JUST A PERSON WALKING SLOWER THAN THE OTHERS, BUT CAN REACH THE INTENDED DESTINATION: A STORY OF A PERSON OVERCOMING AUTISM

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Pichitra Sinsamersuk

JUST A PERSON WALKING SLOWER THAN THE OTHERS, BUT CAN REACH THE INTENDED DESTINATION: A STORY OF A PERSON OVERCOMING AUTISM

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ABSTRACT

This was a study based on real life experiences of a person living with autism and Bone Metabolic Disorder and overcoming the challenges that come with such disabilities. The study was a qualitative research that retrospectively analyzed a life living with disabilities in terms of meaning, experiences, resilience and the coping strategies. The author considered all the aspects above after she was diagnosed with Asperger's Syndrome (a syndrome found in autism spectrum) and when she was diagnosed with Bone Metabolic Disorder. The objectives of the study were: to reflect on the experiences of living with autism, to analyze the meaning of the experiences and the source of the resilience, and describe the coping strategies she used to overcome the seemingly inhibiting challenges. Being a qualitative study, the researcher mined data from personal memoirs, and reflective in-depth interviews with parents, members of the family, and teachers. The researcher describes her past experiences and struggles under the social and cultural structure as a person with disability in stages that include: childhood, life in primary school, high school and university as an undergraduate student. From the study, it was observed that medical practitioners saw her as a person living with congenital physical abnormalities and autism with incurable and fatal conditions, her parents saw her as their child and they had to do their best to look after her, understood the conditions were incurable and they helped her as much as they could to improve her learning and physical development together with medical treatment received from physicians. The strategies that helped the author reach her potential included, parental beliefs and resolve to support and belief in the power of education in transform lives. The positive resilience methods that helped the author to deal with feelings and social stigma included staying positive, consulting with monks, searching for medical and academic information and making sure that the extended family members understood the author's conditions and cooperated in looking after her. The parents rearranged their priorities (the mother leaving her job and offer special care to ensure the author's development). However, the author experienced discrimination in the education system where everything was standardized for all students. She suffered from stigma, devaluation, teased, stared at and criticized by the society. More often the society blamed the family for her condition. The family and the author dealt with the above social stigma by portraying the author's potential, redefining her identity as a person with some limitations but not disability, and somehow living with it. Another strategy was also the acceptance of the fact that the social attitudes towards people with different physical and learning condition could not be changed. From the reflections and analysis of the present narrative, it is recommended that stigmatization and devaluation of disabled people in the society should be discouraged and families should be strengthened and empowered. Resilience by people with disabilities and parents could give them opportunities to succeed and make them positive and successful people in the society. The principles drawn from this present narrative study could be a guideline or inspiration for other people living with disabilities or family member(s) with disabilities. Relevant Authorities should sensitize the community to treat all people with dignity and know that disability is not inability.

KEY WORDS : NARRATIVE STORY / METABOLIC BONE DISORDER / AUTISM / MEANINGS /
STIGMATIZATION / COPING / RESILIENCE / EMPOWERMENT

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“ฉันเพียงเป็นคนที่เดินช้ากว่าคนอื่น แต่ฉันก็เดินถึงจุดหมายเหมือนกัน” : เรื่องเล่าการก้าวข้ามออทิสติก
JUST A PERSON WALKING SLOWER THAN THE OTHERS, BUT CAN REACH THE INTENDED DESTINATION: A STORY OF A PERSON OVERCOMING AUTISM

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ศศ.ม. (สังคมศาสตร์และสุขภาพ)

คณะกรรมการที่ปรึกษาวิทยานิพนธ์ : เพ็ญจันทร์ ประดับมุข เชอร์เรอร์, Ph.D., อุบลพรรณ ธีรศิลป์, Ph.D. พิมพวัลย์ บุญมงคล, Ph.D.

บทคัดย่อ

การวิจัยนี้เป็นการวิจัยที่มาจากประสบการณ์จริงของผู้วิจัยที่เป็นออทิสติก และ โรคกระดูกเมตาบอลิก และได้ ก้าวข้ามอุปสรรคที่เกิดจากความพิการดังกล่าว การศึกษานี้เป็นการศึกษาเชิงคุณภาพวิเคราะห์ประวัติชีวิตที่อยู่กับความพิการในแง่ของความหมาย ประสบการณ์ กลยุทธในการปรับตัวและการรับมือ ผู้วิจัยได้นำเสนอมิติต่างๆ ดังกล่าวหลังจากที่ได้รับการวินิจฉัยว่าเป็นแอสเพอร์เกอร์ซินโดรม (หนึ่งในกลุ่มอาการที่พบในสเปกตรัมของออทิสติก) และได้รับการวินิจฉัยว่าเป็นโรคกระดูกเมตาบอลิก วัตถุประสงค์การศึกษานี้คือ เพื่อสะท้อนประสบการณ์ของการใช้ชีวิตอยู่กับออทิสติก เพื่อวิเคราะห์ความหมายของประสบการณ์การปรับตัวเชิงบวก และกลยุทธในการรับมือที่ผู้วิจัยใช้เพื่อก้าวข้ามความท้าทายที่เป็นอุปสรรคที่ของชีวิต การวิจัยนี้เป็นการวิจัยเชิงคุณภาพ ผู้วิจัยจึงได้ศึกษาข้อมูลแบบเจาะลึก ทั้งจากบความทรงจำส่วนตัว และจากการสัมภาษณ์เชิงลึกกับผู้ปกครองและสมาชิกในครอบครัว รวมถึงครูอาจารย์ของผู้วิจัย ผู้วิจัยได้บรรยายถึงประสบการณ์ชีวิตในอดีตและความยากลำบากในการใช้ชีวิต และการต่อสู้ภายใต้โครงสร้างของสังคมและวัฒนธรรมที่กีดกันคนพิการ การวิจัยนี้ได้ศึกษาช่วงชีวิตตั้งแต่แรกเกิด ไปถึงชีวิตการเรียนชั้นประถมศึกษา มัธยมศึกษา และชีวิตในระดับปริญญาตรีที่มหาวิทยาลัย จากการศึกษา จะพบว่าผู้เชี่ยวชาญทางการแพทย์มองผู้วิจัยว่าเป็นผู้ที่มีชีวิตอยู่กับความผิดปกติทางกายภาพและออทิสติกตั้งแต่แรกเกิดซึ่งรักษาไม่ได้และมีโอกาสที่จะเสียชีวิตก่อนเวลาอันควร ผู้ปกครองของผู้วิจัยมองว่าเธอเป็นลูกและต้องการจะเลี้ยงดูเธอให้ดีที่สุด ทั้งๆ ที่รู้และยอมรับว่าอาการของผู้วิจัยไม่สามารถรักษาให้หายขาดได้ และพยายามช่วยเหลือผู้วิจัยให้มากที่สุดทั้งด้านพัฒนาการในการเรียนรู้และฟื้นฟูสุขภาพให้ดีขึ้นมากที่สุดเท่าที่วิทยาการทางการแพทย์จะทำได้ กลยุทธที่ช่วยให้ผู้วิจัยพัฒนาศักยภาพของตนเองได้คือ การมีความเชื่อมั่นของผู้ปกครองในการเดินหน้าแก้ไขแบบไม่หยุดยั้ง รวมทั้งการเชื่อมั่นในอำนาจของการศึกษาในการเปลี่ยนแปลงและพัฒนาคุณภาพชีวิตให้ดีขึ้นเรื่อยๆ วิธีการปรับตัวเชิงบวกที่ช่วยให้ผู้วิจัยรับมือกับความรู้สึกและการตีตราจากสังคมได้ คือการมองโลกในแง่บวกและการใช้หลักศาสนาในการดำเนินชีวิตเชิงบวก การสืบค้นหาข้อมูลของวิทยาการสมัยใหม่ทางการแพทย์และการศึกษา รวมทั้งสร้างความเข้าใจกับสมาชิกในครอบครัวเกี่ยวกับอาการของผู้วิจัยเพื่อให้ช่วยกันดูแลผู้วิจัยด้วยความเข้าใจ นอกจากนั้นผู้ปกครองยังได้จัดลำดับความสำคัญในชีวิตใหม่ (คุณแม่ลาออกจากงานและให้การดูแลพิเศษตลอดเวลาเพื่อรองรับพัฒนาการของผู้วิจัย) อย่างไรก็ตาม ผู้วิจัยยังต้องประสบกับการถูกกีดกันจากระบบการศึกษาที่มีมาตรฐานเดียวสำหรับนักเรียนและนักศึกษาทุกคน เธอต้องทนทุกข์กับตราบาป การกีดกัน การถูกกลั่นแกล้งรังแก การถูกจับจ้องมองดู และการถูกวิพากษ์วิจารณ์จากสังคม สังคมได้กล่าวโทษครอบครัวอยู่บ่อยครั้งว่ามีส่วนทำให้เธอมีอาการดังกล่าว ครอบครัวและตัวผู้วิจัยเองต้องรับมือกับตราบาปของสังคมแต่ละรูปแบบดังกล่าวโดยการสร้างศักยภาพของผู้วิจัยเปลี่ยนความหมายใหม่ว่าเป็นคนที่มีข้อจำกัดแต่ ไม่ใช่คนพิการ กลยุทธอีกกลยุทธหนึ่งที่ใช้คือการยอมรับข้อเท็จจริงว่าไม่สามารถเปลี่ยนแปลงมุมมองของสังคมต่อการมองคนที่มีความผิดปกติทางร่างกายและพัฒนาการการเรียนรู้ได้ จากภาพสะท้อนและการวิเคราะห์ของเรื่องเล่า ผู้วิจัยเสนอแนะว่าสังคมควรลดการตีตราและการกีดกันผู้พิการลง และครอบครัวผู้พิการควรจะต้องเข้มแข็งและมีพลังอำนาจในการต่อรองกับสังคมมากขึ้น การปรับตัวเชิงบวกของผู้พิการและผู้ปกครองจะมีส่วนสำคัญที่เพิ่มโอกาสสู่ความสำเร็จให้พวกเขา ทำให้พวกเขาเป็นคนที่มีคุณค่าและประสบความสำเร็จในสังคมได้ หลักการจากเรื่องเล่านี้สามารถใช้เป็นแนวทางหรือแรงบันดาลใจสำหรับคนพิการหรือครอบครัวคนพิการอื่นๆ ต่อไปได้ หน่วยงานที่เกี่ยวข้องควรกระตุ้นให้สังคมปฏิบัติต่อผู้พิการทุกคนด้วยการให้เกียรติ และสังคมควรรับรู้ว่าผู้พิการเป็นเพียงผู้มีข้อจำกัดในด้านความสามารถ ไม่ใช่ผู้ที่ไม่มีความสามารถที่จะทำอะไรได้เลย

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CHAPTER I
INTRODUCTION

1.1 Justification

People see me as a disabled person. I have been diagnosed as a patient with both Asperger’s Syndrome, a syndrome found in classic autism spectrum, when I was born and with Bone Metabolic Disorder at about 2 years old. Then the doctor believed that my life expectancy would be around 18 years old. I would be unable to attend school at all. Now I am 25 years old and 103 centimeters tall. I can walk slowly. I use a wheelchair to travel in distance. In addition, I have already graduated with a Bachelor of Science from Faculty of Science, Mahidol University. At the moment, I am in my second year studying for a Master degree in the Department of Social Health, Faculty of Social Sciences and Humanities, Mahidol University.

I see myself as a person with autism who has surpassed my disabled self. I can share my story with other disabled or autistic people and empowering them to do the same. That is the reason I want to study and write about my life story. I aim to portray my own feeling and experience as a person with impairment and my family experiences. I also want to study the strength of my family who loves me with no conditions and supports me to reach my full potential.

The number of disabled people in Thailand, according to National Statistical Office (2017) shown that there were about 1.76 million people with disabilities. The number of physical disabilities group was the highest (48.53%), followed by groups of deaf and dumb (18.28%), blindness (10.52%), mental and behavioral disorder (7.39%), and cognitive and learning disorder, autistic included (1.02%), respectively.

Thailand has adopted and implemented a number of laws, Cabinet resolutions, regulations and policies pertaining to people with disabilities, including their right in decent work production, basic services, workers’ compensation, social security and entrepreneurship development. The Thai Constitution, adopted in 1997 and amended in 2007, contains anti-discrimination provisions based on physical or health conditions and guaranteed accessibility to social welfare and services for people with disabilities. The Persons with Disabilities' Quality of Life Promotion Act B.E. 2550 (A.D. 2007) was a comprehensive rights-based law for people with disabilities and contained an anti-discrimination component. It repealed the Rehabilitation of Disabled Persons Act B.E.2534 (A.D. 1991), which was the first law on disability in Thailand. The Act defined a disabled person as someone limited in living in daily life or participating in social activities due to a physical defect -in vision, hearing, movement, or communication- or mental defect -in mind, emotion, behavior or intelligence- including those who have difficulties in any aspects and need assistance to perform their daily activities or to participate in social activities, in accordance with regulations issued by the Ministry of Social Development and Human Security. In Thailand, the health care system, welfare system, educational system and social security scheme have provided the right to security for people in the event of disability. Social institutes has provided those kinds of services including education, health care, rehabilitation, sheltered workshop, vocational training and so on.

People with disability faced problems such as poverty and social discrimination, and were left behind in the development process. Although a National Act for persons with disabilities has already aimed to promote and develop their quality of life, only a minority of disabled people receive accessible and appropriate rehabilitation services. Regarding to disability registration, not all people with disability registered. There were 1,756,849 people with disability registered for the Disabled Identification Card in 2017 (Department of Empowerment of Persons with Disabilities, October 2017), meaning that, out of about 2 million of them in Thailand, about 600,000 people with disability cannot access the basic service provided by the state.

