stop talking. He was prescribed a drug for controlling his emotions.”* I was surprised this drug was Haloperidol 0.5 mg. per oral hs. He has taken this medicine since he was 7 years old. It is fortunately that he has not got any side effects, especially the extrapyramidal symptoms such as contracted body, drooling, rolling eyes, etc. The type of haloperidol is a conventional antipsychotic drug which has a short acting but high potency and side effects. Thus, it should not be administered for a long time. He has taken that drug for more than 3 years. Moreover, Nat’s symptoms are not severe. He is only ADHD and should take the other drug group for specific controlled his symptom, such as Ritalin, etc.

The Case of Jimmy

Jimmy is an autistic boy with hyperactivity and unable to control his sexual desire. He had psychic trauma when his step father killed his younger brother and hurt him seriously. His aunt took him to live with grandparents while his mother was disappeared. In the beginning, Jimmy has cried in bed. The teacher observed that there was a weeping sound under the blanket when she opened the blanket and found that Jimmy was crying full of tear. Then, he has hyperactive behaviors, flurried, keeps asking about his brother and drawing his brother picture. He has all these symptoms for years. Then his aunt asked her sister to send some drugs for him which are; Haloperidol (Halox2) 1x2 pc.& hs, Depakin (liquid), Artane ½ x2 pc.& hs. Jimmy has taken all these drugs since he was 9 years old, and never changed the drugs or taping the doses for 6 years. The teacher so concerned about the duration of drugs use for Jimmy. After I recommended, the teacher asked his aunt to consult with the doctor again. Finally, Jimmy has taken Risperidol in the other group of antipsychotic drugs with fewer side effects.

To prescribe the medication for children with autism, the physician would consider their symptoms. However, in this study the autistic children with some impairment have been misused the antipsychotic medicines. Moreover, many people usually think the autism could be cured by medicines. I found such questions from families' stories, such as; *"why don't you go to see the doctor, why don't take some drugs? They did not know that we took him everywhere"* *"Sick children have to take medicines otherwise how could they recovered"* Even the teachers have such a belief when they found the children with aggressive, flurried, uncontrolled emotions; the teachers will suggest the parents to take them to consult the doctors and ask for medications. Medications become necessary for autistic treatment. Care providing for autistic children then becomes "a disease cure framework". When the drug has become necessity, the problems of taking unsuitable drugs or over-reliance of drug as in case of Nut and Jimmy are still existed. The point is that if the families and people in the society could accept the impairment of autistic people, the problem of drugs using would be reduced; as following;

The Case of Joy

Joy is a 15 year old autistic girl. From her present illness, her father told me that when she was 6 years old, the doctor prescribed her the white-tablet medicine to take half tablet before going to bed. She had taken it for 5 months. Her father, mother and grandmother observed that she was sleepless, inert, inactive, looked unhappy as she did not smile or laugh as before. So they stop using her drugs. Joy's family could accept her symptoms such as absent-minded, sitting and smiling alone, etc. **As the family has learnt to live with the impairment of their child and never looked it as a problem,** but they could not accept when their child had side effect from drugs as it was too strong for the children.

6.5 The education system for children with autism

The education system was essential as the medical practices in the normalization process. This system had facilitated in the treatment process by restoration of the autistic children's capacity, improving development, adapting proper behaviors, and training the social skills to live with normal children. In the past, the education for autistic children was unclear system in Thailand. Their family had to manage the education by themselves. Some children with autism were left at home and had no education at all. Some were situated in the same class as children with intellectual impairment. In a while, there was the Constitution of the Kingdom of Thailand; B.E. 2540 required that all Thai people have the right for education which including people with disabilities, decrepitude, and poverty people. Therefore, the education for children with autism was commenced and developed more concrete respectively. Beginning with private sector, the group of wealthy families with high education made a movement to impel and claim the significance of the specific education system for children with autism, for example, setting up schools for autistic children, establishing the autistic associations and foundations, i.e. Association for Parents for Thai Persons with Autism, Khun Poom Foundation, the Janthayanont School, etc. While the government sector, as Ministry of Education, had the education reform with child-center concept according to the National Education Act, B.E. 2542. It had become individual education program for special children and developed the

project of 'School of Inclusive Education for children with autism' and the program of 'parallel classroom for children with autism' in the educational year B.E. 2547.

The principle of inclusive education was to assist children with autism to achieve their opportunities with the normal children in mainstream schools. They can imitate the normal children's behaviors and learn how to obtain acceptance from the society. They would be able to learn and improve their own capacities in several aspects in order for independent living, without being as social burden. To be studying in mainstream school would reduce discrimination and provide available social space for children with autism.

Exclusion due to poverty in the inclusive education

According to the principle of management of inclusive education in the mainstream schools, the special children had to gain the extra care in order to reduce their impairment and there were assistants such as the blinds could use Braille letters in reducing their impairments and get assistances from teachers or friends. For the autistic children, they needed behavioral therapy to reduce impairment and improve development at different ages. In this study found that the responsibility of teachers in mainstream school was in ratio of 1:40-50 (one teacher to 40-50 students). The autistic children in inclusive education did not get much attention and care giving as they should. If the autistic children had hyperactive or undesired behaviors, it was really hard to take care. So the solution was thrown to the parents, they had to pay extra money for hiring a mentor or an assistant to take care of their children while learning in the inclusive education. Many families could not afford. They had to work for living and gained a little income only to sustain their lives. Thus it was impossible for them to have their children in the inclusive education as the following;

The Case of Nat

Nat was 9 years old, he was very talkative but mostly he asked questions but did not care to listen for answers. Nat's symptom was not severe. He was not turning around or shouting (raising a hullabalo) but he had short attention or Attention Deficit Hyperactivity Disorders (ADHD) and repetitive behaviors sometimes. Nat was autism at level 1 only, which most of the autistic children in this

level were able to study in mainstream school. Nat used to study in the mainstream school during Kindergarten, 1-3 but at present he could not be in that school because of the poor status of the family. They could not afford to hire the extra teacher to take care him in the inclusive class. Nat was adopted child of his aunt and uncle. His uncle was a noncommissioned soldier and his aunt was a juice and ice seller behind a temple school. His aunt's income was not enough to hire the extra teacher in inclusive education which the hire rate was not less than the minimum wage for labor cost per day. She told us the reason that she could not take Nat to the inclusive education, she said "He knew everything, during the Kindergarten 1-3 he could separated colors though he could not write. He could write on the dotted-line letters and read a little bit e.g. A-Z, Thai alphabets "น.ใ้", and count 1 to 10. He knew the 20 Baht banknote. But the teacher in a school said that he could not learn with others, he needed someone to take care of him. We could not do that all the time because we had to work. So I had no choice but let him studied here in this special school." One year later, his aunt told me that there was no schools accepted Nat. So he had to study with the special children who were severe autistic children, though his level was not that severe.

It was obviously that the obstacle of inclusive education was the poverty, which was a tool to separate the education pattern between the mainstream school and the special education school, while the actual capacity assessment of the special children had not been counted as it should.

Exclusion and Stigmatization on Inclusive Education

In the principle of the inclusive education, it was the practice of both individual and social level. The individual level, the teacher had to consider and manage the suitable education for children's capacity as in the child-centered learning principle. The social level, the autistic children should be encouraged to learn in the inclusive education with normal children. The normal children should be taught to accept the differences and impairment of the autistic children and take them as friends. However, in the reality the deprivation and stigmata were found along the inclusive education system. For example, the judgment that the autistic children were problems as in the case of Mark, and some cases were not practiced to improve their development skills and were excluded as marginal students as in the case of Joy.

The Case of Mark

Mark was 14 years old autistic boy; he was born in B.E. 2540. He was tall and big. There were a lot of scratches all over his face as he would scratch himself when he got upset. As well as his body, there were full of scratches and mosquito bitten marks. Mark lived with his mother as his father was an engineer and worked in another province. Mark was gained preparation before school from his mother, including speaking and behaviors training. He was able to read before going to school. His mother had to do everything because there were neither teachers nor specialists agreed to train him as the reason that he was not paying attention. Sometimes he cried all the training session. With the endeavor of his mother, Mark could step pass this point finally, at the age of 5 he passed the exam and entered to the inclusive education in a private school. He could read and write Thai alphabets Kor to Hor but his behavior was not staying still. He was interested in language, he loved Thai subject very much but he was not quite interested in Maths, he hated it. He had special ability in reading without attending class at school, he could play computer by himself without coaching. However, his future had to be failed when he was not going to pass to Grade 4, with the reason that “Before going to Pratom 4 (Grade4), the teacher called me to discuss and told me that my child could not go further, he was willful and aggressive and he destroyed the classroom attentions. So the teacher suggested coming here at this special school. Actually, all these behaviors were able to be controlled and trained, I knew as I had done that all the time. The policy of inclusive education was there, it was existing but unable to reach”. His mother said with disappointed. “Moreover, the society did not try to understand me as a mother; they blamed me for making him become aggressive.” In the teachers’ view, Mark’s behaviors became a problem though in fact it would be adjusted and changed but it was not possible in the mainstream schools.

In case of Mark showed that the inclusive education was still in the policy, it was not transformed to implement the practices. It was clear that Mark could learn everything except Maths and in the teaching methods there should have a tactic to get children attention. But Mark was jumped to conclusion earlier that he could not study, as there was no education managed for particular case of autistic child like Mark. Finally, Mark was sent to the special education school, here the teachers understood

and knew his aggressive behaviors which caused from sensitive to the sound of children crying. Hearing sense of Mark was so special and different from others. So the solution guideline was trying to avoid the voice that aroused his aggressive behaviors and teaching him how to control his emotions. Although, his aggressive behaviors could be changed he could not go back to the inclusive education anymore.

The Case of Joy

Joy was 15 years old girl. She did not go to school. She lived with her grandmother. Many people might assess that children were lacked of education opportunity because of their families, but this was not Joy's case. Joy's family tried everything as typical caring for autism, so that their autistic child could be recovered and joined the inclusive education. Once Joy could not make it, her life was deprived from the society. The case of Joy reflected that the inclusive education system was only in the principle but it was still lacking of understanding in providing care and training development skills for autism. Joy started out the school when she was 6-8 years old in the mainstream school. At that time, Joy went to the special center one day a week and meet speech therapist in a hospital once a month. Joy had studied for 2 years, at that time a private school announced that they opened the inclusive education and Joy came to that school. She was neither stubborn nor naughty and she followed all instructions, but she did not speak. So she became unwanted and invisible child in the class. Her grandmother tried to be a good teacher assistant, but no teachers were taking care of her. The teachers had never trained her teaching skills of special students. It was sad that Joy did not have friends to imitate the behaviors, as modeling therapeutic concept. As instead the teachers took other normal children to play with her, they took them to stay away from Joy with the reason that their parents did not allow. Finally, the society itself deprived Joy from the inclusive education.

The above stories shown that the stigmatization process happened in the inclusive education, such as case of Mark, if he was a normal child, his aggressive behavior would be fixed and able to study in the mainstream school later on. But since Mark was stigmatized as autism already, when he had aggressive behavior, felt angry or had no attention, he was judged immediately as a problematic child and was unable to study in the mainstream school anymore. The teachers as a specialist had power

based on knowledge in evaluating and judging behaviors of the autistic children. These autistic children's bodies were controlled and managed their behavior in the same way of docile body. When they had unsuitable behaviors, they had to be warned and adjusted such a behavior as well as trained more social skills. The teachers in the mainstream schools should realize all these basic steps of autism caring. If the teachers could not handle the child's undesired behaviors, they should consult with specialists or send the children to special education to adjust the behaviors. After that the children should be back in the inclusive education again. For the case of Joy, she was mistreated and teachers did not pay attention at her at all so she became like over part in the class. There was no developing of impaired skills, no teaching other children to accept Joy and be her friends, they were not allowed to play with Joy because of bad attitude about imperfect being, etc. All these things were complicated strategies in separating Joy from the inclusive education system.

In this chapter, the result findings showed the issues of power, exclusion and stigma happened towards the body of the autistic people and families in the medical discourse. The power of medical knowledge focused on the process of normalization. This process was influenced in supervising and controlling the daily life of autistic people and their families. Furthermore, their living conditions were under worth of normality circumstances and the 'perfection' idealism. They were struggled for health seeking in treatment and special therapists/teachers. With faithful the medical system, they faced and endured the strict behavioral therapy which ignored the individual being of their autistic children. Their children also received the overdose of medicine or the use of strong medicine for too long period. They struggled with the professional's power exercising which stigmatized them as the inefficiency of practice. They capitulated in medical and education system that became commercial. This commercial system was turned to be the obstacles for the middle class to the poor of families with autism even though their children had ability to participate in inclusive education. Moreover, there were several stigmas such as the judgment of autistic person as a problem and having the inappropriate actions, the ignorance to improve the skills of autistic children, and not to teach other children in acceptance the differences. These consequences affected the children with autism as marginality.

CHAPTER VII

CONCLUSION, DISCUSSION, AND RECOMMENDATIONS

This research ‘Sensing the world: meaning, sensory experience and contestation of autistic families’ is a qualitative study that applied a post-modern conceptual framework and Phenomenological approach vis-a-vis the notion of disability. The objectives were to examine life experiences through the senses, perception, and interpretations in the daily lives of autistic families, and specifically, to analyze the life experiences of autistic families through medical knowledge and discourse, as well as social and cultural discourses that are related to the concept of disability in Thai society. Applying a postmodern approach to disability enables one to see the process in which the social meanings and values regarding the disabled/the autistic have been constructed and also how the application of power/knowledge has operated through categorization and normalization processes and caused the public image of individuals with disabilities to be laden with negative meanings that were accepted as factual in all strata of society. The Phenomenological approach, meanwhile, allowed one to understand the complexities of life experiences of families with an autistic child, ranging from sensory experiences to interpretations of familial practices. In effect, this study is a subjective investigation that tries to understand the aesthetic of autistic people and their families.

For methodology, the subjects of the present study were families with autistic individuals aged between 12-17 years who belong to the middle to lower classes, having average incomes to poor economic status. They had different livelihoods and educational backgrounds. They all lived in the urban and rural areas of Lopburi and Singhaburi provinces. The study methods were participatory observations and in-depth interviews. The subjects were selected via a preliminary participatory observation of 23 children with autism who were attending a special school, out of which ten who demonstrated some interesting patterns of behavior and whose families have consented to share their experiences and information were eventually included in the study. One family was included through personal acquaintance, and two more were

added through a snowballing method. Together with the researcher's own family, there were 14 families with autistic children in the study.

With regard to the ethical issues, this study was certified by the Ethics Committee on Human Research, Social Sciences, Mahidol University, for its data collection process. The informants all volunteered and agreed to cooperate, having signed a written agreement, and that all information would be treated confidentially. The roles of researcher were both etic and emic in perspective. The etic view involved searching for information and analyzing it from the perspective of an outsider who looked into life experiences of the families as well as interviewing related people such as class teachers, the executives in schools, etc. In particular, the emic view was considered very crucial in the study. Here, the researcher became involved in the learning process as an insider, participating in the lifeworld of the families, with an open mind and inner reflection to understand things as they were, without holding any particular ideas or beliefs. Importantly, the researcher has been involved with the subjects of the study through shared personal experiences (intersubjectivity) for a lengthy period of time, which allowed me to develop mutual understanding and feelings, to feel empathy with each other, and to learn of the lives of those families with autistic children. Thus, the researcher was able to witness the transition points of suffering in each family, to realize the sense of self of the autistic persons, as well as to appreciate their value as a human being. In total, the researcher has spent eighteen months doing fieldwork (January 2011 – June 2012).

7.1 Principal Findings

7.1.1 Meaning and Contestation for a name

To define autism involves a process of socially and culturally constituted meanings. The mainstream meaning has been dominated by the medical model, whereas in local culture one has witnessed greater diversity and fluidity in meanings, depending on the villagers' sets of explanations. Here, "autism" is a rather recent term; previously, "autistic" children would be called "mad", and such phenomena carry on even now in certain locales. Despite the modernization process which contributes to a

larger flux of information into the rural communities, the representation of autism as affiliated with the much-revered royal family (one of the King's grandsons being an autistic child), supported by repeated reproductions of stories by broadcast and online media about other autistic children being able to overcome their development impairment, have inadvertently resulted in labeling of those children, who have severe symptoms which do not fit the positive projected image, as "mad" instead of "autistic", and thereby considerable suffering by their respective families.

One way to alleviate their situations is to ascertain new meanings for their conditions. For example, the cause of a child's not speaking might be the fright of seeing a ghost, a traditional explanation based on animistic beliefs that enhanced the family's confidence that their child was actually not abnormal and may be able to speak one day. Another reconstituted meaning of autism is to view it as resulting from bad karma, part of the natural order of things, and dealt with by applying medical pluralism together with Buddhist and Brahministic rituals to treat the child, be it through consulting with a fortune teller, seeking a healer monk to bless him or her with holy water, pledging a handsome reward to some magical power if the child is cured, slapping the child's mouth with a frog, getting him or her to drink water from a Caladium leaf, communicating with spirits through a medium, meditating, and offering alms to monks, etc. Such actions provided moral support and inspiration to the family to continue their struggle. Moreover, some families regarded the autistic child as a divinity, and could thus see beyond the disability and focus instead on his or her linguistic intelligence. In effect, such positive reconstitution of meanings was very important in enabling the child to live well with his or her family.

The word "autism" is thus a cultural object laden with a myriad of meanings, ranging from an expression of sufferance, anxiety and grief due to society's lack of understanding, to a striving to be free from the disabled status and become normal again, or even an elevation in status of the autistic child to *Thep* (god) who possesses a special power above the normal people. There is also the meaning gained from experiencing the hardships from living with children with severe autism who have been labeled as "mad". Thus, the meanings of autism are diverse and do not necessarily follow the mainstream meaning, nor imply the necessity of medical regimens when taking care of the autistic. There is neither "right" nor "wrong" since

each of the meaning and practice has its place and meaningfulness for their autistic family.

7.1.2 Sensory experiences in the world of familiarity

Autistic individuals have their self identity, thoughts, feelings and emotions like anyone else, but society tends to overlook their personhood and often negatively interprets their behaviors as being weird, complicated, annoying, disgusting, harmful, and abnormal. In fact, the autistic's ways of expression are neither abnormal nor pathological; they are merely different. To understand the autistic's sense of self will thus allow one to accept and understand their behavioral expressions better, be they the attachment to people in their familiar circle and thus the fear of strangers, the attachment to certain places and thus their unwillingness to leave home or to go to unusual places and to always prefer to sit or sleep in the same space. Several of these children have a sense of order that makes them unable to change their activity timetable; everything must be done at a certain time and in a certain order. Any change or adjustment of their timetable, routine or environment will make them anxious and could end up in a temper tantrum.