Autism is categorized in the group of Pervasive Development Disorder in the Diagnosis and Statistical Manual of Mental Disorders, 5th edition; DSM-5. The definition for "Autism Spectrum Disorder (ASD)" was that, a person with such disability has restriction in routine activities or social activities as the result of the impairments in social interaction development, language and communication, including behavioral and emotional impairments. These impairments caused from neurological deficiencies. The pervasive developmental disorders were common in adolescents with learning disabilities affecting up to 30% of individuals (McCarthy, 2005). However, in my opinion, the exact number of people with autism was much higher than that registered and is increasing every day with the number of daily newborn child.

At the individual and family level, autism was a kind of neurobehavioral disorder where individuals have rather strange habits, individuals with autism do not talk much, or they may not talk at all, since they have a communication problem. Children diagnosed with ASD often exhibit a greater degree of cognitive impairment and difficulty in interpersonal relations. Consequently, they require special care, including adaptations in formal education and upbringing as a whole (Gomez et. al., 2014).

At the family level, due to such behavioral problems (Lee, Harrington, Louie, & Newschaffer, 2008, as cited by Obeid, 2015), the families experienced greater levels of stress and depression, as well as decreased marital happiness and family cohesion (Ingersoll & Hambrick, 2011; Ingersoll, Meyer, & Becker, 2011; Totsika, Hastings, Emerson, Lancaster, & Berridge, 2011, as cited by Obeid, 2015). Further, they were more likely to have unmet healthcare, family support, and service referral needs (Kogan et al., 2008, as cited in Blumberg, 2013). Parents might have experienced negative attitudes from others in their social networks, particularly with regard to expectations about their child's future (Virji-Babul, Eichman, & Duffield, 2004). Despite to those negative experiences, families described the effect of autism on their lives as positive, and express how their families were closer as a result (Bayat, 2007, as cited by Meirsschaut, 2010).

Children with autism have their typical "routine" that they had to do the exact same things every day. People around them labeled or stigmatized them as "the different" because they could not perform or behave like the others. The society would stigma and discriminate autistic people. To me, stigmatization gave the abusive marks of the "abnormality" onto the stigmatized people, including those with autism. It could make living among the society horrible for them as they were unlikely be accepted. Goffman (1963) and others proposed that disability interfered with ordinary social interactions, creating a class of stigmatized interactions. Whether perceived or experienced, stigmatization led to negative outcomes for the recipient. Ingstad and Whyte (1994: 252) concluded that disabled people were generally stigmatized and had poor chances to get married, of employment and social integration in general. They found that none of the definitions of attitudes really acknowledged the social situation in which they were played out. There was no indication that "attitudes" were dynamic in character and socially as well as culturally constructed. In Thailand, as a Buddhist country, disability was regarded an outcome of a vice that a person had in his/her previous life. On the other hand, Buddhism taught people to have mercy on the weak. Because of this, Thais preferred to give money to disabled beggars or to make donations to charities. Though this might be regarded as a good social characteristic promoting the support of persons with disabilities, it could also be viewed as preventing them from joining society on an equal footing. Studies in Thailand, the Chonburi Association of people with disabilities reported that in 1999, Suan Dusit Poll has conducted a survey on attitude towards disabled persons from people in Bangkok and eight large provinces. The total sample size was 1,926. Among these numbers, only 483 had ever dealt with disabled people. The result shows that people feel sympathetic toward the disabled (82.51%). Only 8.5% of them were willing to give a chance to disabled people to gain an equal opportunity in society. 62.48% felt that the disabled should receive more social support. Attitude toward independence of the disabled was rather positive since the people thought that they could help and potentially develop themselves. Therefore they were more acceptable in society.

People of Thailand, practicing Buddhism, viewed disability as a result of failing to lead positive previous lives. Therefore, due to bad karma, the negative things, instead of positive things, happened to them at the present time (Vorapanya, 2014).

People expected children to be enrolled in basic education institutions from age 7 through 16, despite their disabilities. There were three types of “Special schools” in which students with disabilities could receive education in Thailand. First, the class for Talented Students. Second, the class for Deprived Students, those disabled students that usually were not as talented as the students in the previous group. Third, the class for Students with Poverty, both abled-body and disabled. They were specifically designed for students with any type of impairment. In practice, however, disabled children would be accepted in these schools. Moreover, participating principals expressed a different aspect of their compassion toward their students with special needs (Vorapanya, 2014).

There were many factors contributing to people with disability being independent. The International Classification of Functioning, Disability, and Health (ICF) highlighted the interplay between function and the environment among individuals with disabilities. The ICF provided a framework that classifies an individual's functioning in the context environmental domains and assesses the role each domain played as either a barrier or facilitator: products and technology, natural environment and human-made changes in the environment, support and relationships, attitudes, and services, systems and policies. The family was also an important environmental consideration, as this was the smallest society possible. A study found that transition from the educational system represented a major stressor for families and depended on a multitude of factors such as the availability of a transition plan, school support for transition, and local availability of transitional services (e.g., respite care, supported employment). In many cases, particularly in rural areas, children transition out of school into an environment that was conducive to social isolation and prevented them from engaging with their local communities. Many youth with disabilities had become 'trapped' in their home due to families' work schedules and lack of transportation, which led to further isolation and negative health outcomes. The family could serve as an important personal and social resource for young people with disabilities, and could also increase the resilience of the individual. Families with a child with a disability often experienced a strong bond of parent-child interactions.

Nowadays, some of people with disability can overcome their impairment. In addition, social movements have initiated an inclusive society that brings people with disabilities to equally access their basic needs and rights. A positive image has been shown by figures such as Mr. Somjit Duangtakhum, AKA Loung Beaow (Kon-Kon-Kon, MCOT TV Program, Published on Feb. 21, 2012), who was fully paralyzed on his lower half of the body due to an accident. His wife had already left him. However, with both his hands, he kept on working to maintain his life and overcome his own struggles by building a vegetable farm in Chiang Mai. Other people with positive images include…

1. Leu. Ge. Ladda Tammy Duckworth, an American-Thai politician who was elected to be a Member of Parliament of Illinois, Distinct number 8. She uses a pair of artificial legs and a cane to stand (Chicago Tribune, Published on Jun. 22, 2016).

2. Sombat Simla, a blind local musician in North-eastern area of Thailand who played khaen (Khon Kaen University Library: Information Center, Published on Sep. 9, 2015), a musical instrument made from wood and taught people how to play it. He was invited to join in various bands on special occasions.

3. Tanong Khotchompoo, a limbless artist who drew artworks with his mouth for over 25 years (Nation TV, Published on Nov. 21, 2009). His art was very well-drawn so he was invited to teach artistry to non-disabled students.

Medical model of disabilities might suggest that an individual's health condition or impairment was viewed as the cause of disability. Moreover, the medical model said that, by fixing their body, disabled people would be able to participate in society like everyone else. While the social model of disability suggests to empower disabled people and to encourage society to be more inclusive, we cannot design inclusive society if we do not understand how people with disability live and what their needs are (the researcher summarized on her own).

This study aims to portray self-experiences of me myself as I am the main researcher of this study and I also am a young woman with autism and encourage new understanding of "autism". On behalf of every Autistic people, we experience stigma and infringement and need resilience to overcome physical impairment and development. This is the voice of a person with disabilities. I hope that this story of my life and my ability to overcome my past self will encourage more parents of disabled children to provide them with educational opportunities. My auto-biography is my narrative life story which I voluntarily want to create since I graduated my bachelor degree. My auto-biography will start from the moment I was born with a developmental delay. My auto-biography will tell how I was diagnosed as autism and bone metabolic disorder. Some doctors predicted that I would not be performed well in my studies and I have short life expectancy. The auto-biography shows my family's efforts to help me overcome myself. This story helps people to understand more about the difficulties of being disabled by both autism spectrum and bone metabolic disorders and being called by various negative names.

1.2 Objective

The objective of this research is to portray self-experiences of a young woman with autism who created a new understanding of “autism” and found ways to overcome the physical impairment and turning into the ability to live.

1.3 Research Question

What are the experiences of my life, being a person with disability?

1. In the past, how had I been stigmatized for being an individual with disabilities?

2. How could I and my family cope with the stigmatization?

3. What was the resilience of my life and my family?

1.4 Scope of the Study

The samples in this study were my mother and me as an individual with multiple disabilities of both Autism Spectrum Disorder and Bone Metabolic Disorder. The scope of my self-narrative study was the meaning, experiences with the medical treatment, social and family response and coping, the developmental training and the educational learning in a series of events from birth to graduate a bachelor degree.

CHAPTER II
LITERATURE REVIEW

2.1 Social Dimension of Disability and Autism

Disability is referred to as "*Pii garn*" in the Thai language, a broad term that is also applied to people with other impairments. There are, however, important differences between impairment, disability and handicaps. The following definitions are based on those used by the United Nations:

Impairment: Any loss or abnormality of psychological, physiological, or anatomical structure or function.

Disability: Any restriction or lack of ability, resulting from an impairment, to perform an activity in the manner or within the range considered normal for a human being.

Handicap: A disadvantage for a given individual, resulting from an impairment or disability, that limited or prevented the fulfillment of a role that is normal, depending on age, sex, social and cultural factors for that individual.

A handicap is therefore a function of the relationship between disabled persons and their environment. It occurs when they encounter cultural, physical or social barriers which prevent their access to the various systems of society that were available to other citizens. Thus, a handicap is the loss or limitation of opportunities to take part in the community on an equal level with others (U.N. 1983 p6-7 as cite in Wendell 1997, p262).

People with disabilities (PWDs) in Thailand are a disadvantage group that should have equal access to health and welfare services as the rest of the population. The number of people with disabilities has increased, statistically. In 1986, there were 0.4 million disabled people, or 0.7% of the total population. In 1996, there were 1.0 million, more than double. The increase has been attributed to social and economic changes. According to figures from Thai Disabled Persons, in 2001 there were 1.1 million disabled.

With few exceptions, people with disabilities fared worse for every indicator compared to people without disability; those with intellectual and psychological impairments were most disadvantaged. While overall women with disabilities were more disadvantaged than men, the magnitude of the relative differences was lower than the same comparisons between women and men without disabilities, and there were few differences between women and men with the same impairment types (Kavanagh et al., 2015).

Autism spectrum disorders were characterized as development impairment by severe deficits in socialization, communication, and repetitive or unusual behaviors. The classic autism syndrome was common in adolescents with learning disabilities affecting up to 30% of individuals (McCarthy, 2005). It incorporated a range of disorders characterized by difficulties in social interaction, communication and social imagination/theory of mind (Frith and Happe, 2005; as cited by Ryan, 2008), including Asperger’s syndrome (AS). Some people diagnosed with AS could be described as high functioning in some areas while struggling in others (Attwood, 2006; as cited by Ryan, 2008). There was considerable controversy surrounding the definition of AS (see, for example, Mayes et al., 2001; McLaughlin-Cheng, 1998; as cited in Ryan, 2008) and the existing literature tended to present a stereotypical picture of people with AS, as unemotional, non-communicative and anti-social (Stazmari, 2004; as cited in Ryan & Räisänen, 2008).

Social construction of disabilities stated that disabilities are not mental or physical conditions of the organism which prevent or impair function, and therefore conditions a rational agent would wish to avoid or remedy, but rather, physical and mental impairments may be either positive, negative or neutral (Harris 2000).

Autism Spectrum Disorder (ASD) is stated as a neurodevelopmental disorder characterized by delays and deficits in social communication and by a pattern of repetitive stereotyped behaviors and interests. The disorder usually starts in infancy then changes as development proceeds, although the two core phenotypes in social communication and behavior generally remain. The disorder occurs in roughly 1 in 100 children, with boys outnumbering girls by approximately 3–5 to 1 (Elsabbagh et al., 2012 as sited in Szatmari, Zwaigenbaum, et al. 2016).

Not only are there significant variations in social communication and repetitive behavior between individuals with ASD, but such variation can also exists within the same person over time. Moreover other phenotypes also co-vary with these core phenotypes, so it is now clear that ASD is a “multivariate” phenotype rather than a single “spectrum.” These comorbidities include variation in cognitive and language abilities, the presence of mental and physical health problems, and a variety of other phenotypes. The emerging clinical picture is that ASD is really an overlay of many different dimensional phenotypes in addition to social communication and repetitive behavior that change over time. It is also true that a greater understanding of the etiology of ASD has emerged (Szatmari, Zwaigenbaum, et al. 2016).

I was diagnosed with both autism syndrome and metabolic bone disorder when I was about two years old. Those two diseases caused me impairments, which meant they were giving me disability, too. I would have to register as a disabled person when I got my national identification card at the age of 15. However, while the medical team could give me treatment, they could not give me the sense of people in Thai society I, and every disabled person, want to have.

When I was young, I used to believe that I was the same as those normal people around me. I also failed to understand the gestures and stares from the others looking at me. I did not realize my own disability until I was 15 years old when someone in the city hall suggested I make a card for the disabled. Making such a card let me know that I was not the only disabled person in Thailand.

ASD is a type of intellectual impairment which has been categorized as the most disadvantaged group of impaired people. Having been diagnosed with ASD, I was also categorized in the most disadvantaged group. It was then I realized people were looking at me strangely because of the feeling of inferiority I had due to ASD. So, what is ASD?

Autistic children, who are categorized under the Rehabilitation of Disabled Persons Act B.E.2534 (1991: 7-8), are characterized by four abnormal conditions. First, emotion: They have fluctuating moods, scream, are very bad-tempered, self-destructive and tend to destroy things. Second, social interaction: Autistic children display a lack of interaction with others, even their own parents. Third, communication: Autistic children developed their own language, which is incomprehensible to others. Fourth, behavior: They exhibit such behaviors as walking on tip toes, swinging around themselves, monotonous repetitive behavior, waving their hand, rocking themselves, or staring at a circling fan in motion. (Penkae Limsila, 1997: 10; as cited in Gunvipa, Wajjanin, Jirapa, & Orn-anong, 2003).