Moreover, some autistic individuals may demonstrate an even more special sense of perception in one way or another. With regard to the **visual sense**, the autistic may have the ability to read by relying on their photographic memory and thus does not have to learn how to spell according to the grammatical rules. Some can reproduce the exact details of a picture they have seen onto their drawings due to their excellent visual memories. However, this may cause a problem in some cases as the autistic persons cannot modify their visual memories, for example, every object must stay exactly at the same place and cannot be moved nor changed. For the **sense of touch**; some of the autistic individuals learn about new objects and environments by tapping with their fingers, not unlike the blind tapping things with their walking stick. Their sense of touch can be used for communication, for example, when an autistic child placed his caretaker's hand on his chest to indicate he was having an asthmatic attack. The sense of touch can also help the autistic in relieving stress and anxiety such as through feeling grains of sand in their hand or crushing leaves into crumbles. On the other hand, some autistic individuals may have touch sensitivity which causes them to

feel easily irritated by rough clothes, brand tags or sanitary napkins, and some could not wear trousers at all. Regarding the **sense of hearing**; some autistic individuals have sensitivity to sound, for example, a child's cry may trigger aggressive behaviors. Some may be sensitive to loud and unfamiliar music such as rock music. While most people would find classical music relaxing, some autistic individuals may feel irritated and have a tantrum, so their families must avoid exposing them to such sound or try to stimulate other senses to reduce the sound sensory overload, such as diverting their attention from sound to touch instead. Some children may be able to shut off their hearing as if shutting down a computer, and behave as if they were completely in their own private world and not paying any attention to the external environment.

Autistic individuals may develop their sense of personhood, learning from how others have treated them. Expressions of disgust, fright, or insult will thus make some of the autistic individuals, who still have the capacity to learn and absorb those experiences, feel inferior, disliked and uncertain about how to behave. Their lives will become even more difficult if society fails to understand them and instead regards them as being weird, eccentric, or abnormal. Autistic individuals have feelings and fear, so they need a safe environment. When they feel unsafe, they will react by becoming taciturn, avoiding interactions with others, and shutting themselves in their private world. Co-existence thus requires an understanding of the autistic's sense of self and how their sensory perceptions work. Society should try to learn more about the world of the autistic in order to help these individuals to develop their sense of personhood and live happily with others.

7.1.3 Contestation for normalcy in medical discourse and education system

The majority of families living with autistic individuals have subscribed to the definition of autism from the mainstream medical paradigm, which considers autism as impairment in development, communication, and socialization, that needs to be alleviated to approximate the so-called "normal" as much as possible. The normalization process, however, has been interplay of power, stigmatization and exclusion that dominate both the medical discourse and the education system. Here, "power" refers to the power of knowledge of how to control the body i.e., the accepted

knowledge indicates that the caretakers of an autistic child must try to correct his or her impairment or get him or her to learn how to speak within the first five years; otherwise, the opportunity to be 'normal' will be reduced accordingly. The process of normalization thus involves granting values to the notions of ableism and perfection, and has thus become a tool among the circles of medical professionals and educators to control the individual body.

The struggle of families with autistic children has taken various forms. Most families expected their autistic children to achieve a 'normal' level, and have surrendered to the power of knowledge that treats their children as a "docile body". This can be seen in the phenomenon wherein the parents try all means of medical treatment available, or blame themselves for not having done enough. On the other hand, some families suffered and accepted the pain of being blamed or surrendered themselves to the power of knowledge for a while, and afterwards chose instead to ignore and/or deny any further treatment. The narratives of the experiences of the latter group uncover how the caretakers have had bad experiences with the treatment process, be they the exclusion of children marked with hyperactivity, drug overdoses or prolonged use of drugs with strong effects, or strict behavioral therapy that ignored the autistic's sense of personhood.

Likewise, the educational discourse has been dominated by the exercise of power not unlike in the medical discourse, especially in the so-called inclusive education system that has been plagued by commercialism, screening and subsequent exclusion of children with autism from mainstream schools simply because their parents/caretakers are too poor to afford paying a special teacher to help them learn along side of their classmates. Some autistic children have been judged as having improper or aggressive behavior, and were put in a special educational program to correct their undesired behaviors, and even then still could not return to the mainstream schools again. Thus, autistic children have often been excluded from learning with other normal children in the education system.

7.2 Discussion on research findings

7.2.1 Autism as a name and a category is problematic

The word “Autism” was coined in the Western medical model, while Thai society has been aware of it for only the past two decades. Thus autism seems a relatively modern disease for Thai people, almost as if it arrived with the modern times (Sanua, 1984). A closer scrutiny found such a view is not true, however. Autism has had its history, of which the myriad sets of explanations have been successively modified and adjusted to the changing time. *In this study, it was found that, in the past experiences of Thai villagers, children with Autism would be called “mad/crazy”, and although they are referred to nowadays more as “autistic”, the villagers still consider some autistic persons with severe symptoms as mad anyway. A similar phenomenon happens in the history of Western medicine.* Autism was first recorded in 1799 after the French Revolution, when J.M.G Itard discovered a child with an abnormal behavior that would be similar to autistic children at present. The child lived in the forest, appeared retarded and was uneducated. However, at that time, no one paid attention to the abnormality of this child nor considered the child to be ill. The discovery remained undefined over the next 150 years, as the naming and definitions of diseases were then still based on the theories of diseases being caused by biological abnormalities and degrees of instability (J. K. Wing, 1978).

During the last century, the state of “non-illness” would be defined as “illness” when there were obvious symptoms such as in the case of syphilis, tuberculosis, typhoid, cancer, and heart failure; they were all diagnosed as diseases. Later, the definitions or diagnoses were gradually expanded to cover more symptoms, such that it seemed as if many new diseases were discovered, for example, hysteria, obsessive compulsive disorder, depression, anti-social behaviors, homosexuality, domestic violence, infertility, and learning disabilities. *The definition of illness has thus changed from its literal meaning only to encompass a more metaphorical meaning* (Szasz, 1974). Similarly, with regard to autism, social scientists contend that the higher incidence of autism might relate to the broader and more inclusive diagnostic criteria which resulted in an increasing number of children diagnosed with

having autistic symptoms, in addition to a greater awareness of doctors and the general public (Grinker, 2008; Silverman, 2008).

Before the term “autism” was adopted in the medical lexicon, the American Psychiatric Association had specified the diagnostic criteria for children with such symptoms, both in DSM I in 1952 and DSM-II in 1968, as Schizophrenic reaction, children’s type. Schizophrenia was then used to refer to individuals who demonstrated certain psychiatric disorder, aka “madness.” At present, however, schizophrenia is associated with adults’ illness, of which the symptoms usually started during the late teens to early twenties (18-27 years old). The term Schizophrenia, children’s type has since been replaced by the terms “Infantile autism” in DSM III in 1980 and “Autism Disorder” in 1987 respectively. From then on, the term “autism” has become known worldwide. Nowadays, the term has been changed to “Autistic Spectrum Disorder” (ASD) in order to broaden the meaning to cover the impairment in development of both high and low functioning individuals. Subsequent researches pointed out, though, how the use of such a broad definition has resulted in the stigmatization of the High Functioning or Asperger’s group, thus a recommendation to separate this from ASD in DSM V in 2013. (Bagatell, 2010). Asperger’s is not separated from ASD but has been changed to the category of functional autism. At present, some researches are being conducted to study the relationships between autism and schizophrenia (Bates, 2013; Sifferlin, 2013) because the symptoms of autistic adults are similar to negative symptoms in schizophrenic patients. Therefore the names or diagnostic criteria might be changed again in the future.

Those who have the power to determine which person is mentally ill and must receive diagnosis and treatment are psychiatrists or psychiatric institutes. At present, the American Psychiatric Association is the body that produces the Diagnostic and Statistical Manual (DSM) and the International Classification of Diseases (ICD) that specify the diagnostic criteria used worldwide until now. However, the current definitions have been drawn up by not only physicians and psychiatrists, but also by representatives from other important sectors in the society, namely philosophers, lawyers, and experts in various fields. The labeling of mental illness or disorder has thus encompassed other aspects of human experiences like failure in family life, divorce, celibacy/singlehood, or infertility that results in an inability to fulfill the

parental role, etc. Ironically, while mental illness is now considered a metaphorical disease, a number of therapists continue to subscribe to the predominantly science-based paradigm or emphasize their role as physicians, thereby turning the psychiatric diagnoses into stigmatizing labels. In effect, psychiatry does not only concern medicine but also politics and morality, and the healing of mental patients should therefore take into consideration both the medical processes as well as social, cultural, and moral factors (Szasz, 1974).

The process of naming and framing what constitutes disability depends on the political conditions and philosophical principles of each individual country. In Western society, the naming and framing process is based on the philosophical principle of equality (Benedicte Ingstad & Whyte, 1995). The definition and classification of persons as disabled and the categorization of the severity levels of disability have thus been used as criteria when passing legislation concerning the provision of welfare, management of environmental structure, and citizenship rights to achieve across-the-board equality. The diagnosis has thus become a tool that is tied to the political issues of the day (Brown, 1985). In other words, **the diagnosis is the politics of definitions** (Conrad and Schneider, 1992:22). In Thailand, the naming and framing of disabilities follows the Western concepts. The classification of “autistic/disabled persons” alerts the society of the problem and allows the autistic individuals to access the health service and other social assistances, to receive protection under the law as well as a monthly allowance worth 500 Baht a month. The parents of autistic individuals are also entitled to tax benefits worth 60,000 Baht a year. In the future, if these disabled persons get employed, they can ask for tax deductions worth up to 190,000 Baht a year (Revenue Department, 2012).

In this study, it was found that the categorizing of “autistic/disabled persons” and provision of healthcare, education and other welfare services has been beneficial, thus allowing the families of autistic individuals to accept the labeling more easily. On the other hand, the naming and framing of what constitutes disability may not always bring a positive result. After a person is diagnosed or named as being autistic, his or her way of life could be drastically changed, becoming subject to a certain form of control all the time. Among the autistic individuals included in this study, aged between 12 and 17 years, it was found that those who were diagnosed as

being autistic usually encountered problems at school. One example was Nong, the genius painter who had problems learning arithmetic. After diagnosis, he was given a special tag pinned on his uniform that informed everyone else that he was “special”, prompting his friends to tease him as being an “Autistic child” and thus a constant embarrassment. Nong thus continues to hate the term even now, since his life has been affected by the diagnosis. Another example was Note, the model autism. After being diagnosed as autism, he was put under control and forced to correct his behaviors, by both the so-called experts and his mother. He must follow the treatment program that has been accepted by mainstream society. In the future, if we follow these autistic individuals into their early adulthood, we might see the social impacts in various ways, be they in terms of job opportunity, selection of mates, and lifestyles.

Szasz (1974) explained that the medical definitions or diagnoses were a social construction and a form of social control. The definition of mental illness and the psychiatric knowledge were born out of the history of power and economic and cultural pressures. The presence of differential diagnosis _ determining if a person is ill or not and if yes, whether the illness is physical or mental _ has turned a physician’s role into that of a judge who can determine the patient’s fate. Following the medical diagnosis, the patient’s life will be changed wherein he or she will encounter difficulties in adapting themselves to society.

From the post-modern perspective, however, this naming business 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 an autistic family, the power of knowledge has penetrated into their identity. 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 was initially willing to subscribe to the medical discourse but when the treatment result was not to their expectation, they have chosen to disregard

the naming of autism and turned instead to positively accept their child as she is. Likewise, in Jimmy's family, he was labeled as being "mad" according to the villagers' set of explanations, and the family was subjected to the power of mainstream social and cultural discourses that try to influence what should be done toward Jimmy's body and his family, through discrimination and social exclusion. However, the family has been struggling to free themselves from the power of such naming.

Apparently, the naming and categorizing of autism has been a social construct wherein the mainstream biomedical model has dominated. However, the medical definitions have to be constantly modified and adjusted not unlike the lay's explanations. Indeed, the lay's definitions of autism may not be as widely accepted but they are also meaningful, as each and every definition comes with its own set of 'discourse practice'. For example, when the locals defined someone as "ill and not able to speak because they had been frightened after seeing a ghost", the corresponding practice must address the given cause of the illness be it through seeking to communicate with the spirit through a medium or consulting the fortune teller. Such animistic definitions of autism were found in the Himalayan communities some local villagers there believed their grandchild was possessed by a devil because the child's parents had defied the holy power of the community by refusing to sacrifice their goat when the child was born, thus the punishment (Grinker, 2008). In contrast, during the 1990's, most parents in Southern India did not consider autism a problem, and it was acceptable to the families. But as Western medicine became more influential, the meaning of autism in India has changed to follow the Western paradigm, although the patterns of treatment for autism continue to employ a mix of Ayurvedic treatment, such as SuperNu Thera, pranic healing, reflexology, astrology, acupuncture, speech therapy, vitamin therapy, tutoring, Siddha medicine, behavioral therapy and yoga (Daley, 2002).

The present study also uncovered the naming of the autistic as a god, wherein the corresponding practice was in the forms of acceptance and even respect with no discrimination or condescension. There have been similar instances, such as in an ultra-orthodox Israeli community which believed in reincarnation and viewed autistic children as having a high spiritual status and a special ability to perform

religious rites; for a child was believed to be a medium from heaven, and a disabled one was not at all a sinner but the spirit of a reborn Jew (Shaked, 2005). In Sri Lanka, the families accepted autistic children as reincarnated warriors (Leonard, 1985). In Latin culture, there was a belief of “fatalismo” _ one cannot change much of his or her fate after birth. Such belief systems influenced how the locals chose the different treatment methods based on their folk illness beliefs, which may delay their search for western medical therapy (Flores, et al., 1999; Pachter, 1994). On the other hand, in this study, most families of autistics did not have problems of delayed search for Western medical treatment, but many have experienced failure there and thus resorted to the local therapies or combined both methods in the treatment of their autistic children.

7.2.2 Epistemology in taking care of Thai Autistic persons: the diversity of knowledge in health care

In the bio-medical model, autistic children are children with impairment in development, communication, socialization, and behaviors. Medical personnel have been trying to identify the causes and treatment methods. Previously, it was believed that the deprivation of love and nurturing from the child’s mother, dubbed the ‘Refrigerator mother’, was the cause (Bettelheim, 1967), thus the practice of psychoanalysis with the family. Subsequent research has pointed to brain disorder (Gurney, et al., 2003; Pornprot Limprasert, 2008; Silverman & Brosco, 2007; L. Wing & Potter, 2002; Yeargin-Allsopp, et al., 2003), and the treatment methods thus focused on rehabilitation of the child’s skills, encouraging his or her abilities and development, and correcting their behaviors. The treatment strategies have ranged from speech therapy to applied behavioral therapy, psychotropic medications, practicing social skills and learning in inclusive education. Underneath the various components, all these treatment methods have been restricted to the biomedical model.

Modern researches have come up with new treatment techniques, such as Magnesium supplements, hyperbaric treatment, stem cell transplants, and so on. Every treatment has to be scientifically proven as whether or not they are efficient in treating autism, and the methods have to pass a set of objectively measurable tests in compliance with the existing scientific and internationally accepted methodology. However, the newer medical technologies seem to be increasingly reductionist in

nature, as they try to determine abnormalities in certain parts of the body, be they the genes or the deprivation of oxygen, instead of looking at the whole existence of the person undergoing treatment. In short, the bio-medical view of autism as a disease has failed to respond to the personal needs of both the autistic persons and their families.

The present study has uncovered a diversity in the meanings of autism as given by the families of autistic persons, ranging from expression of sufferance, anxiety, and sadness at society's lack of understanding, to a striving to become normal, an elevation in status from the so-called autistic to that of 'a god' with special prowess, and experiences of hardship when the family's member who has severe autism is labeled as "crazy". In effect, the representations of autism have been much more diverse than seen in the bio-medical model.

The different definitions of what constitutes Truth have thus led to the different epistemologies and methodologies. The medical science epistemology relies on the scientific methodology and its objective measurement methods. On the other hand, the lay's or Indigenous Epistemology is based on a worldview dominated by beliefs in the existence of the Three Parallel Realms (*Trai Phume*), animism and folk Buddhism, wherein no objective measurement methods can ever dissect such abstraction of truth adequately.

"No medical system could respond to the society in all areas, in all places, and at all time. This was because the knowledge gained from the medical theory of each system referred to one or another truth but might not be sufficient for explaining the knowledge gained from the theories referred from each series of truth" (Komatra Chuengsatiansup & Yongsak Tuntipidok, 2550, p.148)

In modern society where science prevails over humans' thinking, only the scientific methods have been accepted, with their emphasis on objectivity in examining the truth, reductionism that pays more attention to the individual parts than the whole, and the precision and reliability considered the standards of knowledge construction. The search for science-based treatment methods is thus viewed as being right, legitimate, and superior to all other treatment modalities. In the present study, a number of families have been faced with questions like: "Why don't you take your child to see the doctor?"; "The physicians there are very good"; and "why doesn't the child take the medicine?". The predominance of mainstream medical discourse has

pushed many families to follow the bio-medical regimen, while other families that do not subscribe to a similar regimen have been looked down upon as being out-of-date, old-fashioned, unscientific, and responsible for the failure of the child's treatment.

However, a number of the autistic persons included in this study have already tried such science-based treatment methods, but with poor results. The symptoms have not improved despite the claims of efficiency. Worse, some children have been treated improperly, receiving wrong prescriptions or even overdoses. The negative results are usually attributed to the family for not regularly practicing the treatment regimen at home, with no attempts to identify any shortcomings of the treatment method itself. Thus the family was criticized for not being able to apply the knowledge to treat their child well.

Therefore, even within the biomedical model, there should be acceptance that certain illnesses may not belong to the "Disease cure framework". Most illnesses in the "Disease cure framework" usually have a "literal meaning", i.e., they could be cured, for example, diarrhea, cold, heart disease, etc. On the other hand, illnesses like autism have a "metaphorical meaning", i.e., the treatment methods continue to be in the experimental stage with no absolute treatment formula or guaranteed results. Unfortunately, when the treatment results do not turn out as expected, **the family of the autistic person is often blamed as the wrongdoer.**

The history of medicine has witnessed a series of trials and errors with rationalization being applied every now and then to correct the incurred mistakes. In the past, the spread of epidemics, physical disabilities and other forms of suffering, as well as socially unacceptable behaviors including madness were attributed to supernatural forces. A number of theories thus arose, such as the theory of spirit possession that has some ghost or alien object inhabiting the human body thus causing the sickness, or the theory of sorcery wherein a sorcerer could recite a magical mantra to cure the person, etc. Intriguingly, the use of Peyote by a native Indian tribe in Mexico to treat sick people was once frowned upon by the medical establishment that argued the substance contained a hallucinatory agent called mescaline, which has since been used in the production of Reserpine, a common sedative nowadays. It can be seen then that a number of 'discoveries' were often accidentally tied to the local myths, rather than a process of systematic development being held as rational. Similar to the

local myths and beliefs once accepted in the past, modern-day practitioners also have their own sets of beliefs and myths to which they subscribe. Indeed, several theories previously considered pseudo-scientific are now well accepted and have actually been through the trial and error process (J. K. Wing, 1978).