Leo Kanner, an American psychiatrist of Johns Hopkins University, was the first person to define this specific behavior found in some children. Autism comes from a Greek word “auto,” meaning “self”. The term autistic means lack of communication with others, turning toward self, and no contract with the outside world (cited in Rojana Tantranont, 1984: 18, Winadda Piyasilp, 1994: 12; Kalaya Wiriya, 1996: 8-9; as cited in Gunvipa et al., 2003).

Maxine Field (1990: 10) defined autism as a child psychiatric illness that affects many areas of behavior. The children have a social deficit, no social interaction, are unable to control themselves, have both verbal and non-verbal communication impairments, and have no imaginative play (Gunvipa et al., 2003).

Rutter, M. (cited in Penkhae Limsila, 1995: 359) has defined autism as a pervasive development disorder age, with the onset from birth to infancy (Gunvipa et al., 2003).

According to Rimland (cited in Olay, 1992: 5), autistic children have impaired language development, specific learning disorders, schizophrenic characteristics and are shut in (Gunvipa et al., 2003).

The World Health Organization (cited in Kalaya Wiriya, 1996: 9) has stated that autism is a pervasive development disorder, which begins before a child is 30 months old. The disorder includes deficiencies in social interaction, languages, verbal expression and imaginative play (Gunvipa et al., 2003).

Penkae Limsila (1993: 276) stated that autistic children were those who have severe developmental disorder, especially in language, emotional, and social development (Gunvipa et al., 2003).

Winadda Piyasilp (1994: 10) stated that autistic children have a repetitive and predictable pattern of behavior. Furthermore, even though they have normal physical development, they had severe defects in their sensory visual perceptions and language development (Gunvipa et al., 2003).

In 1987, the American Psychiatric Association compiled information on abnormal behaviors of autistic children to be used worldwide based on the diagnosis called DSM III-R (The Revision of the Third Edition of the Diagnostic and Statistical Manual of Mental Disorder). The association categorized autism as a pervasive developmental disorder (PDD), which was differentiated from mental retardation, disorder in language development, learning disorder, schizophrenia, or personality disorders (cited in Payorm Inkatanuwat, 1999: 16; Penkhae Limsila, 1993: 1-7; as cited in Gunvipa et al., 2003).

In summary, autism was the name of a disorder shown by the specific behaviors of linguistic-impaired patients. Autism is usually noticeable by the time a child is three years old. Patients with autism could not speak their mind or express their feelings as much as others of their age. So, communication between autistic patients and normal people tended to fail because of misunderstanding.

The diagnosis of Autism Spectrum Disorders (ASDs) required disturbances in each of following domains:

(1) Social relations, including marked impairment in non-verbal communication, peer relationships and social-emotional reciprocity

(2) Communication/play, including either a delay or total lack of spoken language and a lack of developmentally appropriate make-believe or social play, and

(3) Restricted interests and activities, including encompassing preoccupations, adherence to non-functional routines or rituals, stereotypes and motor mannerisms (Autism Resource Center, 2013; as cited by Aziz, Abdullah, Adnan, & Mazalan, 2014).

Autism's diagnostic history began in 1943 (Kanner, 1943; as cited in Hollin & Pilnick, 2015) and while there have certainly been significant changes in the perceived symptomology of autism since that time, autism has come to be characterized as featuring a triad of core features in “impaired social interaction, impaired verbal and non-verbal communication and the presence of repetitive and restricted patterns of behavior” (White, 2013: 114; as cited in Hollin & Pilnick, 2015).

From time to time, autistic people have faced social and health difficulties relating to their impairment. Children with ASD might have shown early and severe symptoms in the areas of socialization, communication, and cognition. Before the diagnosis, the families raising a mysterious child with hidden autism lived with the challenge of trying to identify the disorder. After an autism diagnosis, new difficulties for parents arise, such as coping with the symptoms and poor health care, education, and leisure services (Gomes, Lima, Bueno, Araújo, & Souza, 2014). 'For a student described as having cognitive impairment (e.g., IQ = 50), first grade general education teachers placed the student in a more restrictive setting than the student who have average cognitive ability' (Segall & Campbell, 2014).

Family can affect both the disabled child's ability to adapt and his/her experience. On the other hand, the family itself needs to adapt to the disability that individual has, too. It also has to deal with the social effects and the disabled child's limitations. My mother quit her job when I was diagnosed and has since completely taken care of me 24 hours a day whereas my father was the only one financially supporting us. I did not know how to avoid being teased, which I was by most of my peers when I was young, so I always needed support from my mother.

2.2 Stigma and disability

The diagnosis features of Autism Spectrum Disorder (ASD) include impaired social interactions, impaired communication, as well as restricted, repetitive, and stereotyped behavior patterns. Those people who lack proper social skills and perform inappropriate affective behaviors were considered impolite and dangerous (Pugliesi, 1987; as cited in Werner, 2012). Those factors are considered socially unacceptable, and result in discrimination against and stigmatization of patients with disabilities, including autism. Public stigmatization of individuals with disabilities takes several forms. Individuals with disabilities might be exposed to teasing and stares, and might be avoided by others (Pratt, 2010; as cited in Werner, 2012). Discrimination toward individuals with intellectual disability (ID) was evidenced through the lack of decent services and discriminatory treatment within hospitals, such as the humiliation in public bathing, lack of privacy, and an overly restrictive environment (Jahoda & Markova, 2004; as cited in Werner, 2012).

From Goffman's definition, stigma was a phenomenon whereby society rejected an individual with an attribute which was considered deeply discredited. The effect of being stigmatized, when known about or apparent, spoiled a person’s social identity, cutting them off from society and from themselves. They stood as a discredited person facing a world which did accept them (Goffman, 2009). The question is, how does society stigmatize people with disabilities?

Stigma is a process by which certain groups, such as those with mental illness or intellectual disabilities, are marginalized and devalued by society because their values, characteristics or practices differ from the dominant cultural group. At the individual level, stigma might become internalized (also known as self-stigma; Ali, Hassiotis, Strydom, & King, 2012), which is the process by which individuals endorse cultural stereotypes in relation to a particular group, consider these apply to them and believe that they would be devalued (Corrigan, Kerr, & Knudson, 2005; Corrigan, Watson, & Barr, 2006; Ritsher & Phelan, 2004; as cited in Ali et al., 2012). One of the earliest studies found that individuals released from long stay institutions into the community attempted to hide their disability due to their fear of being stigmatized. The experience of stigma might involve overt acts of abuse or discrimination, or might be more subtle, such as being denied the right to make choices or having over-protective families (Jahoda, Wilson, Stalker, & Cairney, 2010; as cited in Ali et al., 2012).

Stigma not only impacts the discredited individuals themselves, but it also affects individuals who are closely associated with them (i.e., family members, caregivers, friends, or service providers). This is known as courtesy stigma (Birenbaum, 1970, 1992; as cited in Ali et al., 2012). This might result in family members being teased, abused, blamed or considered responsible for the person’s disability (Larson & Corrigan, 2008; as cited in Ali et al., 2012). One way to approach understanding stigma is to see it as negative attitudes. Attitudes are evaluative statements toward a person, object, or event. Attitudes are composed of affective, cognitive, and behavioral components (Chan, Livneh, Pruett, Wang, & Zheng, 2009; as cited in Ali et al., 2012). Attitudes are a combination of seemingly factual statements and an emotional reaction or value component. Attitudes can be either negative or positive; however, stigma is comprised explicitly of negative attitudes (Corrigan & Lundin, 2001; as cited in Ali et al., 2012).

It is often thought being disabled is a sign of a person’s imperfection, tainting them, and leading to stigmatization. Moreover, such imperfection can also taint their close relatives as well. Grandparents in Eastern Asia, and some in Europe and the United States, tend to reject children with disabilities because they thought they would give the family a bad name. The mother, who has the most responsibility for childbirth, was inferred to be a tainted woman if her child was born disabled. Some parents decide to hide their children with disability from society to avoid such stigmatization.

In their 2012 study, Self-stigma in people with intellectual disabilities and courtesy stigma in family carers: A systematic review, by Afia Ali, Angela Hassiotis, Andre Strydom, and Michael King (2012) looked at seventeen other studies that examined self-stigma in a total sample group of 618 people with intellectual disabilities. They used various methodologies and the studies were conducted in various countries, mainly in the United Kingdom.

Two qualitative studies, from the United Kingdom and the United States of America, have explored the impact of cultural factors on the experience of stigma. They suggested that ethnic identity is important (Azmi, Hatton, Emerson, & Caine, 1997; McDonald, Keys, & Balcazar, 2007) and enabled participants to form a close bond with their community, despite the negative attitudes of their community towards disability (McDonald et al., 2007). However, there was an issue of double stigma, when there are two or more stigmas presented on the stigmatized individual, reported from the South Asian community residing in the United Kingdom. Two other studies from the United Kingdom observed the relationship between awareness of intellectual disability and the stigma associated with it.

A Few studies have found that students with intellectual disabilities use coping strategies when they are in mainstream classes, including concealing the fact of having a “handicapped card” and monitoring the behavior of other classmates. Some avoided forming relationships with their peers who did not present any form of intellectual disability to avoid confrontation. Others consciously developed their skills and showed their ambition to learn new skills.

Four qualitative studies from the United Kingdom have reported family carers (caretakers) experiencing negative attitudes or responses from the public. This was shown when mothers were blamed or stared at for younger children’s disobedience and older children exhibited improper public behavior. Five studies outside the United Kingdom, mostly non-Western countries, also show the difficulties experienced by carers in interacting with others from their community. Some parents apparently avoided exposing their child to the community. Three studies reported a lack of support from the community and isolation. The mothers of the disabled in India received little support from members of the community. Mothers in Taiwan bore the shame of public stigma more than fathers. In Africa, the availability of support was vital as a lack of support left mothers isolated from the outside world (Livneh 1982).

As well as being excluded from society, six studies of non-Western cultures suggest that family carers, usually the mothers, were marginalized within families after they gave birth to a child with disability. Some Taiwanese parents chose to conceal the birth of a disabled child from other family members (Chang, 2009; Crabtree, 2007a; Huang et al., 2012). After the child’s birth, family members and relatives (from the father’s side) provided little support to the mother and child because of a lack of acceptance of that child, forcing some mothers to solve this by seeking support from their own family.

Seven studies, three from Western countries and four from non-Westerners, involving a total of 1,159 participants have examined the relationship between stigma and psychological factors. The results were, 1) parents who had higher levels of courtesy and affiliate stigma perceived less control over the causes of their child’s condition, behavior and stigma, and were more likely to blame themselves and feel responsible for their child’s disability, 2) the most distressing reactions were people staring at or ignoring the child, drawing attention to the child and treating the child differently from his or her sibling, 3) there was little change over the seven-year period between the amount of stress parents felt and the types of reactions they found distressing, thus suggesting that the impact of stigma was enduring, and 4) mothers reported a greater care-giving burden as a result of perceived stigma towards their child with disability. Mothers were more likely to consider residential placement of their child if they perceived higher levels of stigma.

One study examined affiliate stigma in mothers with intellectual disability, the quality of maternal care-giving, attachment to the mother and the self-esteem of 36 children who were not affected by the disability. Lower perceptions of stigma in the child were associated with a secure attachment to the mother and the relationship between stigma and attachment was fully mediated by warm care-giving. Higher levels of stigma were associated with the perception of the mother as a cold or ambivalent caregiver. Self-esteem in the child was not found to be related to secure attachment.

Baxter and Cummins (1992) studied parents' responses to the negative attitudes of others. Stress in parents was associated with two types of responses: controlled affect and dissociation. The study suggested that verbal explaining might be helpful in reducing anxiety in some cases. However, parents tended to disclose their child's diagnosis to avoid misunderstanding and as a preventative move. In some cultures, like in India, having faith in God could help mothers cope with the stigma their child faced (Crabtree, 2007a, b; Edwardraj et al., 2010).

The study, Internalization of stigma for parents of children with autism spectrum disorder in Hong Kong by Winnie Wing Sze Mak and Yvonne Ka Yin Kwok (2010), examined 199 returned questionnaires. The study indicated that parent's internalized courtesy stigma directly, through perceived controllability, and through perceived responsibility and self-blame. It initially theorized that raising a child with autism might be stressful for Chinese people because having a child with autism directly affected the social identity and self-worth of the parents themselves (Fung, Tsang, Corrigan, Lam & Cheng, 2007). Their concern for face also contributed to a higher level of stress and psychological distress (Mak and Kwok 2010).

Chinese culture is characterized by collectivism, or having close linkages between individuals and a greater sense of obligation to the group than to the individual. Further, Chinese people tend to emphasize the biological roots of intellectual disability (Kung, 2001; as cited in Mak, 2010) and might be more prone to considering children with disabilities as "bad seeds" and disgraces to their families (Sue & Sue, 1987; as cited in Mak, 2010). As such, they might keep their children a family secret. Given these beliefs, these families might be exposed to the experience of family stigma (Mak & Cheung, 2008; as cited in Mak, 2010) while placing only a limited amount of focus on self-stigma. This finding strengthened the need to expand this line of research and develop culturally sensitive scales (Werner, Corrigan, Ditchman, & Sokol, 2012).

My father was from a Chinese family himself. Whenever I had a chance to pay them a visit, I felt that they stared at me as if I was a bad omen for them. Imagine if I did not go to school at all; I would not be accepted by them.

Studies have reported family carers experiencing negative attitudes or responses from the public. Mothers report being blamed for younger children's disobedience, and disapproval and lack of acceptance of older children who behave inappropriately in public (Ryan, 2005; as cited in Ali et al., 2012); being scrutinized, stared at or monitored in public (Power, 2008; Ryan, 2005; Todd & Shearn, 1997; as cited in Ali et al., 2012); and having to make excuses for the child's behavior (Ryan, 2005; as cited in Ali et al., 2012). The label of intellectual disability posed problems for all members of the family, including siblings (Todd & Shearn, 1997; as cited in Ali et al., 2012). Families were frequently faced with the dilemma of whether they should disclose their relative's disability to others due to fear of negative reactions. Chang (2009) found that stigma associated with having a child with intellectual disability was experienced by mothers but not fathers in Taiwan, as women were considered to be responsible for reproduction and it was their moral duty to produce healthy children. In fact, family members felt pity and sympathy towards the father for having to support his stigmatized wife and disabled child (Ali et al., 2012).

In their 2015 study, Intersections between disability, type of impairment, gender and socio-economic disadvantage, Anne M. Kavanagh, Lauren Krnjacki, Zoe Aitken, Anthony D. LaMontagne, Andrew Beer, Emma Baker, and Rebecca Bentley undertook a disability-focused survey, questioning a nationally representative sample of 33,101 working-aged Australians (aged 25-64). Using the Confidentialize Unit Record File as a tool, the study indicated that people with disabilities fared worse in every indicator of socioeconomic disadvantage compared to people without disabilities. Among people with disabilities, women and men with sensory and speech impairments tended to experience the lowest levels of socio-economic disadvantage, follow by those with physical impairments, whereas those with intellectual impairments, psychological impairments and acquired brain injuries had the highest prevalence of disadvantage.

People with disability are one of the most socially excluded groups and encounter stigma, prejudice and significant barriers that restrict their human rights. From the literature earlier, stigma is a negative mark or name given to specific individual. Therefore, stigma attached to disabled people is a sign that their identity is devalued. Those with disabilities are likely to be marginalized in terms of education and miss out on the right to participate in society.

From my narrative, I was stigmatized as a person with multiple disabilities since I was diagnosed about the age of two years. My classmates teased and harassed me throughout my studying life due to my deformed appearance.

2.3 Coping strategies with disabilities

Stigmatized people often develop coping strategies for the stress they endure as a consequence of their status. Literature on stress and coping indicates that people have many responses to stress, which include physiological, cognitive, emotional and behavioral responses (Holohan, Moos and Schaefer, 1996). To handle these issues, one way to cope with stressors and stigma was active avoidance (emotion-focused) coping in the form of social isolation and disengagement. Forms of disengagement include physical and social avoidance of situations in which stigma might be a problem, and denial or minimization of prejudice and discrimination (Ruggiero & Taylor, 1997).

Coping was a strategy used to endure issues while seeking a way to solve them. Families with autistic children have to cope with each issue such children can bring. Furthermore, the children themselves are also forced to cope with the problems of being stigmatized and discredited in order to peacefully live among the society.

Coping strategies have been posited as one mechanism by which individuals respond to threats of stress, including stressors associated with parenting a child with autism. Based on the stress and coping model of Lazarus and Folkman (1984; as cited in Benson, 2010), researchers have often grouped coping methods into two general types, problem based coping (strategies aimed at solving the problem or doing something to change the source of stress) and emotion based coping (strategies aimed at reducing or managing feelings of distress associated with the stressor) (Benson, 2010).

Conversely, engagement coping or problem-focused coping, specifically support- and knowledge-seeking strategies, is also valued. Spousal support and knowledge-seeking strategies are also effective maternal coping strategies highlighted by Kuhaneck, Burroughs, Wright, Lemanczyk, and Darragh (2010; as cited in Dababnah & Parish, 2013). In addition, engagement coping, included a variety of ways of coping, such as planning and active problem-solving, correspond closely to the category of problem-focused coping as generally conceptualized in the stress literature (cf. Lazarus & Folkman, 1984; see also Hastings, Kovshoff, Brown, et al., 2005; as cited in Benson, 2010). Engagement coping was also found to correspond to the construct of approach-oriented coping (Roth & Cohen, 1986; as cited in Benson, 2010) in that engagement coping strategies oriented the mother into more direct contact with sources of stress related to their child’s autism (Benson, 2010).

Regarding coping strategies to manage the stigma associated with disability, Chen and Shu (2012) found that students with disabilities used avoidance, such as concealing information about the possession of a handicapped card and managing and monitoring the behavior of other classmates with intellectual disability, when they were amongst mainstream students. Cunningham and Glenn (2004) found that strategies for maintaining a positive sense of self in individuals with Down’s syndrome included minimizing their difficulties and believing that they could achieve competency if they worked harder.

My parents coped by not talking about my disability to hurt my feelings. They taught their children that there was no reason for me to skip school because I was not disabled but just different. So I had no idea what the meaning of disability was until I was 15 years old, when I discovered the truth of my condition.

Coping methods were important to helping me bear the suffering in that time. I was able to keep myself up by ignoring the stigmatization I was subjected to and kept on studying. Yet I had to manage my own feelings since they were badly affected by the stigmatization I received.

2.4 Resilience

I was born with disability, so I have always been stigmatized by people who saw me. For example, adults and children at schools, as department stores, at academic learning centers, at national monuments, etc. I coped with the stigmatization. I also sought for external support, mainly from my mother. Yet my tormented feelings could not be fixed without one last factor, resilience.

Resilience is a term that rose to prominence in psychology literature after World War II (Masten, 2014 as cited from Szatmari, Zwaigenbaum, et al. 2016). It referred to the capacity of individuals to avoid a poor mental health outcome in the face of adversity. Historically, adversity was characterized in terms of environmental events such as war, natural disasters, extreme poverty, child abuse or neglect, or living with a mentally ill parent. The importance of highlighting resilience arose from the finding that not all children exposed to severe adversities developed a “disorder” or poor mental health outcomes (Masten, 2014 as cited from Szatmari, Zwaigenbaum, et al. 2016).

A more nuanced appreciation of resilient “outcomes” is also emerging. A child might be resilient regarding a particular outcome (eg, not developing a mental disorder) but not another (eg, poor school performance or poor ability to form social attachments) (Masten, 2014 as cited from Szatmari, Zwaigenbaum, et al. 2016). In addition, resilience must be seen in a developmental context. A child can be resilient at one time point (eg, in early childhood) and not at another (eg, later in adolescence) (Masten, 2014 as cited from Szatmari, Zwaigenbaum, et al. 2016).

To apply this more nuanced concept of resilience to ASD, one must agree that the initial adversity is a risk genotype that predisposes the individual to develop ASD. There may be other adversities that are either biological (such as epilepsy) or environmental (such as limited family income and support, or lack of access to evidence-based services) that influence development for child with ASD, but the initial and most prominent adversities are the biological (in this case genetic) and environmental mechanisms (which are not yet known) that lead to ASD (Szatmari, Zwaigenbaum, et al. 2016).

Resilience is perceived as a personal characteristic in some studies, but in some others it is considered as a quality that can be learned and a process that can be established. The accepted view is that resilience was not a personal and innate characteristic, but it is a process revealed as a result of the interaction of several factors in the case of one's experiences in difficulty (Erdogan, 2015).

Luthar, Cicchetti and Becker (2000) defined resilience as a dynamic process encompassing positive adaptation within the context of significant adversity. It was essential to understand what factors place teenagers at risk, as well as what protective factors might be nurtured in order to develop and support resilience (Anghel, 2015).

Negative stimuli, such as stress, can severely damage a person's feelings. To fix such damage, resilience is needed. Resilience is an acquired factor among each individual, one which gradually restores their feelings after being stressed out. An individual who has a stronger mind has more resilience, and thus recovers faster mentally, than others.

Positive family adaptation in response to, or despite, social stigma and the stressors associated with bringing up a child with disabilities and behavioral problems might constitute evidence of resilience. Early theories posited that family resilience was determined by intra-family factors. McCubbin and McCubbin (1988), for instance, defined the study of resilience as the search for "characteristics, dimensions, and properties of families which help families to be resistant to disruption in the face of change and adaptive in the face of crisis situations" (p. 247) (as cited in McConnell, 2014). More recent theories place greater emphasis on social-ecological factors and transactional processes (i.e., the family's interaction with their environment/s). Ungar (2011), for example, suggests that "resilience is more dependent on the availability and accessibility of culturally relevant resources than individual or within-family factors". Similarly, with respect to individuals, Masten et al. (1999) observed that, if reasonably good resources were present, outcomes appeared to be good, even in the context of severe stressors. There was evidence to support the contention that the positive adaptation of families bringing up children with disabilities in general (i.e., with or without behavior problems) was at least in part influenced by intrinsic, within-family factors. A number of studies have found that positive maternal and family adaptation was associated with better family functioning, and psychological variables such as parent-carer optimism, positive affect, internal locus of control, and the use of meaning-focused and problem-focused coping strategies (Baker, Seltzer, & Greenberg, 2011; Bourke-Taylor, Pallant, Law, & Howie, 2012). For instance, in a recent longitudinal study involving families of children with an autism spectrum disorder, Baker et al. (2011) found that family-level adaptability, measured in Year 1, was a unique predictor of maternal depression symptoms, measured in Year 3. Research on resilience showed that children's ability to cope with adverse situations varied over time depending on biological, psychological, environmental influences and interaction between them (Folostina, 2015).

Those studies indicated that resilience could help families facing and adapting to problems. It depended on the availability and accessibility of relevant resources.

Features of resilience such as positive thinking, low anxiety levels and good interpersonal relationships have been associated with lower levels of depression in young adults. This held true even for those at risk of depression given the presence of variables such as mental health disorders in their families, their medical history and anxiety or depressive disorders during childhood and the beginning of adolescence; family violence; or large families (Carbonell et al. 2002 ; Benetti et Kambouropoulos, 2006 ; Ng, Ang & Ho, 2012 as cited by Marcotte, 2014).

In their 2014 study, Resilience in families raising children with disabilities and behavior problems, David McConnell, Amber Savage and Rhonda Breitkreuz surveyed a stratified (by child age group) random sample of 538 families raising children with disabilities in Alberta, Canada. Using the Family Life Survey as a tool, the study indicated that higher levels of child behavioral problems were associated with higher financial hardship and lower social support, and these were in turn associated with lower family life congruence. Families with high levels of social support and/or low levels of financial hardship, indicating good resilience levels, typically enjoyed average or above average levels of family life congruence, even when the number and intensity of child behavioral problems was high.

In 2015’s Psychological and Educational Resilience in High vs. Low-Risk Romanian Adolescents, Ramona Elena Anghel studied 251 urban Romanian adolescents, from ninth through twelfth grade, (mean age of 16.1 years, 64.5% females and 35.5% males), recruited from five high schools in Bucharest who completed her questionnaire. Using the Adolescent Resilience Scale, the Academic Resilience Scale, the Stressful Events Scale, and academic performance as tools, the study indicated that Romanian adolescents faced a great number of risk factors for which they might not have the appropriate resources to handle. On the other hand, many of the high-risk adolescents demonstrated resilient functioning, both psychological and educational, which suggests that they were successful in overcoming these different types of adversity.

The term "optimal outcome" was introduced by Fein and colleagues to characterize children with a past diagnosis of ASD whose symptoms later fell below thresholds for the diagnosis and who no longer showed evidence of delays in intellectual and adaptive functioning (Fein, Dixon, Paul, & Levin, 2005; Kelly, Paul, Fein, & Naigles, 2006; Sutera et al., 2007 as cited from Szatmari, Zwaigenbaum, et al. 2016). Their work built upon past research examining predictors of outcomes in ASD, and specifically, efforts to characterize autistic individuals who ceased to meet criteria for the diagnosis. Much of this research was done in the context of natural history studies (eg, Rutter, Greenfeld, & Lockyer, 1967; Sigman et al., 1999 as cited from Szatmari, Zwaigenbaum, et al. 2016).

Fein et al. (2013 as cited from Szatmari, Zwaigenbaum, et al. 2016) defined optimal outcome (OO) as the presence of a documented ASD diagnosis by age 5 years (including speech delay), coupled with: (1) not meeting criteria for ASD; (2) not showing evidence of social impairments "of an autistic quality" on the Autism Diagnostic Observation Schedule (ADOS); (3) having communication and socialization skills within 1.5 SD of the mean on the Vineland Adaptive Behavioral Scales (VABS); (4) being in a regular classroom placement with no special education services specific to ASD (eg, social skills group); and (5) having relationships with typically developing friends according to parent reports. Subsequent studies using the Fein et al. (2013 as cited from Szatmari, Zwaigenbaum, et al. 2016) case definition have used a case–control design, such that rates of OO cannot be estimated. However, recent studies have examined OO during late childhood and adolescence, providing a unique window into how resilience in ASD may be expressed at this critical stage of development.

Fein et al. (2013 as cited from Szatmari, Zwaigenbaum, et al. 2016) also studied a group of 34 individuals aged 8 to 21 years who had a history of early ASD and later OO, comparing them to an age, sex, and nonverbal-IQ-matched group with a current diagnosis of continuing ASD, as well as to typically developing (TD) peers. Although 7 of 34 (20.6%) in the OO group were rated on the ADOS as having mild social impairments interpreted as being unrelated to ASD (eg, reduced eye contact due to shyness, or inappropriate social overtures due to poor impulse control), there were no significant differences in social or communication or adaptive skills between the OO and TD groups, both of which were rated as more advanced than the ASD group. Orinstein et al. (2015a as cited from Szatmari, Zwaigenbaum, et al. 2016) reported on mental health outcomes in the same sample, finding that both the OO and ASD groups had higher rates of ADHD symptoms and diagnoses as well as specific phobias, relative to the TD group. An earlier report identified subtle pragmatic language deficits in 5- to 8-year-old children with OO, including difficulty identifying the goals and motivations of story characters and misinterpretation of story events (Kelly et al. 2006 as cited from Szatmari, Zwaigenbaum, et al. 2016), although follow-up at age 8 to 13 years suggested that these deficits were no longer present (Suh et al., 2014 as cited from Szatmari, Zwaigenbaum, et al. 2016). Notably, children with OO also had a history of earlier referral to services and more intensive intervention (particularly prior to age 3) than the ASD comparison group (Orinstein et al., 2014 as cited from Szatmari, Zwaigenbaum, et al. 2016).