The development of medical science has often disagreed with and even challenged Folk-beliefs, while propagating the views of what good health should constitute among the public, supported by the use of probability statistics vis-a-vis the incidence of diseases. Here, the Disease Theory has been widely accepted. However, it has since been found that the Disease Theory could not explain every condition, sickness, or social deviance or disorder. The medical treatment methods may be highly beneficial but have often ignored mental aspects and social contexts.

In effect, although scientific explanations have been commonly used and prevail in the mainstream treatment of autistic children, such rationalization-based medical models also have limitations and cannot answer every question. The shortcomings become evident especially when we consider an illness like autism that encompasses a wide spectrum of disorders, ranging from limited social skills (difficulties in communicating with others) which are considered rather mild, to the more severe symptoms such as disruptive behavior, social interaction and communication (non-stop talking and refusal to listen to others, repetition of vocalization or echolalia, or inability to speak), or even lack of ability to control oneself altogether. The processes and methods of medical treatment can be effective for some individuals, but not for several others. Moreover, such processes have caused anguish to the families, prompting them to search for new meanings and views of autism, be it as a form of divinity, a result of bad Karma, or ironically as autism-but-definitely-not-madness that can happen to anyone including a high-class family. These meanings are not based on scientific logic, but rather attempts by the individual families to come up with alternative sets of explanations to alleviate their misery, while searching for indigenous knowledge to take care of their autistic children. Therefore, the science-based epistemology cannot be used as the principle in caring for every autistic child, while the Indigenous Epistemology and the practice of folk Buddhism may provide some answers to some of the family's problems, and thus should receive more attention from the Thai public.

7.2.3 Contestation for Normalcy: the life experiences of families with autistic children

7.2.3.1 Contestation with power and Stigmatization in medical treatment

The principles for caring children with autism: after a child was diagnosed with autism, they will receive treatment in Western medicine such as behavioral therapy, social skills training and speech therapy. The drugs administration will be considered only in patient with aggressive behavior, hurting themselves and some symptom such as seizures. For autism treatment, it requires a multidisciplinary team such as clinical nurses, speech therapist, occupational therapist and activity therapist including special education teachers. Therefore, the relevant personnel who can take good care of children with autism are the expert professional from medical institutions and educational institutions. This study found the issue of power, stigma and discrimination by the medical systems that acted on to children and families with autism.

The word "power" means the medical knowledge that conducts directly to the body. It has been created from the expert knowledge in medical field. The medical knowledge has diffused into parents with autistic children and drives them to seek for treatment and inclusive education. The autistic children should be treated and be able to speak before at age 5. Otherwise their opportunities to speak would be decreased over time. This knowledge caused the process of commercial medicine. Furthermore, there is the power-relation between the therapist and the autistic family, and between teachers and children with autism. Therapist gains superior power/knowledge than parents. While parent will surrender to that power and give everything to their children for receiving treatment. They can bear all the blame as bad caring their kids until their kids could not improve their capacity. The parents must accept and cannot claim anything. Some parent may blame themselves and stop seeking any medical treatments and despair to it.

The establishment of power system has begun in Thailand since the modern society. The era that has changed the power structure and the emerged of new middle class during the year BE 2498-2520. The social, political and cultural condition of Thailand has been influenced by the United States of America or

called "Americanization". After World War II, the U.S. had used Thailand as an army base for operating the Cold War against the socialist countries. The U.S. fully supported the authoritarian governments of Thailand and pushed Thai government to accelerate the country development to be the modern state. The US dedicated budget, technology and manpower to Thailand as stated in the National Economic Development Plan 1 and Plan of National Economic and Social Development, issued 2-4. The result of the country development to be modernized caused the formation of new middle class which had major role to Thai social movement. The number of students and intellectual persons were increased rapidly. This era had changed Thai society from agricultural society to be modern capitalist society.

For doctors and teachers are the directed outputs of the development and modernization policy by accelerating the expansion of education. This group was ready to be the part of modern power structures. They were ready to exploit those who had less knowledge than them. Doctor who represents the power of new knowledge can completely defeat traditional medicine in Thailand. They could exploit from local people with the merciful face (Choosak Pattarakoolwanich, 2553, pp. 315-334). About the autistic children, they have gained the treatment based on Western medicine and personnel such as speech therapist and occupational therapist which has highly demand from autistic families. Some family offer to pay extra money to bribe the therapist therefore their child can be trained at the first 5 year olds. Government could not provide the available treatments. The poor families, therefore, cannot access this treatment.

The psychiatric therapies based on moral treatment. From this study, there were inappropriately administrated in psychotropic medication therapy. Some autistic individuals had received overdosed medication regardless of side effects. Behavioral therapy which focuses on the outcomes looked over the human being 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. In speech therapy, if a child who has at age over 5 still cannot speak; family would be blamed for that failure. Many professionals refuse to train the autistic individuals who are growing up to adolescences, these seem to be excluded them from treatment process. The autistic families have to contest with power, stigma and discrimination through

treatment process. This process is needed to be changed and solved for the better solution.

7.2.3.2 Contestation for Normalcy in Inclusive Education

This research study would like to claim that even though there was the excellent education policy for autistic children, and management of inclusive education based on normalization concept, there were still problems occurred. These situations are similar to the beginning period of management of special education in Norway, which was considered as a successful model in Welfare state and Equality (B. Ingstad, 1995). Even in the countries as the US and Canada, at the beginning period of arranging the special education in mainstream schools, there was the social deprivation problem as well.

Based on this study, it could make the summary of problems in managing inclusive education for Thai autistic children in the past decade as following; the government has identified the policy of inclusive education in mainstream school but in the practical way there are no preparations for teachers, their responsible works are still high, the teachers themselves lack of skills and experiences in taking care of autistic children, they do not understand the natures of autistic child. Though there is a principle of Individual Education Program (IEP), in the reality the children are still evaluated universally, not specifically. There are no additional skill trainings to correct the impairments of children such as the children who were good at language but unable to calculate, lacking of continuously skills training, etc. Moreover, another important problem is the teachers tend to ignore taking care of the autistic children and treat them like the surplus or unwanted person in class. To solve the problem of inclusive education in the individual level means to let the family take responsibility in finding solution alone; in fact, normalization principle the autistic children and disabled people should have been responsibilities of the public. This phenomenon is the same as the situation in Norway about 1973. During the beginning period of inclusive education, the mainstream school which was responsible for the education for the disabled people did not consider the types of disability when it organized the education. The teachers were lacking of expertise and experiences in teaching as well as insufficient background in taking care of special children (B. Ingstad, 1995).

When analyzing the problem of inclusive education in Thailand, it is found that the inclusive education is in the competitive world and in the context of perfectionism that people in the society praised the perfectness. Therefore, the management of special education in mainstream schools is not simple. Education is considered very important to Thai people and it is giving higher pressure to children. In the historical contexts, only high class people were gained education, the common people were hardly reached to the education as they were slaves until 1890 (B.E. 2435-2448) in the reign of King Rama V, who kindly developed and modernized the country as the Western countries. There was a process to modernization from absolute monarchy, expansion of government official system. People in high society were no more retained the government works for them anymore. It was the period that Thai common people had higher education, and adjusted their status to be in the exclusive level. Many of middle class people gained the government scholarship to study abroad (Nujaree Jaikaig, 2008, pp. 36-37).

In addition, there was another period of expansion fundamental education in era of Field Marshal Sarith Thanarach (B.E. 2501-2506). There was more development in rural area and the government education office in B.E. 2504 was received budget supports from The US to operate in cold war. This era, the educated people preferred to work as government officers as the discourse of being bosses/renders and sent to control rural areas. Later, there were changes from agricultural society to be modern capitalism society. There were many new middle class people emerged and rural people stampeded to the capital city. The middle class people in the provincial areas sent their children to the universities in the city, while the high class people in the city tended to send their children to study abroad. (Anderson, 2010, pp. 4-19) This shown that the discourse of being bosses/renders was believed that if people got higher education their opportunity to get better jobs and higher position was higher too. Especially, when they graduated from famous universities, therefore this became more pressure for new generation children. Education became like in the competitive world and being a person in the competitive world must have high capacity. The space of inclusive education with normal children for the autistic children seemed to be more limited. Also, the deprivation, stigmatization, and mistreating in the inclusive education had already pushed away the

autistic children to be in the special education. The phenomenon of Thai autistic children that happened was not different from those happened in South Korea where the government had not provided more educational supports as it should. They had to grow up in the competitive world and there was only limited space of education for them (Grinker, 2008).

The ideal of perfectionism appears in the inclusive education. Many parents wanted their children to go to famous schools, being in good environment, having friends who could support them in education and having families in the same economic status level. Most of autistic children in the inclusive education could not help their friends. It was even worse if they had intellectual impairments, not speak or having undesired behaviors, they had no friends to play with. In some worse cases, the parents of normal children did not allow their children to play with the autistic ones. They had the attitude that they need their children to be perfect; such an attitude already deprived the autistic children from the inclusive education unconsciously. Besides, the teachers emphasized on competitive exam and to response to their parents' needs, there were no focusing on acceptance of personal differences, loving, sharing each other. All these things were left out, and the autistic children have been taken out of the system.

Problems of arranging the inclusive education in Thailand at the beginning was similar to the operation of community-based mental health policy in America in the first decade of 1960s which was not rather successful. One reason was the negative attitude towards the mental disabilities was reflected the policy that encouraged the patients back to community and reduced roles of institutes in taking care of mental illness patients. The deinstitutionalized policy seemed to push the burden to the community and create fear for the community people (Brown, 1985). The negative attitude towards mental illness was existed in the middle era and the beginning of modern era.

This phenomenon happened in Canada. The policy of inclusive education for the disabled children in the mainstream schools faced the obstacles after deinstitutionalization movement in 1980s. Although, the normalization principle had adjusted the philosophy in taking care of disabled people in the giant step manner, the children with intellectual impairment co morbid psychiatric symptoms so called

“Cinderella of Psychiatry” was still the problem because of their behaviors. Such behaviors were accepted in asylum or institutes but not in the community. The community people were lacking of understanding in taking care of this group. So these children were still excluded and marginal status (Ouellette-Kuntz et al., 2005).

In this finding, if the autistic children with undesired behaviors were in the inclusive education with normal children, they had to adjust themselves a lot under the high competitive circumstances and the ideal of “perfect”. As well as their families had to make preparation in all aspects from physical, mental, social, economic status, in order to reduce the differences as much as possible. Otherwise, their autistic children were deprived out of the system finally.

7.2.3.3 Striving for Normalcy: Medical model and social model of disability

“To be normal” in the series of medical explanation was based on the Medical model of disability considering the disability as individual deficit. This medical disability focused on preventing, curing, and restoring the efficiency. According to this study, the families accepted that their children were deficit and needed to be solved. This was based on the medical model. Meanwhile, the families confronting the sufferance from the society had to struggle to be free from sufferance. From their experience, taking care of autistic children was not based only on Medical model of disability, there 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 toward their livings.

Similarly to the autism researches in Thailand, most of them tried to find the methods of stress reduction for the families. All were in the framework of Medical model of disability, focusing on working individually not socially, for example, giving consultation in group (Gunvipa Hongngam, 2003), developing the plan especially for the families of autistic children (Meena Wongsalee, 2005), planning to encounter family problems (Onsiri Pisek, 1999), adaptation and needs of autistic child parent through psychological reaction stage (Wongdern Tacharin, 2003), promoting the self-efficacy of caretakers (Patrabul Puttahraksa, 2005), caregiving preparedness among parents of autistic children (Somjit

Pheephimai, 2004) and social support among families with autistic children (Nareelak Mongkholsirigul, 2003). However, a lot of researches were in the frame of Medical model of disability, there were some researches attempted to consider the problems which caused by the experts, for example, problems in providing behavioral therapy. That finding indicated that the therapists focused on changing the behaviors of children without considering the families. They did not understand the limitation of the parents in the role of special teacher and caretaker. They were tired and stressful from nurturing their children with problematic behaviors all the time. Some families got conflicts while other families were broken. This recommended the therapists should concern the family aspects combining with behavioral therapy (Harris, 1984). However, another research found that the family therapy which performed with behavioral therapy was not attained the outcome. The Family-centered practice existed only in principle, not in practicing. In principle, the therapists must transfer the power in decision making and practicing to the families. But the therapists mainly used their decision making instead. They did not realize or pay respect to the decision making of families (Dodd, Saggars, & Wildy, 2009a).

Although the Medical model of disability was necessary in taking care of autistic children, this study indicated that there was power exercising in medical discourse. The autistic families were struggled in the behavioral therapy which were strict and ignoring the autistic individuals' being. The autistic individuals were also taken the drug overdose and prolong use of the high potency drugs without concerning the side effects. Professionalization was used in decision making and excluding the autistic individuals who labeled as a problematic child. Moreover, the autistic families were blamed when their children could not correct their undesired behaviors. Although the knowledge and proficiency was also important for the therapeutic process and rehabilitation for autism, the problems as above were necessary to concern especially the moral treatment, ethical drug administration and respecting the personhood of autistic individuals and their families.

For the Social model of disability, the autistic families did not demand the previous concept which focusing on the social aspects and ignoring the individual deficit. They demanded both medical and social aspects in order to correct their children as normalcy. The previous concepts of the Social model of disability

revealed the disabled persons were oppressed and excluded from the society systemically. They were categorized as handicap people by the professional groups. They wanted to have the civil right without the limitation in health, education, and occupation. They wanted to have their identity as they were. The society should accept their identity without insulting and stigmatizing. In living with autistic individuals, I agreed with the recommendation of 'Social construction of disablement interpretation' (Smith, 2010). This model focused on both individual and social aspects. The concept believed that disability was the individual's impairment and the negative social construction affected toward the identity of disabled persons.

Considering autism and the concept of 'the Social construction of disablement interpretation', it was found that the knowledge was produced and reproduced the negative image of autism. In medical discourse, autism viewed as a disabled and dependent person who needed to be treated. In socio-cultural discourse, autism with severe functioning viewed as the person who could not control oneself or madness. These constructed knowledge worked together until the image of autism as the incompetent and devalued person became true. Since the meaning of autism was constructed, why do not we construct the positive meaning? As the experience of autistic family in this study, their experiences told us to think positively. Their autistic children were not the symbol of difficulty, exhaustion, uselessness or their Karma. Adversely, the families thought that Karma and reincarnation of parent-child relationship had motivated them to nurture their autistic children.

7.3.4 Anti-psychiatry: Sensory experience of person with autism

Autism was categorized as pervasive development disorder in psychiatric illness group. The criteria of autism included repetitive behavior, the impairment in social relation, communication, and speech development, and lacking of imagination. In perspectives of Psychiatry and Cognitive Psychology, autism views as the person who had limited neurodiversity of human mind. Therefore, their emotional expression was indifferent. They did not have intersubjectivity and were excluded from the society (Solomon, 2010).

According to this study, there was the information supporting that autistic persons had identity, emotion, thought, and feeling like normal people. Some of them could not speak but they could communicate by using their vocal sound, non-verbal

language and touching. Every vocal sound had meanings, such as hungry, angry, or going out. The families could understand when they had the intersubjectivity. **This study indicated that the autistic persons could communicate in various different ways if we had closed relationship and empathetic understanding. Importantly, using norm could not judge the self identity of autistic person.** As Sterponi and Fasulo (2010) stated that the communication of autistic persons occurred from the basic trust in the intersubjectivity between children and parents (Sterponi & Fasulo, 2010). Moreover, autistic persons often had repetitive behaviors, turning around, and rocking the body. They loved to laugh to themselves and stay in their personal world. Such behaviors meant difference, not abnormality. This supported by the statement of Sack (1995) in *Anthropologist on Mars* that:

“Although Dr. Temple was different from us, she was not inferior to us. She was the special kind of human with the ability in perception, thinking, and action differently. It was not the abnormality.” (O. W. Sacks, 1995, p. XViii)

Considering that autistic persons had social impairment may not correct. If analyzing their special senses, some sense affected the interaction with other people, for example, the sense of place, the attachment to familiar people, and the sensitivity to sound, etc. This study found that autistic persons had interaction only with familiar people. They did not want to go to unfamiliar places. They liked to stay home and go to schools with repetitive routine. Changing their environment and their daily routine aroused them to get temper tantrum or undesired behaviors. Grandin, an autistic person, explained that changing the environment and routine caused them to be frightened, anxious and severe to panic in some case (Grandin, 2006).

Although the autistic persons have seldom interaction with others, they could perceive and interpret others' acting, even those with severe functioning. Their social impairment may not cause by their perceptual ability directly. From this study, one reasons of social impairment was the lack of the learning experience 'how to react with other people'. They would difficultly interact if the society did not understand, not accept, and stigmatize as bizarre or madness. Their lives were excluded from the society. Same as disable persons did not want to be socialized because they had to encounter the prejudice toward disabled people. Even though there were more supporting system for their convenient living, the disabled persons were still insulted

until they felt as worthless persons (R. Murphy, 1995). Thus, if the autistic persons were stigmatized in the form of insulting, looking fearful, danger, and madness, they would perceive and embody such experiences of stigmatization. They would feel depressed, devalued, and uncertainty in how to act and react to others. Their expression as mute, staying alone and not socializing with others, made them feel safer in the difficulty situation. This was similar to the study of homeless people with chronic psychiatric illness in Boston, USA. They had to struggle to live in the streets as homeless and to be controlled in the recovery center as patients. Their ultimate expectations were not receiving the treatments but were the places which were safe and friendly. This reflected the sense of displacement as marginal group in the society (R. Desjarlais, 2005).

Lastly, in medical perspectives, autism was categorized as the person with disability needed to be corrected their impairments and changed the undesirable behaviors, for example, laughing and seeing in their personal world, turning around, and laughing at the opposite letters in the mirrors. The autistic families in this study did not agree with that. They accept the differences and the nature of autistic persons. They viewed such behaviors as the nature of autism. They let their children to stay in their personal world sometimes, in order to make them happy. They denied using the psychotropic medication due to concern the adverse effect. In case of Ton, his father understood his sense of touch. To touch the delicate objects was desensitization to make him calm and happy. His father denied the professional suggestion to prohibit his son's behavior. With the medical reason, his son would be worse if he let him stay in his personal world while squeezing the dry leaves. Squeezing the dry leaves was considered as undesired behavior to be resolved. His father still insisted and thought that touching was the best method to reduce his son's aggressive behavior.