While interesting, these findings are nevertheless accompanied by three methodological concerns. First, the studies were largely retrospective and sampling was completed by advertising for volunteers who were now “free” of their ASD diagnosis. As a result, the generalizability of the findings is unclear. The control groups were often children with ASD who did not have optimal outcomes so the design was effectively case–control (Szatmari, Zwaigenbaum, et al. 2016).

A second methodological concern lies with the definition of optimal outcomes. “Optimal” is a value-laden concept mainly defined to date by researchers as the absence of an ASD diagnosis with “typical” intellectual and adaptive functioning. Yet others may have a different perspective. Many adults with ASD are “proud” of their diagnosis and in fact celebrate the talents and strengths that are unique to the condition. In turn, many parents of children with ASD are more concerned with mental health or adaptive functioning than with the persistence, or not, of an ASD diagnosis. Recognizing that it is possible to have many autistic symptoms and still have good mental health and adaptive functioning, many parents might consider these particular outcomes as markers of success to be celebrated as well (Szatmari, Zwaigenbaum, et al. 2016).

Third, not only should multiple perspectives be incorporated into the definition of “optimal outcomes,” but the very notion of an “optimal outcome” in the singular also ignores the multivariate nature of the ASD phenotype. As noted above, it is important to take a lifespan perspective so that a good outcome may occur at one point in development but not necessarily at another. The multivariate nature of ASD also means that an optimal outcome may be present for one phenotype but not necessarily for another. The key is to see resilience as a process whereby the child may avoid poor health outcomes associated with a specific adversity, in this case the ASD genotype. This perspective allows for a much more nuanced concept of “optimal” outcomes in ASD (Szatmari, Zwaigenbaum, et al. 2016).

Havighurst (1972 as cited from Szatmari, Zwaigenbaum, et al. 2016) proposed that the stages of human development may be best conceptualized as a series of integrated tasks. Examples of these tasks include: developing speech; developing the ability to regulate emotions and behavior; being ready to attend school; and adjusting to a changing physical sense of self, to new intellectual abilities, and to increased academic demands.

While the early years have been the main focus of ASD research to date, adolescence is also a crucial developmental stage—in that skills developed and mastered during this period have important implications for making a successful transition to adulthood, including independent living for some people with ASD. However, the tasks associated with developmental health for “typical” adolescents need to be conceptualized, taking into account the specific strengths and challenges associated with ASD. The results of these focus groups were remarkably consistent and are reflected in the following five themes that we propose as key aspects of developmental health in ASD during adolescence (Szatmari, Zwaigenbaum, et al. 2016).

1. Socialization: positive peer and family relationships, sexually healthy behavior, and full community participation.
2. Functional independence: competent at activities of daily living, functioning safely in the community, and taking responsibility to manage life tasks relevant to adolescence.
3. Self-determination: setting appropriate goals, problem solving, making good choices, and engaged in vocational planning.
4. Educational achievement: good academic achievement, positive relationships with teachers and school peers, a feeling of connectedness to school, and full participation in school-related activates.
5. Emotional/behavioral regulation: good self-regulation of anxiety and mood, low frequency of challenging behaviors.

Resilience is the name of a process when someone deals a certain obstacle in life. Among the challenges of being stigmatized, I was sometimes scolded so badly that my mental state could have been fallen into bad shape. Resilience helped me fix my distorted feelings back to their normal state. When I was feeling down, I think resilience was the reason I unknowingly, gradually felt better.

2.5 Conceptual Framework

This study was based on narrative story using the concept of Disability, Stigmatization, Coping, and Resilience. My purpose was to demonstrate how a person living with disability experienced stigmatization through life and how I and my family coped with such circumstances. Moreover, I aimed to state my resilience and my family's resilience to have the right to live and being as a person. For disability, it was studied on the meaning my personal term, my family, and society. Moreover, disability in this study focused on my disabled conditions by both Autism and Metabolic Bone Disorder. For stigmatization, it was studied on self-stigma, social stigma, discrimination, and a small part of courtesy stigma as well. For coping, it was studied on problem-focused coping and emotion-focused coping. And lastly, for Resilience, it focused on what the capacity of individuals to avoid the negative outcomes including the meaning and the process in the case of one's experiences in difficulty

CHAPTER III

RESEARCH METHODOLOGY

This study used a qualitative and narrative approach writing narrative interview in examining one’s self experiences of being an autistic young woman. This study aimed to understand life experiences of person with autism and their family. Life story was regarded as the channel for learning about and understanding the individual’s inner world. This approach was not only the way to access inner or subjective realities and their experiences, but also helps individuals understand their ideal and their current situations through the processes of constructed and reconstructed stories.

The study collected data from the viewpoint of me using the process named self-narrative, which was a form of self-reflection and writing that explores the researcher's personal experience and connects this self-narrative story to wider cultural and social meanings and understandings. In this study, I was the subject of the study and the writer, who wrote, recorded, and shared my experience and stated the meanings of these life experiences. I used my own story to organize my experience into life scenarios coping with stigma and being a person. To study the story was to reveal the experience owner’s reflection. Instead of studying the story, the researcher became a part of my own story.

Data collection was conducted for 8 months, from December 2015 to July 2016. Trustworthiness of the data was a major concern during conducting field work.

This narrative study research study was a qualitative research studying on my self-narrative story for the researcher myself was affected by both autistic disorder and metabolic bone disorder. The story consisted the detail about daily living in each age including the relationship of me to people around, every members in my family, my classmates from kindergarten to secondary level in 2 regular schools, colleagues from the Bachelor’s Degree of the current university, every teachers in my academic life, and other people related to the details in the story. The detail was about treatment from 2 general, public hospitals in Thailand and a health center also included. I portrayed my personal experience of problem solving, socializing, every possible ways of coping with issues, and my family's resilience strategy to recover everyone's mental state and form our mental protection, in my narrative story. I began the story from my mother's pregnancy to the day I graduated Bachelor's Degree, including the detail about means providing, stigmatization, coping, and resilience. I also used the including details to analyze the story later on.

The objective of the narrative story writing was to publish the entire story to the society. It has 3 main components.

1. The heart contents, which were the main topics that was meant to tell the reader.
2. The plot, which was the story's summary.
3. The narrative methods, which were the flow of the story itself, giving it power. (Aekkanok Panadamrong, 2015)

Diary writing was the writing about the daily living basis lacking of plans and formats. It has no means to publish itself unless it can be highly benefit to people and the writer themselves had gone.

So, the narrative story writing and the diary writing have a completely distinctive difference.

To achieve the objectives' goal, which would be possibly benefited at the most for every people studying on this research, my family and I chose to make this study research report in English.

Things to think carefully before writing one were, the third person's and property's privacies were needed to be secured by giving the let names to each of them and the whole story and feelings must be revealed in the writing without concealing.

3.1 Research Design

Qualitative and self-narrative methods were used to study and understand the researcher's life of individual disability, her past experience and struggle under the social and cultural structure. A narrative story was a story with the narrator as the main character himself or herself. It's always true to the narrator as he or she was experiencing it himself or herself. In this study, the researcher collected information about the context of my life story and situate my story within my personal experiences and my family experiences, social support and historical contexts.

The researcher studied on the narrative story about herself. If a story was a sequence of events in time and space, then the world of the story was the contextual time-and-space in which that sequence of events occurs (Raven, 2015). In some cases, narrators may have their own opinions, attitudes and worldviews, which was where the intrinsic subjectivity of narrative lies as if the narrative was their account of the story's events (Raven, 2015). The most important parts in each story were the plot of the story, which was the story's detail, and narrative.

People around me do not believe that I was an individual with autism since the researcher did not have any evidence to show them. That was a prime reason she wrote the narrative of her life story in this report, to study her life to reveal her past self and her struggle to overcome her own disabilities to readers.

In this study, the researcher expressed her feelings, life meaning and life experiences along with her life histories and situation. The story followed its own timeline, from the beginning to the end. She also wrote a narrative story by interviewing her mother. The more a story was detailed, the more reliable the story would become.

3.2 Respondents

The narrative study used purposive sample selection. The researcher was the main subject of this study. This study aimed at examining life experiences of person with disability and demonstrated reflexivity feeling. She wrote and recorded her life experiences and the feeling towards the life events. She included her parents as key informants of this study. They provided data to support her entire story and they also narrated the story from their perspectives on life experiences of family having children with disabilities.

The researcher chose them as her key respondents because, as parents, they have the close relationship to her and had major roles in her life. Other people might have such relationship as well but she could not make any contact with them at all. She told them the benefit each other would get from the study to let them decide to join in it on their own. There was also a very-low risk level that her key respondents could no longer participate in case they were working abroad, severely ill or die before the data collection process was over because they paid the cash to take care of themselves.

In conclude, there would be 5 participants in total which were interviewed at home. The place where the interviewing sessions took place was her current house.

3.3 Data Accessing

1. As a member in the family, the researcher received a large amount of love and kindness from each of the data providers who were other members in her family that she could ask to interview them with ease.
2. To get the data, the researcher could use her current house as the interviewing place to get, gather, and receive the data. There was a data provider, her grandmother, whom she should visit at her place to interview her. Her house was near hers so it did not bring any issue on traveling there.
3. During the interviewing session, if any data provider felt discomforted or if their feelings got distorted by such session in any ways, the researcher could console them, for that was the action she always did in the past.

3.4 Research Methods

This study employed narrative interview and observations along with the data collection. The data for this narrative story was stories gathered from the researcher’s life experience who had experienced to all the issues and obstacles led to having her own coping, issue solving and self-encouraging in order to overcome her health limitations and disabled self and to make her life to be positive. So, the methodology used was in-depth interviewing with using the sound recorder during the interviewing sessions, starting by interviewing the mother to gather the major data used first, then other key informants would take turns to gather the missing data until the gathering data was completed.

The process of in-depth interview with key informants

In the beginning, the researcher thought that in-depth interview her family members for data collection could not be difficult for her. However, it was actually hard to set the interviewing questions to gather the necessary information for the narrative story writing later on, that she had to frequently edit her questions after each interviewing session. For the precise and direct questions she had in hand gave her informants, which were her family members, discomfort and avoid answering them. So, she had to make a conversation to them prior to each interviewing session. The most important was that she had to restrain her mind before bursting her feelings to her informant; when he or she began to answer off-topic, the researcher had to avoid being angry, and she had to provide her informant unlimited time in each interviewing session to allow them to answer as much as he or she pleased. Whenever the questions turned to be difficult ones that could alter people's feelings in a bad way, the researcher had to allow her informants more time to answer them, especially my mother whose relationship was really close to her for always living with her. In case the questions were difficult for her to answer, the researcher had to provide as much time as she needed to answer them. So, she herself could not predict when each interviewing session would end. It also implied that, the information gathering process would consume time, depended on the amount of raw information needed until it reached the sufficient amount, which was more difficult than she ever though.

The researcher told and made understanding to my family about the interview, and everyone voluntarily joined the interviewing sessions. She chose to interview her mother first, because she was the one with the closest relative to her who always spent times with her. She found that she looked so enjoy telling the story about her childhood. She always found to smile and giggle when the story about her first teaching to her was told, showing her humor. However, when she told her about the medical treatment or about her critical decision, like when the doctor told her the reason she could not talk and always acted naughty, or when she could not sit for the metabolic bone progression had gone worse, which the doctor had to give her the surgery to treat it, including when the other doctor predicted that her disorders were impossible to be treated or be cured, she could not join in the society, and she needed to be under specific care and treatment for life. She would response by speaking slowly and struggling, and even consequently ending the session for her hardly able to answer, any more. Almost every time while she was answering the related questions, her tone of voice dramatically changed into sad and depressed-down tone. She also had to wipe out her tears with her hands. She tried to talk about them all at once, so she would not have to repeat them once again. The researcher took her hands to encourage her, and felt the cold from the hands, so she remained silence with her to stop mentally harming her. At last, after stopping a session to avoid pressuring her to depression, she gave her the offer to write the answers in the paper and give it to her later on. The researcher would like her mother to avoid answering directly to the question and to avoid crying when answering. She would fluently answer to the question about when she battled for her rights. She told the researcher that her feelings then never fade away from her since she did not like anyone who was deploying others or unjust. Mostly, she could literally talk to her all the time about the narrative information. She asked her to entail more about the necessary information and arrange the story as much as she wanted to.

My father had to work outdoors, so the researcher chose to appoint him in the day he was not go to work – mostly were Saturday and Sunday. In each interviewing session with him, when she asked a question, he would response by his question. For example, if her question was “When the doctor diagnosed me that I was affected by both Autism and Metabolic Bone Disorder, how did you feel?”, he would reply “Did you really want me to say my feelings that I haven’t even tell anyone, Jib?” She felt that her father was a person who concealed his feelings really well, but since he did not have properly spent time with his daughter like his wife did, he then was ready to answer her everything she asked. Whenever he had the interviewing session about his feelings, she had just realized that he was sorrowed for the conditions she was suffered from. He also was sad that she could not live as long as her other siblings lived. Moreover, when he had the session, he tried to hold his tears up by halting his speech, yet his tone would be so low and squeezed down, as if he was concealing something in his mind. For example, when he said “I am so sorry that your life wouldn’t be the same as your siblings’, Jib”, she could clearly sense his sadness hidden in his tone. Both her parents had the same feelings when the researcher was being disadvantaged or deprived from her rights by people in the society. Their fluent, quickening tones, including to the father’s rhyme knocked the table with his pen, showed their displeased to the events when she was deployed or lost her rights by her teachers and the examination board. The father always gave excellent reasons and ideas in each session. Each session she made with him consumed a huge amount of time that she felt that she got too heavy information from him, yet after rearranging it; it was actually a good piece of detailed information that could be used in almost every parts of the study later.

The researcher’s sister had been married and has a son, so she did not have enough time to conduct the interviewing session at any time the researcher wanted to. She had to appoint her at the house where she lived. In the session with her, she needed to conduct in another quiet room because there were too many people gathering around in the appointing days. She precisely answered the questions with as compact answers as she possibly could, just like what the researcher wanted, and she also added her suggestions that she thought they would be useful for the research project. For example, when she was given or stigmatized by various negative meanings, she would express her clearly displeased moods, telling me “other non-related people outside the family had no rights to mock you, Jib”. She would give her interviewing quotes about many people with disability who need equality and help. The researcher could put such information into the research project.

Next, the researcher’s brother was the one living in the house where she lived, but he worked in weekdays and returned very late at night, so she chose to interview him in weekends. He usually gave not so useful information in the interview which could not really useful to the narrative story, as if he wanted to avoid responsibly answering the questions. However, when the questions about the moment she was deployed or lost her rights, he would express his displeased feelings which was shared with hers about the teacher whom they both experienced to. His feelings were given to the same teachers and the examination board. For sharing the same experience, they could share their common feelings to each other. The brother was a person who understood more than other family members, about the disability she and some other people had. He showed his direct regards to suggest her to seek for her careers in order to gain the same experience as other people did.

The last person was the grandmother who was an old woman the researcher spent some times in her childhood to live with, yet time could not make her bond with her niece to fade away, so she was a part of the informants. From the interviewing session, the researcher found out that her information was slightly discrepant from her memory. However, it was the opinion from her lovely and respectful old woman. Therefore, the information from her was not edited.

Information collecting from the researcher herself began after the interviewing sessions' end, for having issues on her own blurring memories, caused by the condition of Autism. So, all the gathered information from the in-depth interviewing process would be reviewed once more to recover the lost memories. She found that people with Autism like her would have issues of the memories due to they never focused on any surrounding things. When she had to write the narrative of her own life experience, she had to spend so much time to review her own memories, even took longer times than interviewing time of each informant. From all the interviewing sessions, every informant quoted the stories that mentally affected them, which were not being told before. So, in order to completely write the narrative story, she willingly revealed her hidden stories as well. Such as, when her sanitary health gone worse after using the improper toilet, having her own new personal world in the cyber world which affected my learning life later, secretly having a "sweetheart", etc.

The researcher did not collect and note the detail from the Master's Degree onwards, for she was afraid that she might consume too much time on producing the final thesis on time. Furthermore, she failed to see the negative impacts from the stigmatization in this academic level, since she had only 4 classmates, 3 of them were employed adults, led to fewer chances to stigmatize her. As she thought about it carefully, she found that the story since she was born to when she was graduated a bachelor degree had covered the details about all stigmatization, coping and resiliency strategies in her life as the objective was planned for. So, she would like to skip the detail about her life story from the master's degree onwards.

3.5 Research Tools

1. Voice recorders and field notes Interview was audio recorded with the consent of the respondent(s).
2. The researcher herself as an important tool in data collecting
3. Interview guideline

The guided questions were used during in-depth interview. There were two sets of interviews, for the researcher’s parents and for her herself. The interview questions followed the objective of the research study which included the medical treatment, both physically by doctors and mentally by her mother, the developmental training and the educational learning in a series of events from birth to graduate a bachelor degree.

The example questions included, “how was I in general at that time?” “How did I look?” “How would you describe my health that time?” And “how did people react when they saw me?”

4. Key informants – assigned to people with close relationship with the researcher who experienced with her life and could be contacted.
5. Computer – A tool to store written-form information in.

3.6 Data Analysis

Data collection in qualitative data analysis was an ongoing process from the beginning to the end of the study. Notes were taken during the interviews and an audio recorder was used with the permission of informant(s). The recorded files were transcribed word for word. The researcher checked the data after the interview was transcribed and checked with informant(s) to ensure that he or she agreed with the transcribed data.

Then, the researcher described the story or objective set of life experiences living with disability and place it in chronological order, she read my voice, the narrative story from her family and identify the story and the context of the life events to answer the research questions. Narrative analysis was used to analyze the story.

Narrative analysis was a process to find out the sequence of the story to explain what happened, who said what to whom and where or in what situation the speaking took place. To use such analysis on my story, the researcher read for the sequenced events in it and seek the best answer(s) to the research question(s).

3.7 Credibility of Data

The researcher was aware of biased concerns and validity of data. However, this study aimed to apply the self-narrative methods that were used to study and understand her life as who has been experiencing Autistic. It is always true as she was experiencing it herself. However, she got second opinion on the self-narrative story from many sources to make sure that there was no bias during the mentioned procedure. Triangulation was applied using sources of data and methods. Different data sources were collected from different times, spaces, and people. Different informants were required, such as her herself, her mother, her father, her brother and her sister, in order to check the consistency of different data sources within the same method. Method triangulation of data collection also conducted, such as conversations, observations, and in-depth interviews in order to gain consistency from different data collection methods (Patton, 2002).

Concerning the possible bias from the data providers, for example the researcher’s family, they might avoid giving some sensitive or negative information about the main researcher due to their personal relations. A fictional character, an unreal character that could be found in television, book, or music, could be used as the researcher herself in the question to solve this issue. The data providers felt more relaxed to answer sensitive questions without having to directly mention the researcher in question at all.

3.8 Ethical Consideration

3.8.1 Privacy

This was a work revealing the researcher’s personal details, narrative and feelings as a disabled person who wanted to reveal them. However, the researcher needed to interview her family members, and she considered their privacy, which was not the secret itself but the access to the secret of the others (Moor, 1997).

3.8.2 Confidentiality

Just a Person Walking Slower than the Others, but Can Reach the Intended Destination: The Story of a Person Overcoming Autism was the story of the researcher's own narrative life story. She put in the most detailed story that her memory can provide. In addition, she interviewed her mother, who raised her from the beginning, for further details about her childhood from when she was born because that was her cognitive limitation. In addition, she kept the third person's name a secret.

3.8.3 Informed consent

The researcher asked her informants to sign an informed consent document, which must be obtained and honored to show as proof that she was not forcing her informants to be but they rather would voluntarily be data providers for her study.

The researcher also asked the rest of her informants like she asked her mother. Yet only her grandmother, whose eyesight was too poor to read the document, therefore she could not see well, could only provide the researcher her verbal consent.

3.8.4 Beneficial

The researcher was not interrupting any interviewee during any interview going on to let the informants answer her questions as much as they want to. She also made sure that the readers would get the most benefit on knowledge from her research. So, she included every detail of the interview in it.

The benefits the researcher's key respondents got when the study was completely done was that, it was a guideline for parents having children with autism to provide their children the educational opportunity. It can provide the nurturing guide for such parents, too.

3.8.5 Risk Outcome Management

To make sure that this study would not negatively affect the researcher's respondents and the researcher herself, she had a psychologist who was willing to listen and help her and her informants on their emotional problems any time. This psychologist can be contacted for 24 hours a day.

CHAPTER IV

A SLOW WALKER LIKE ME: STIGMATIZATION, COPING AND RESILIENCE

This chapter following the narrative life aims to show some main points answering research questions. The finding includes the social meaning of disability from medical and cultural perspectives, the stigmatized experiences, coping and resilience.

Introduction to Me and My Family

This chapter portrays my narrative life that included my family, my infancy and my everyday life. It include the detail about me being stigmatized and my strategy to cope and resilient to each stigmatization, either caused by my own disability or not.

I am 25 years old. I was diagnosed with Asperger’s syndrome, which is found in the autism spectrum, and bone metabolic disorder (skeletal dysplasia). The syndromes resulted in my current figure as a dwarf, with an imbalanced body, misshaped legs and a larger head than average. I have a short concentration span. I rarely talk and I do not like making eye contact. I prefer isolation.

After finishing my morning routine, I would do some work, which consists of searching for information from the internet. I occasionally swap to reading books. I like to play Japanese games and watch my favorite Japanese animations in my leisure time. My bedtime is around 10.30 PM. My responsibilities in the house are helping my mother arrange the dining table, folding up laundry, taking out the garbage, feeding the cat, and giving my mother a massage when she feels tired. Lastly, I am in charge of giving everyone moral support when they feel down.

I was born in Bangkok. My religion is Buddhism. My father is 56 years old. He works for a private company. My mother is 55 years old. She is a housewife.

She also takes care of me full-time. My mother wakes me up every morning before preparing breakfast for everyone. She is the one who prepares my clothes for the day depending on my activities. She does the laundry for the family as well. After breakfast, I will take the medicine my mother set for me. When I need to go somewhere, she will drive me and take care of me. My father will take this role in weekends. Returning in the evening, she will prepare dinner for us. After dinner, she will do the remaining household tasks, such as cleaning the house, folding clothes, washing dishes, etc. She will finally have free time afterwards, when I am either studying more or taking a rest. At about 10.30 PM, my mother will remind everyone to go to bed. All of these are her roles as she takes care of the family.

I have two siblings. All three of us have higher education. My older sister is 30 years old. She has a Master's Degree in Peace and Conflict Studies from a university in Sydney with an Australian government scholarship. She is married and has one son. I am currently in the third year of my Master's Degree of Arts in the faculty of Social Sciences and Humanities, Mahidol University. My youngest brother is 24 years old. He has Bachelor's Degree from the Faculty of Engineering at a well-known university in Thailand. He has just started working for a private company. My brother has played a significant role in stimulating my development and helped me live with autism.

4.1 Social Meanings towards a person living with Autism and bone metabolic disorder

4.1.1 Meaning from the modern medical perspective

Meaning from the modern medical perspective had the major role in my family's life since I was born until I was diagnosed as a patient of both autism and metabolic bone disorder, as the narration arrayed.

Figure 4.1 When I was born

I was born on October 15, 1991 at about 9 o’clock in the morning, which was two weeks ahead of schedule because my mother had the preeclampsia condition during her pregnancy. She told me that she received prenatal care at a hospital nearby.

> *“I thought my baby was a boy when I was pregnant with Jib since I was glowing and looking good unlike when I was pregnant with my first daughter. I was eating so much that everyone wanted me to stop by saying “eating this much will make you fat, it will be harder to labor the child”. With my first daughter, I had a hard time eating and wanted to eat weird food only. My skin was darker during the pregnancy as well. Everybody around me had to find rare food for me to taste in hope that I would be able to eat some of them. These differences to my first pregnancy made my husband and I thought that the baby would be a boy. My husband was also frequently reminded by his father to give him a grandson to continue the last name (Chinese traditions). I kept thinking about his words and wondered if I gave birth to a girl, would I be asked to have more babies until a boy is finally born? (Laughing)”*
>
> Mother

When my sister was about three years old, my parents had to go abroad. My father was sent by his company to be trained in Denmark for six months and my mother accompanied him. As that trip was her first time going abroad, she was very excited. My mother was nervous preparing for this trip as the weather in Denmark is very different from Thailand. Though it was decades ago, all her memory is well kept in the photo albums.

She shyly told me that I might be an “export/import” child from Denmark because she discovered that she was pregnant with me after her Denmark trip. She was so glad got pregnant as she waited for many years to have another child to play with her eldest daughter. She was also confident that I was a boy because the pregnancy felt so much different from her first one.

When she was in Denmark, she saw people there drank a lot of milk and ate protein-rich foods which she understood that people there got healthy and big form that eating habit. She tried to adopt that habit as well for thinking that it would make her fetus healthy like Danish people that she saw. She drank milk like water and ate a lot of pork cartilage which she understood that it can help with the fetus’ bones.

As a result of her new eating habit, she developed asthma and became almost 100 kilograms. She was only 64 kilograms before this pregnancy. My mother needed a special doctor for her prenatal care as she has developed complication in her pregnancy. In her seventh month of pregnancy, the doctor found a high concentration of protein in her urine. Her body was swollen, especially in her legs and feet. High protein and edema led to preeclampsia. Her asthma deteriorated to the point where she was admitted to hospital.

In the thirty-fourth week of pregnancy, she felt labor pains so she quickly went to the hospital. She remembered that it was October 14. It was also a government-designated public holiday since it was during the period of a three-day World Bank meeting, until October 15. At the hospital, a nurse performed a pelvic examination and said that she was dilated. However, her doctor was on holiday so my mother was asked to come back on October 16. My mother was with her parents at that time. My father was working in another province and was worried about my mother very much. He asked my grandparents to take my mother to another hospital instead of waiting for two more days. At arrival, the officer there asked for her medical history and the reason she changed hospitals. A nurse was asked to give her an injection to halt the contraction of the uterus to observe her condition for a night and to wait for the full medical history to arrive. The doctor in charge told my grandparents that my mother might have some more serious conditions that were hidden from the doctor herein that hospital that only the doctor from previous hospital knew. The new hospital wanted to do a further analysis before allowing the labor to proceed. The reason that she can remember everything in details is that she was asked to repeat the story so many times by my doctors and other people that wanted to know.

> *"I was angry at that first nurse for she seems to fail to understand anything I tried to explain. It was also clearly noted there that I am a patient with a high-risk condition. She didn't even call the doctor to report this and ask for further action, but she choose to tell me to go home! If I had believed her and waited for two days like she said, what could have happened to my child and me? And whose responsibility is that? Right?"*
>
> Mother

From the narrative story about the time before I was born, my mother thought that I would be a boy assuming from the extreme difference from her first pregnancy with my sister. Excited about having a boy, my mother tried to eat foods that she thought were good for her foetus. After coming back from Denmark, she believed that milk and protein-rich foods are good for her baby so she ate so much of those. However, the protein-rich foods were not good for her as she developed asthma, excessive protein in her system and being overweight. She was admitted at the hospital for her asthma attack.

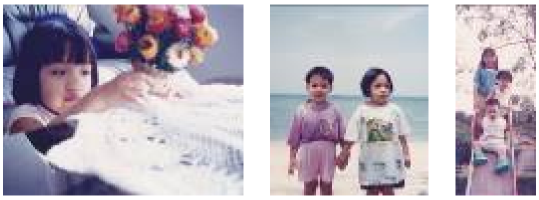

Figure 4.2 Meaning as autism: starting Point of Stigmatization

Many reasons led to me being born two-week premature. On the day I was born, the doctor that had always been looking after my mother was on vacation. My parents decided to not wait for that doctor to come back as suggested by the nurse at the hospital. My mother went to another hospital and there were some complications in transferring my mother to the new hospital. My parents felt that those complications might also be a cause of my illness and disabilities.