Furthermore, the autistic persons had strong sense of place and attachment to familiar person. They were afraid of strangers and being in the new environments where no one could understand them. In medical perspective, this behavior was considered as the problem of interpersonal relationship. They needed to be treated with the social skill training program which emphasizing individual level. If the clients could not adjust their behaviors, this meant that they failed to practice themselves. Same as the parents failed to train their autistic children. This perspective did not

concern the social aspects which altered the interpersonal relationship. Therefore, understanding senses of self of autistic persons is very important for the medical professionals need to learn and apply to the therapeutic treatment and rehabilitation program.

7.3 Limitation of study

1. This study analyzed everybody in the autistic families who involved in taking care of autism, such as grandfather, grandmother, aunt, father, mother, brother, etc. This study did not analyze the parental roles; for example, the ideology of motherhood affected caring of autistic children, the conflicts of father between the role of responsibility as social expectation and the role of caretaker.

2. The samplings were the autistic persons and their families who were in the middle to low class. I, as the researcher, did not focus and analyze the issue of class. This study found there was only the poor families could not access the medical service and had to use local wisdom treatment instead. For the middle class families, they could access the medical service; however, they applied various treatments. Some family had chosen both medical science and local wisdom. Some had selected one of them. If the sample group was the high class families, the research result may be different.

3. The age of sample group at 12-17 years old was beneficial to identify the problems during a transition from children to adolescence. Studying through rite de passage could understand the suffering process, especially the struggling with miserable feeling until passing the process. However, it was difficult to assess the data during their autistic children at first 5 years old because their remote memories were limited. Some family has passed the suffering for a while, so I could not acknowledge their feelings.

4. Sense of some autistic cases was very interesting but their families did not allow to indepth interview. They were willing to participate only in greeting and parental meeting. Some family did not allow visiting their homes. So the data of living with autistic individual was limited. This data was important because some autism had behaviors at home differently from at school. For example, Jack did not have

aggressive behavior at school. He could help the teacher to care his friends. While, he was aggressive and assaulted his mother at home.

5. Autistic persons had thinking process not logical, but associated, for example, talking about “dog” meant running outside (Grandin, 2006). However, according to this study, it was very difficult to approach the thinking process of these persons especially for the non-verbal children. Therefore, the data was inadequate and some was limited to be summarized. Some situation could be understand, for example, Jack asked his mother, “Can I hurt your eye?”. This meant if the mother still told some bad things about him, he would use the stick to stab her eyes. When I asked him to visit my home, instead of saying “yes or no”, he replied “I’m afraid of being tired”, etc.

7.4 Recommendations

1. Medical system

The use of Medical model of disability was necessary in taking care of autistic persons. To increase effectiveness in medical service system, this research gave some recommendations as follows:

1.1. Less use reductionism and more consider the lived body by applying holistic care which covered the physical, mental, emotional, family and society. For example, the autistic persons should be considered their personhood during intervening behavioral therapy. The therapists should acknowledge their feeling and emotions in order to reduce their anxiety and unfamiliarity. The training should not be rigid and devalued their personhood.

1.2. In speech therapy, it is necessary to understand the sense of autistic individuals. Some case had oversensitivity to sound and were frightened the command voices. They would not practice following the regimens. So, using gentle voices and creating familiar relationship is important. Also, learning their sensory perception would be helped in cases of autism who perceive only one sense modality at the same time, for example using visual sense may interrupt the sense of hearing.

1.3. In pharmacological treatment, it is necessary to understand the sense of autistic individuals, as well. For example, the medication is

administered in case of severe symptom of tantrum and self harm. If the therapists understand their senses, they could avoid the causes of oversensitivity which induced the undesirable behaviors or temper tantrum, instead of using medication. However, if drug administrating is necessary, it should be based on the professional standard, especially avoiding the drug overdose and high side effects.

1.4. Concern the principle of the therapeutic relationship in order to reduce the power relation. The families should have a chance in expressing their opinion. The use of the therapists' authoritarian should be reduced and avoid using one-way communication. More importantly, the autistic persons and families should not be considered as problematic persons and be excluded from the therapeutic system.

1.5. Promote autistic persons and families to access the health care services. Do not discriminate and exclude the impoverished families.

1.6. Integrate the medical pluralism in the therapeutic process by combining local medicine, Thai Traditional medicine, and the alternative medicine, as the medical pluralism in India. Accept the autism meaning of locality which is different from medical explanation, such as autism as god. Do not insult on the regimens which applying the local wisdom and local Buddhist belief.

1.7. Enhance the network of autistic families in order to exchange the experience in learning and nurturing their children. Provide mental support each others. More importantly, do not present only medical knowledge and do not promote only the case of successful treatment. Open mind and accept the several forms of autism regimens.

1.8. Provide medical services and researches based on human dignity of autistic persons. At present, the therapeutic process of autism is in the experimental era. New researches and advanced technologies occur all the times. Most of them based on reductionism concept, which easily ignore the identity of autistic persons. Their lives seem to be the experimental objects. From the explanation of families in this study, autistic children had perception, emotion, and feeling although they were not correlated with social norm. Autistic persons are human who have the right in survival and security in living. From family perspective, seeing the values of differences of autism is to maintain their humanity and to protect their lives

from insulting and suffering. Thus, it is necessary to provide the humanitarian health service in order to enhance the sense of dignity of autistic persons. The humanity should be concerned throughout the therapeutic process by understanding their senses, accepting their identity and giving their opportunity to present their self as they are, even though their deficit could not be corrected.

2. The Education system

The education system had the important part in development and restoration of capacity in the autistic children. This research study, then, had some recommendations in bringing up Humanistic Approach in developing of Individual Education Program (IEP) in order to make it become more concrete. The approach helped realizing the Uniqueness of each autistic person and accepting the differences to show respect to the dignity of human being, as follows;

2.1 In the policy level, the government sector should give an importance of education to the autistic people and disabled children seriously in order to increase education space by considering capacity of autistic person as the criteria of recruitment in the inclusive education or to the special education. When the children had behavioral problems, then they were already solved, they should be able to go back to the inclusive education system again. Also, the ratio of teachers and students should be reduced in the class, in order that the teachers would have more time to take care of the special children. There should be the organized trainings for basic caring of persons with autism; such as management of undesirable behaviors, self-harm, anger management, awaiting practice, as well as sensory integrations interrelated with their senses.

2.2 In the implementer level, inclusive classroom should be arranged with atmosphere in warmth and less competition so that the children could learn together. At the same time, the teachers had to accept the differences and taught all students to accept the differences of their friends. The attitude towards the impairment/disabilities as objects should be changed, in order to create positive identity and social interaction skills for the autistic children. The teachers should mutually understand senses of the unique of persons with autism, and find out their potential/genius. Arranging classroom activities correlated with the senses and

intelligence of persons with autism. This would be increased their self-esteem, i.e. the complex activities for those children with high touching senses such as inventing of things by sand and seeds, for those who were over-sensitivity to touches the teacher should use gentle touch during the therapy of Sensory Integration. For those who are sensitive to sound, they should be avoided the sound that stimulating unsuitable behaviors. For those who had special visual sense they should do drawing activity or using visual strategy so that the children would be able to speak and read faster.

3 In social aspect:

3.1 Create the understanding about taking care of autistic persons in cultural aspects to the families, communities, and medical services. Especially, the medical personnel, who work and faith within “a disease cure framework”, should be realized every persons with autism do not well respond with the medical regimens. This would reduce the pressure to the families who could not cure their children as normalcy and promote an acceptance of the pluralistic treatment. Enhance positive identity of autistic persons

3.1.1 Understand and accept the identity of autistic persons as well as participate in stimulating them to interact with others by creating the safe environment without oppressing, insulting and stigmatizing.

3.1.2 Family institutes and education institutes should cooperate to find out the intelligence of autistic persons, including who could not reduce their disability. Promoting the potential of persons with autism in order to decrease the negative image toward autism and disability.

3.2 Enhance the inclusive society, as follows:

3.2.1 Understand the senses of autistic persons in order to increase the acceptance of their identity and reduce the exclusion of autistic persons from the society.

3.2.2 Change the value system of ‘normal’ as social norm. The people who are competent and perfect are not only promoted, but also accept the values of the persons with disability.

3.2.3 Constitute the positive meaning of autism by considering the autistic persons as human who have different senses, perception,

feeling and acting, but not an abnormal person. Eventually, a new autism discourse as a human phenomenon will be occurred.

7.5 Recommendations for further study

1. Study the lived experience of other disable people under the medical and socio-cultural discourses.

2. Study the lived experience of autistic adults in socio-cultural discourse affecting their living, for example, the opportunities of employment, mate selection, and their freedom in living, etc.

3. Study the experience of life of autistic persons who are living in several regions of Thailand in order to gain the knowledge of caring autism in cultural aspects.

4. Study the experience of life of autistic persons in urban context. From this study, the traditional supporting system was found. There were grandparents and relatives nurturing the autistic persons. Some family was a single family but had the relationship as an expanded family. If the family is in the urban with high competitive context, how do they strive and maintain their personhood of their autistic children?

5. Study gender and sexuality of autistic persons with low functioning.

6. Study the lived experience of autistic persons with high functioning in order to understand their lives in aspects of the oppression and the difficulty in passing when studying in inclusive education.