At 9am in the next morning, the doctor has given her the contracting stimulator, yet my mother could not push me out on her own so they had to use suction machine. At birth, I was 55 centimeter in length and 3.950 kilogram in weight. I did not cry when I was born which was not a good sign of a healthy baby. I was big, chubby and hairy, especially on my forehead.

I did not cry for milk or tried drink when my mother breastfed me. She had to pump her breast milk for me and fed me little by little together with formula milk. The doctor has discovered that I had neonatal hyperbilirubinemia at level 12 which was fatal. I had to be in an incubator for a month and my mother had to visit me at the hospital every day to feed me.

> *"At the moment I heard this from the doctor, it was almost like my heart was about to stop because Jib had just been born yet had to bear such a condition. I blamed myself for being the one who was always sick during the pregnancy. I blamed the previous hospital's doctors and nurses for not taking care of me when I was going into labor. I even blamed the government for giving us a three-day holiday for no reason. If we had kept waiting, Jib might get worse and worse. However, when I saw her in the incubator as a fat, pale infant with such a cute face, I was suddenly relieved and had much greater confidence. I no longer worried about myself, having just given birth the other day, or my ability to travel around to feed her."*
>
> Mother

After finishing the treatment for the severe jaundice I had earlier, I could go back home. I still had other difficulties after coming home from the hospital. I did not sleep much and I threw up most of the milk I drank. I had to go back to the hospital very often. My mother coped by looking after me very carefully. She also needed help from my father to cope with difficulties in taking care of me together with looking after my sister and being pregnant with my brother.

My mother told me that, as an infant, I was very hard to raise since I always cried, never drank milk, and rarely slept. When I slept, it was for a short moment, unlike my sister's behavior at the same age. She would go to sleep soundly after she drank milk. My mother added that I continually cried and it was difficult to calm me or make me stop. I had to be carried all the time by my mother or my father. She admitted that taking care of me was very tiring. Without my father's help, she alone might not be able to stand it. My sister was a four-year-old toddler at that time and my mother was pregnant with my brother not so long after I was born.

My mother noticed that something was wrong with me one day. After drinking milk, I cried, swirled and vomited. She took me to see a doctor for that and discovered that my intestine was twisted. The doctor diagnosed that the symptom could be from formula milk allergy. The treatment for my twisted intestine took a very long time.

She also noticed that I cried when I laid face-down. Taking a bath, she discovered a small bump on my back above the cervical vertebrae. She took me to see a doctor at a hospital nearby. The doctor said that my spine was bent which can press on my spinal cord and result in paralysis. He also said that I needed a surgery to fix my bent bone before it damages my spinal cord. However, I was too young for the surgery at that time. My case was transfer to a bigger hospital in town. I received my bone surgery at 21 months old.

My development was very much slower than other babies and toddlers at the same age. When I was six months old, I could not roll over on my own. When I was nine months old, I could not sit on my own. I kept falling forward with my head between legs. My parents had to help me sit properly on their laps or in the walker. When I was one year old, I was unable to stand by myself. My parents had to put me in a walker to help me walk on my own.

These delays made my parents worried that I might not be able to walk until I receive my backbone surgery. The doctor told my parents to wait for me to be old enough for the surgery. While waiting for my surgery, I had regular check-ups with my doctors to see my conditions and progress. I did not respond well to the stimuli when my doctor tested my progress. I did not turn to acknowledge voices calling to me as if I could not hear them. I did not make any eye contact but looked around like I was absent-minded.

At home, I always salivated. I had no tears when an onion or a garlic was cut nearby. I did not stay still. I did not take a nap at daytime. I did not show any signs of interactive or linguistic development when I was one year old. At this age, most children can walk, lean to hug their parents, call them, respond to questions, tell their needs in simple words; such as, “I want…”, “I’m hungry…”, “I have to pee” or “I’m sleepy”. I could not do any of those. My parents thought that my delays might be caused by my bent backbone and being sick so often.

The best things my parents could do then were to take very good care of me and to never leave me alone no matter what happened. My mother tried to teach me some simple words, like “stand”, “walk”, “sit”, “sleep”, “eat”, “food” and “water” by repeating and acting the words in the hope that I could understand and say some of them.

> "*I admit I was surprised by that, because Jib’s sister was not anything like this. It’s almost a year but Jib couldn’t flip over in bed, sit right up, stand, walk, or talk. I was so worried, yet I understood that she was sick so often that it might cause her development to be delayed from the rate it should be. Nonetheless, I took good care of Jib by trying to stimulate her development. I thought Jib would be able to do all that like her sister did when she was a year old.*”
>
> Mother

My parents noticed how delay my development was. Other children at my age could already walk and tell their parents their basic needs, yet I still could not. However, they did not give up on me. Instead, they tried their best to overcome my conditions. They took me to see doctors and tried to find the cause and to cure for my delays and illnesses. They also kept teaching me to speak some basic words in hope that I would be able to understand and communicate.

My mother realized she was pregnant with my brother when I was two and a half months old. She had to go to hospital for prenatal care and she had to take my sister to a nursery. My father, on the other hand, went to work in another province and he returned home late every day. My parents decided that our family needed a nanny to help my mother do the household chores and babysit me.

When I was about one year old, my mother noticed that I refused to eat or drink. My mother thought that I had blisters in my mouth from the heat. At the hospital, my mother was surprised by the diagnosis. The doctor said that I had many cuts inside my mouth. The cuts were in the shape of fingernail marks which the doctor suspected were from being pinched with fingernails. Later on, my nanny confessed that she pinched the inside of my cheeks because she could not stand my naughty behaviors.

I did not take a nap during the daytime. I rebelled against whatever she was getting me to do by slamming my back on the floor. This incident made my mother realize that she could not let anyone else look after me. Other people did not understand and was not willing to tolerate my behaviors. She only trusted her family and my father to look after me in her absence since then.

When my mother took my sister to the nursery, she always took me along. The nursery owner observed me and noticed that I have signs of autism. She told my mother to take me to a hospital to check whether I have autism or not. At the hospital, a doctor confirmed that I had autism. The doctor explained that autism is caused by an impairment in the part of the brain that manipulates speech and action results in impaired communication and social skills. He further explained that autistic people have developmental delays overall. Autistic people have repetitive behavior with a very low level of interest in the environment, said the doctor.

Without proper stimulation and care, autistic people will not be able to speak and always behave like a child and will not be able to socialize at all. This inability to socialize and to fit into the society led to suicide in many autistic adults. The doctor suggested immediate treatment to improve my symptoms and my behaviors in order to enhance my development. My mother had no idea what autism was at that time. She wanted to know the severity of this illness and the potential effects on my life. She searched for more information from asking the doctors and from reading books that the hospital suggested to her.

> *“I was so worried and lost in my thoughts since the nursery owner made the suggestion. When the doctor confirmed to me that Jib has autism which is an incurable brain conditions, I couldn’t hold back my tears anymore. Just thinking that she has to live with it for the rest of her life… (Stops speaking as she turns away.)*
>
> *“(Takes a long sigh before turning back to the interviewer.) I could barely catch the doctor’s explanation. I was still confused when I returned home for I didn’t know what to do next. All day long I sat still,*

looking at Jib and couldn't believe that Jib would be as the doctor and the nursery owner said... (Halted a bit before struggling to continue.)

"When my sense returned, I thought that no matter what Jib is or will be, Jib is still my daughter. So? Will I really let my feelings about the word autism, or whatever was impairing my own feelings, negatively affect my feelings about Jib? On the other hand, I think that, no matter what the illness is, it will eventually be treated and cured. That's why I don't want to suffer from this news anymore..."

Mother

My father had an opinion about this as follows.

"I wanted to know scientific cause of my daughter's disease. I did an intensive research about autism as I knew there must be other cases like Jib. She cannot be the only one and I wanted to know how other people look after their autistic children. My curiosity overpowered my sadness. However, my sadness never went away."

"To be honest, my sadness for Jib becoming like this never left my mind … (The interview suddenly stopped. The researcher noticed him squeeze his hands together before continuing the interview with a shaky tone and tears) … because up until now, I can't find the answer to the question, what caused it. There was never a proven answer to the question. I still am trying to work it out. Not knowing the cause and the solution of Jib's disease make me sad. I am not sad about Jib's autism all the time. I only feel sad when I think about why she has it which I don't in my daily life. It is like this sadness is kept in a drawer in my heart. I only feel sad when that drawer is open."

"From my research, I found out that autism is caused by reasoning part of the brain impairment. It is unknown why such impairment happened. The only cure is to improve the other part of brains that is not impaired. That was what I learnt from the books back then. The impaired reasoning part of the brain might sound large, but it didn't mean that the whole brain was damaged. According to the books, autism had so many levels of severity. Some of them might lose their reasoning ability in

> *total. Those cases are difficult to handle. But Jib's case isn't that severe. She still had some function in the reasoning part of her brain. Then, the thing I must do is (he put a hand on the researcher's head) improve this brain part, make it stronger so that it leads to her development. That was the thing I could do to help, to strengthen other parts of Jib's brain.*"
>
> Father

Doctor tried to explain to my parents about taking care of an autistic child as follows.

> *"I had to remind your mother that, if you still want your daughter to be normal, you have to look after her by yourself. If not, she will end up being someone else's daughter.*"
>
> The doctor

Upon knowing that my developmental delays were from my autism, my parents were worried that I might not be able to have any development without any treatment for my autism. The books and the doctors said the same thing that the symptoms and development of autistic people cannot improve without proper treatment since young age. They took me to the hospital nearby to see pediatricians, therapists, and speech therapists. However, they were still skeptical about the treatment from that hospital.

In addition to the medical treatment from the hospital, my parents decided to find other ways to help me as well as they did not want to rely on doctors only. My mother decided to resign from her career in order to take care of me full time. My father took care of earning enough income to support the entire family. My parents asked their friends and the extended family to seek for other families with autistic members to learn from their experience. My father searched for more information about autism to support my mother, while she closely observed me and took care of me. My mother noticed that water and sparking items attracted me as well as her movement like hand-clapping, dancing, jumping, knocking, whistling, etc. She used those things and movements to teach me.

About a year later, my case was transferred to a hospital in the city for my surgery. Doctors in that hospital also diagnosed that I had autism. The diagnosis from the hospital in the city was almost the same as that of the hospital near home. Since the hospital near home has done so many tests on me, only an IQ test was added in the procedure. The diagnosis concluded that, I was affected by autism but still could go to school. That was the reason the doctor sent me to a local autistic therapy center in the city.

> *“At that place, they took a lot of autistic children together in a single room with a trainer giving instructions to those children to improve their behaviors. Jib at that time rebelled and was uncooperative. She walked out of the group and faced a wall. Before too long, someone approached Jib and hit her back, then drag her to the group.”* From the scene, my mother reflected that: *“The picture I saw that day made me think and decided not to take Jib there anymore. I didn’t believe in using violence to train autistic children. I think that they would just react by rebelling even harder.”*
>
> My mother explained the experience that led her to think this way: *“When I was angry at Jib once, I unintentionally hit her. At first when she was hurt, she stopped doing that behavior just because she was startled. Soon after, she did the same thing again. Her behaviors of being naughty and active made me hit Jib again, but that time she hit me in return. Jib’s action finally made me understand that she was mimicking me. So, I didn’t see that taking Jib there would help her improve in any way. I determined that I would train Jib my own way.*“
>
> Mother

Figure 4.3 Another meaning as Bone metabolic disorder:

"Wasn't autism alone bad enough? Why must she have this bone disease?" At that time, nothing could explain my family's story more than my father's quotation here, that emphasized the word "my family's suffering" as portrayed in the narration.

When I was close to 21 months old, my mother noticed that I preferred crawling to walking. She also noticed that my legs had lost their strength to step up the stairs. I had to hold the banisters with my hands and throw myself upward and climb the stairs on all fours. My ability to walk had worsened drastically. Finally, I lost all strength to walk or even stand firm. I wriggled on my bottom or crawled instead without worrying about anything happening to me. My mother said when my legs were still strong, I did not like to stay still but rather walked aimlessly the whole day. There was a time I was left alone while she was taking a shower, I went out of the unlocked house and went to the main road in front of the village where the traffic was heavy. A neighbor yelled for her to go help me before anything bad happened to me. However, when anyone saw me wriggling on my bottom or crawling instead of walking, they thought I would never walk again.

Given all the above conditions, my mother said she and my father could do little other than wait in worry for the day of the surgery. My mother recalled her feelings on the day of operation: "I had so much sympathy for her because she was so young yet she had to have a surgery. Jib's cries were deafening. She refused to cooperate with the surgeons and nurses and wriggled hard to avoid having the saline drip inserted. The scene I remember most was Jib being wrapped tightly before the saline was injected prior of surgery. The wrapped cloth was so bloody that I could not look at it, as if my heart was going to break apart. But as soon as the surgery was done and she finally recovered from the anesthetic, Jib tried to sit up and play even though she was wearing a half-body cast. She wouldn't listen to anybody's objections. She had just returned from the surgery, though."

From that day on, I was transferred to a larger hospital in Bangkok to start the medical treatment for both bone metabolic disorder and autism. Based on her memories, my mother said that the doctor in charge of treatment said there were a few cases of bone metabolic disorder, Skeletal Dysplasia type in Thailand. Most of them were because of deprivation in calcium and Vitamin D as fetuses. The symptoms were porous, fragile, and slim bones; bones that had grown abnormally; and small overall figures. If the symptoms grew worse, every bone joint in the body could collapse and press on important internal organs, potentially causing the respiratory system to fail. If the patient was not treated properly, he or she might end up dying young. The doctor could not forecast how severe my symptoms would be so he could only suggest alternative caring methods. Both parents had to be cautious not to let me fall down or bump into anything if possible. From the statistics, patients with this disorder would come back to the hospital to fix bones which were already porous, fragile, and slim. Worse than that, if they had fallen or bumped into anything, the bones might be broken. Most of the time, the broken bones were in their arms, legs, hip, ribs, and neck which was the worst case. My parents took care of me with the highest level of caution. They took me to hospital for every appointment and strictly followed the medicine regimen the doctors set for me. Their effort lessened the risk of my bones being broken.