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APPENDIX

Characteristics of Key informants of autistic families for in-depth interviewing

No.	Name of autistic person (Alias)	Key informants for in-depth interviewing	Age of autistic persons	Type of family	Hometown	Occupation	Salary per month (Bahts)	Methods of accessing data
1	Notte	Father/mother	13	Single family	Amphur Meuang Lopburi/Singburi	Doctor/Nurse	500,000	My friend's family
2	Mui	Mother/Aunt	13	Extended family	Amphur Meuang, Lopburi	House wife	50,000	Snowball from my mother's friend
3	Por	Father/mother	17	Single family	Amphur Meuang, Lopburi	State Enterprise/Government officer	100,000	Known from practicing behavioral therapy
4	Jimmy	Grandmother/Grandfather/Aunts	15	Extended family (กำพร้าพ่อและแม่)	Amphur Chaibadan, Lopburi	Farmer/Fruit wholesale dealer	Uncertain salary depending on the season	Access from special school

Characteristics of Key informants of autistic families for in-depth interviewing (Cont.)

No.	Name of autistic person (Alias)	Key informants for in-depth interviewing	Age of autistic persons	Type of family	Hometown	Occupation	Salary per month (Bahts)	Methods of accessing data
5	Jack	Mother	15	Single family (His father is an Engineer. He usually comes back home every 2 weeks.	Amphur Meuang, Lopburi	House wife	60,000	Access from special school
6	Game	Father	17	Single family	Amphur Meuang, Singburi	Teacher	60,000	Access from special school
7	Art	Grandmother	15	Single family (Homeless)	Amphur Meuang, Singburi	No occupation	1000 From the elderly pension, disability pension	Access from special school
8	Nut	Aunt	13	Extended family (Nut lives with his uncle and aunt as an adopted child. His father and mother live in Bangkok, as day laborers.	Amphur Meuang, Lopburi	Uncle: Government officer/ Aunt: merchant at temple school	30,000	Access from special school

Characteristics of Key informants of autistic families for in-depth interviewing (Cont.)

No.	Name of autistic person (Alias)	Key informants for in-depth interviewing	Age of autistic persons	Type of family	Hometown	Occupation	Salary per month (Bahts)	Methods of accessing data
9	Ton	Father	17	Single family (He lives with his father. His mother died when he was a little child.	Amphur Meuang, Lopburi	Policeman	35,000	Access from special school
10	Mark	Mother	15	Single family (His father is an Engineer. He usually comes back home every 2 weeks.	Amphur Meuang, Lopburi	House wife	60,000	Access from special school
11	Twin Fha/Phon	Father/mother	12	Extended family (Her twin is diagnosed as cerebral palsy. Her grandmother gets Staging IV, cancer. Her aunt gets epilepsy.	Amphur Inburi, Singburi	Farmers	Uncertain salary, depending on the season	Access from special school

Characteristics of Key informants of autistic families for in-depth interviewing (Cont.)

No.	Name of autistic person (Alias)	Key informants for in-depth interviewing	Age of autistic persons	Type of family	Hometown	Occupation	Salary per month (Bahts)	Methods of accessing data
12	Gap	Mother	12	Single family (He lives with his grandma. His father and mother live in Samutprakarn province, as day laborers.	Amphur Banmi, Lopburi	Day laborers.	200-300 baht/ day	Access from special school
13	Joy	Father/ mother/ grandmother	17	Extended family	Amphur Meuang, Lopburi	Father and mother: Private company/ Grandmother: housewife	70,000	Snowball from the teachers

Questions for In-depth Interviewing

The Study of Lived Experiences of Families with Autistic Children

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Personal and Family Data

1. How old is your autistic child? Where does he/she live? And, who does he/she live with?
2. How many members of your family do you have? Who is the head of your family? Who does take care of your autistic child?
3. How old are they? What is their relationship with the child? (Such as father, mother, grandfather, grandmother, etc.) How closed to the child?
4. What are your occupation/ education/ salary and household expenses?
5. How many siblings does the child have? How old are they? What does their health status? Does anyone in your family have autism?
6. What is your family illness history?

The questions for in-depth interviewing

1. What do you think about your child illness?
2. What was the first symptom you noticed? How old was he/she at that time? What did your relatives or your neighbors tell you about his/her symptoms? Such as he/she can't speak due to tight lip, idiot, mental problems, poor nurturing, etc
3. What is your opinion when you have an autistic child? How do others view on you? What do you think about that? (Such as they view you have "Kharm" or have gene related autism.)
4. What is the cause of your child getting autism?
 - 1) Have you ever explored the cause of autism by thinking of your pregnant history or your parenting?
 - 2) Did you explore your family history? Who got autism or mental illness?
 - 3) Have you ever reconsidered your past behavior related to your child illness? For example, your 'Kharm' or your bad habits; smoking, drinking,

unhealthy foods, depressed mood, not enough sleep, ect. Do you believe in “Kham” cycle of life or rebirth?

5. Do you have any experiences to be shamed or stigmatized that your child got autism because of you? How did they blame you? Please indicate the painful situations.

6. What do you think about answer no.5? Did the answers or their beliefs impact on your identity? How?

7. After your child was diagnosed as autism, what did your relatives and others think about that?

8. Where did you take your child to cure? What was type of treatment? And, why do you decide to take that treatment? (Such as go to the physician, Thai traditional medicine, fortune tellers, the monk, the oracle ceremony or treat with the person who can communicate with spirit/mystery/ghost/god, alternative treatment, etc.)

9. In case of taking modern medicine:

1) When did you take your child to see the doctor? What was the hospital? And where? Who suggested you?

2) To differential diagnosis, what kind of investigate treatment did your child get? Did the doctors use high technology in differential diagnosis? (For example: development examination, ABR, CT scan, MRI, ect.) What was the kind of specialist you meet? What was the result? Did you accept it at first? When did you accept the result as autism?

3) What was the treatment? (For example: behavior therapy, speech therapy, medicine, Hyperbaric Oxygen treatment; HBOT, bone marrow transplant, acupuncture.)

4) How do you feel when your child was in treatment process? What was the problem that you got? (For example, medical professionals did not understand your feelings. They blamed you when your child was not progress. They thought you did not manage and train your child’s behavior at home.)

5) Did you think the treatment help your child got better? How about that? What is your expectation about the treatment? Did you continue to see the doctors or medical professionals? If not, why?

10. Have you ever taken your child to treat following your religious beliefs? For example: fortune tellers, palm reader, alternative treatment, Thai traditional medicine, the monks, etc. Why did you select those treatments?

(Supposed you faith in Buddha power, you decide to take your child to see the monks who work as the physician. How was your faith contributed to your child and your family?)

11. How does your child's illness affect to your family, especially your marital status, social status, and socio-economic status? How do you manage this consequence?

12. What is your child's symptom now? How do you take care of him/her comparing with his/her sibling or not disabled child?

1) How do you perceive your child's behaviors? (For example, sameness, hit everything around him/her, stereotyped moving, masturbations, etc.) Do you accept these behaviors?

2) Does your child have bizarre or strange behaviors? How do you feel and how do you understand that behaviors? For example, sleeping with the blanket tied the body, staying at the corner for a long time, touching the shoes instead of seeing when getting the wrong side, smelling food instead of taste.

3) In case of mutes or little speaking, how do you understand your child? How do you understand his need? And how do you communicate each other? Why is he/she not able to speak? Do you believe this cause from modern medicine or Thai's religious belief? Please indicate. (For example, deaf in past life, "Kharm", "Paknak" means can't speak due to tight lips and difficult to open.)

4) Have you perceived your child's psyche and shared each other? For example, you thought the child tried to tell you about his worse situation in anyplace. When you got there, it happened as you thought.

5) In case your child was cheat or got accident, how did he/she communicate or mediate you? How did you understand him? For example, some parents perceive or sense his/her emotion from reading his/her eyes. Or, some autism at the age 10 was still approaching and hugging mothers as, the age of 3. The mother understands protection as needed.

13. What is your everyday life? What is your obstacle in daily living?

14. When did you take your child to school? Did you face any problems? What were the problems? For example, you found the teacher can't understand the way of caring autistic child. The autistic child was neglect and received poor nurturing.

15. What is your serious concern? Is it difficult to handle?

16. What do you think about "autism is classified as disability"? Do you accept this? Why?

17. Do the siblings accept autistic brother/sister? What do they think? How do they play/act/perform each other?

18. When your child is growing up, what do your neighbors view your child? Please tell the story that is painful memorizing. And how do you anticipate it?

19. Do you accept your status as "family with disabled child"? How do you feel? Do you feel embarrass or not?

20. In your experience, what is your expectation about your autistic child? How much is your expectation? For example:

- With high expectation, you think your child will be normal. You have ambition to search any treatment both in modern medicine and pluralistic medicine. You've never given up. You will dedicate everything, i.e. time, money and life.

- With less expectation, you just think how to make your child happy. You will practice in "Dhamma" concept to adapt your new identity and status. You prefer to living with "autism/disabled child".

21. From your experience, how does your daily activity or your role change? Do you think "label of disabled child" affected to your work? Have you ever concealed others?

22. Do you concern of your child's future? What is your concern? For example, his/her occupation, capacity in self-care, care-taker if you or your family member pass away.

23. From your experience, how do you stand in this position? What is your motivation in your success or having today?

24. Do you have any friends, group or social network to support you? What are their activities? How do they support each other? What are their expectation of their autistic children, especially their education, occupation and social exclusion?

25. What do you think about government policy toward autistic children? Are you satisfied it? Do you have any suggestions to improve the system of autistic caring?

BIOGRAPHY

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