> *"I remember that I hugged Jib while I listened to the doctor, yet I couldn't remember where the fallen tears came from. My tears steadily poured out for I didn't know why such a horrible disease had fallen upon my daughter* (Paused). *I lost most of my confidence. I was afraid of everything. I think everyone had come to aggravate me. Having a brain disease was already bad enough, why must she also be affected by a physical disease like this?* (Struggling tone) *Whenever I thought about this, I couldn't help but end up crying. I was hurt inside* (Pointed to her right chest) *every time I thought about these things."*
>
> Mother

> My father's feeling was not that different from my mother's when he learnt about metabolic disorders. He said *"My feeling back then was really sad. Why did such thing happen to Jib? Wasn't autism alone bad enough? Why must she have this bone disease as well? My sadness multiplied by this notion* (spoke with struggling tone). *Why must Jib become like this? So how could she live on? When I heard what the doctor said, my feeling was the same as those standing still in front of the doctor without knowing what to ask or reply. I could only ask him a short*

> *question, what should we do next? Just that question, yet he said he didn't know."*

Father

When my parents received the bad news about my metabolic disorder from the doctor, they were stressed. They were confused by not knowing the exact causes of two diseases, which also stood in such contrast it made parenting difficult. With the condition of autism, I was so active that I refused to stay still. I did not speak as a result of my developmental delay. The bone metabolic disorder caused me to have very fragile bones which did not get along with my hyperactivity. Looking after was a challenge as my parents had to be careful not to let me fall over or bump into anything but I was too hyperactive to stay still. No one could stop me from running or walking aimlessly. Giving medicines to me was difficult since I tended to fight back to avoid taking them, so I took less medicines than the amount the doctor prescribed.

The development of my metabolic disorder was even more apparent. My bones in my arms, legs and joints, grown in various abnormal asymmetric shapes since they grew horizontally instead of vertically, making my arms, legs and fingers slowly bent. When I was three years old, I was only 103 centimeters tall and never got taller than that. When I stood, it was noticeable that the tip of my feet pointed to each other, which made it hard to stand still as I tended to fall down. When my parents took me to travel but I did not want to walk, they took pity on me and carried me on their hips or put me in a stroller. I also resisted eating so that made me look skinny with a big head.

From above narration, medical definition had affected my parents' thought. My mother blamed herself and everything around her for being the causes of my illness. She blamed herself for not taking care of her health well enough during her pregnancy and made herself sick. She blamed the doctors, nurses, and the long holidays for her delayed medical care in giving birth to me.

4.1.2 Meaning from Thai cultural perspective

Meaning as Karma

Karma was another perspective my mother used as reason for my disabilities. Upon knowing about my autism, my mother was really sad as she told me that,

> *“I was so worried and lost in my thoughts since the nursery owner made the suggestion. When the doctor confirmed to me that Jib has autism which is an incurable brain conditions, I couldn’t hold back my tears anymore. Just thinking that she has to live with it for the rest of her life… (Stops speaking as she turns away.)*
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> *“(Takes a long sigh before turning back to the interviewer.) I could barely catch the doctor’s explanation. I was still confused when I returned home for I didn’t know what to do next. All day long I sat still, looking at Jib and couldn’t believe that Jib would be as the doctor and the nursery owner said... (Halted a bit before struggling to continue.)”*
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> *“When my sense returned, I thought that no matter what Jib is or will be, Jib is still my daughter. So? Will I really let my feelings about the word autism, or whatever was impairing my own feelings, negatively affect my feelings about Jib? On the other hand, I think that, no matter what the illness is, it will eventually be treated and cured. That’s why I don’t want to suffer from this news anymore...”*
>
> Mother

However, my father, who did not believe in karma like my mother did, had another idea as follows.

> *“I felt sad when the doctor said that it was an incurable disease. The notion of Jib has no chance of being cured from it made me feel very sad.”*
>
> *“My first question was what is the reason? Some people just simply put the cause of such disease to be the nature, the karma from previous life, or things like that. We are taught to embrace bad luck by putting the cause of bad things on invisible hands like the nature, the karma or god. Such simple thoughts make you feel better easily without solving any problems or make anything better. That is not how I operate.”*
>
> *“I wanted to know scientific cause of my daughter’s disease. I did an intensive research about autism as I knew there must be other cases like Jib. She cannot be the only one and I wanted to know how other*

> *people look after their autistic children. My curiosity overpowered my sadness. However, my sadness never went away."*
>
> *"To be honest, my sadness for Jib becoming like this never left my mind … (The interview suddenly stopped. The researcher noticed him squeeze his hands together before continuing the interview with a shaky tone and tears) … because up until now, I can't find the answer to the question, what caused it. There was never a proven answer to the question. I still am trying to work it out. Not knowing the cause and the solution of Jib's disease make me sad. I am not sad about Jib's autism all the time. I only feel sad when I think about why she has it which I don't in my daily life. It is like this sadness is kept in a drawer in my heart. I only feel sad when that drawer is open."*
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> *"From my research, I found out that autism is caused by reasoning part of the brain impairment. It is unknown why such impairment happens. The only cure is to improve the other part of brains that is not impaired. That was what I learnt from the books back then. The impaired reasoning part of the brain might sound large, but it doesn't mean that the whole brain is damaged. According to the books, autism had so many levels of severity. Some of them might lose their reasoning ability in total. Those cases are difficult to handle. But Jib's case isn't that severe. She still had some function in the reasoning part of her brain. Then, the thing I must do is (He put a hand on the researcher's head) improve this brain part, make it stronger so that it leads to her development. That was the thing I could do to help, to strengthen other parts of Jib's brain."*
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> Father

Upon knowing that my developmental delays were from my autism, my parents were worried that I might not be able to have any development without any treatment for my autism. The books and the doctors said the same thing that the symptoms and development of autistic people cannot improve without proper treatment since young age. They took me to the hospital nearby to see pediatricians, therapists, and speech therapists. However, they were still skeptical about the treatment from that hospital.

In addition to the medical treatment from the hospital, my parents decided to find other ways to help me as well as they did not want to rely on doctors only. My mother decided to resign from her career in order to take care of me full time. My father took care of earning enough income to support the entire family. My parents asked their friends and the extended family to seek for other families with autistic members to learn from their experience. My father searched for more information about autism to support my mother, while she closely observed me and took care of me. My mother noticed that water and sparking items attracted me as well as her movement like hand-clapping, dancing, jumping, knocking, whistling, etc. She used those things and movements to teach me.

My mother said this was everything they could do for me back then. She also consulted with a monk that she respected to comfort her feelings. The monk told her that everyone and everything in this world is destined by karma.

Four years later, as a proof to keep on studying in that primary school, I needed to have any treatment until I was capable to do so. During the summer break before grade one, my father trained me to read and write while my mother tried to train my concentration skills to make sure I would behave in class but it did not work as they planned. They were so worried that I did not get any better. One day, a neighbor who lived opposite to us invited my mother to a famous temple in Pathumtani Province. She said that there was a good masseuse who could heal paralysis patients at that temple. She saw that my legs at that moment were so twisted that I was barely able to walk or live happily so she suggested that I should try the massage.

My mother remembered that it was a day before Makha Bucha Day that the neighbor led us to a cloister at arrival. There were many monks and people preparing for the ceremony the next day. We waited for a long time and my mother was so busy taking care of me as I was not behaving myself. She decided to take me home before getting the see the masseuse since she could not stand my behavior any longer. When she was carrying me and was about to leave the cloister, she heard a monk calling for her to stop. When she turned back, she saw an old monk stepping from the cloister and sat on a long bench. He asked her who she was and the reason she was there. She told him the stories. The monk kindly looked at me, then said that I had been freed from my karma which meant that my bad lucks were about to get better.

The monk said that because he knew a doctor that could help me. He also told us about his relative who had an accident to the brain. That relative had his damaged part of the brain cut out during surgery yet he still lived and was as happy as he could from the treatment by a private medical center. He told my mother he wanted us to meet a doctor from there. He arranged a meeting for us to that doctor later. My mother told the whole story to my father, and suggested that they would meet the doctor there. We never got to see the masseuse the neighbor told us about.

From the narrative story, my father refused to believe that the conditions I had were caused by intangible things like karma, destiny, or nature. He only wanted scientific answer. However, my mother had a strong faith in Buddhism and believed in karma and reincarnation. She had a monk that she respects dearly. He reminded her about the life cycle of being born, sick and dead. As she believed in life cycle and reincarnation, she tried to take best care of me hoping that I can carry over my good merits and knowledge from this life time to the next life time. Though education might not lead me to a good job, at least it can be asset for my next life according to my mother's belief.

My sickness was viewed as my life karma in Buddhist society. When the abbot knew a doctor that he thought could treat me, he said that my karma was over (the storm has passed). Buddhists relate disabilities and sickness to karma from this life time and previous life. Not only my life karma was over, my parents' worries were also relieved from my effective treatment.

2. Courtesy stigmatization: Meaning as born from an imperfect mother/woman

Stigma not only impacts the discredited individuals themselves, but it also affects individuals who are closely associated with them (i.e., family members, caregivers, friends, or service providers). This is known as courtesy stigma (Birenbaum, 1970, 1992; as cited in Ali et al., 2012). This might result in family members being teased, abused, blamed or considered responsible for the person's disability (Larson & Corrigan, 2008; as cited in Ali et al., 2012).

Courtesy stigmatization is a type of stigmatization that usually stigmatizes on people related to the individual as the reason the individual became a marginalized person.

My grandfather’s house was a shop house in one of the main fresh markets in Bangkok. My great aunt, aunt and two uncles lived there. My father is the second child out of the four siblings. He is the oldest son of the family which made him the main responsible person of the family after his father. My grandfather’s next-door neighbor used to be wholesale sweet and snacks shop. I called his neighbors grandpa and grandma too. When we visited my grandfather, his neighbors always gave us some sweet and snacks from his shop as they saw us as their family too.

My siblings enjoyed visiting my father’s father as they enjoyed the company of the family, the kind neighbors and the market. We used to visit grandfather very often and cooked together as all the ingredients can be found in the market.

I, on the other hand, did not enjoy the visit much. When my mother took me out in the market to do some grocery shopping, I could not stand the smell of the market’s floor and vomited. The market’s floor was very dirty and full of fluid from meat and water from vegetable and fruits. My mother never took me out in that market again. I got bored very quickly at my grandfather’s house.

My grandfather loves me and gets excited every time to see me. He used to open the car door where I was sitting in and carry me to his house when he was healthy. Upon noticing my distinctive abnormalities, he quietly complained as it could be translated as, the reason I was born like this was because my mother was an incomplete woman. He used Chinese words for the pot of medicine to compare my mother as a sick and incomplete person.

I can also remember that my grandfather always asked my parents “When will Jib be cured from this?” and my parents replied “The doctor didn’t tell us when”. Other relatives always talked with me for fun and entertainment because I could not speak very well. They especially liked when they asked me questions and I struggled to answer or my answers did not fit with their questions which was enjoyable for them. Their favorite question was “What do you want to be as you grow up?”. My answers were always different because my intention had changed each time they asked me.

I do not feel as bonded to my father’s side of the family as much as much the family on my mother’s side. That might be because I have never stayed at their place like when I stayed with my mother’s family.

Thai-Chinese families still adhere to the tradition of preferring boys to girls as only boys can carry on the last name while girls will have to marry into others' families. Unhealthy girls are considered "the shame to the daughter-in-law and the unfortunate to the family" and mostly hidden in the house away from the society. As the head of the Thai-Chinese family, my grandfather did not accept me who was born to be "a girl with impairments" and blamed my mother using Chinese word that means "Moh-ya (the pot of medicine)" which is slang for sick woman. He said that my father had married a bad woman and brought her into his family and gave him an impaired granddaughter.

4.1.3 Social stigmatization: Meaning as born uselessly deformed from a bad and evil woman

From Goffman's definition, stigma was a phenomenon whereby society rejected an individual with an attribute which was considered deeply discredited. The effect of being stigmatized, when known about or apparent, spoiled a person's social identity, cutting them off from society and from themselves. They stood as a discredited person facing a world which did accept them (Goffman, 2009).

One way to approach understanding stigma is to see it as negative attitudes. Attitudes are evaluative statements toward a person, object, or event. Attitudes are composed of affective, cognitive, and behavioral components (Chan, Livneh, Pruett, Wang, & Zheng, 2009; as cited in Ali et al., 2012). Attitudes are a combination of seemingly factual statements and an emotional reaction or value component. Attitudes can be either negative or positive; however, stigma is comprised explicitly of negative attitudes (Corrigan & Lundin, 2001; as cited in Ali et al., 2012).

It is often thought being disabled is a sign of a person's imperfection, tainting them, and leading to stigmatization. Moreover, such imperfection can also taint their close relatives as well. As my narratives:

Everyone in my village could remember me. They smiled at me, some rubbed my head and patted my shoulders to encourage me, which made me feel better even though I could hardly speak. Most of my neighbors were kind and considerate people who liked to share. However, some of them did not like my family and used to stare at me in disgust. My parents knew that they used to gossip about my family and thought the worst of us. My parents did not pay much attention to those people has they had better things to do.

> *“The first time I read that letter, I was surprised. I asked myself, 'What have I done to displease the sender? And why did my daughter get involved in this?' I asked myself further, 'Why do people choose violence or threats to mentally attack mothers of children with distinctive differences or who are weaker than them?' If I didn't have faith in myself or if I lost the confidence to be myself, this letter might have mentally threatened me that I might think I was the neighborhood's pathetic person. Instead of that, I thought I pitied the sender for she has a very poor mental basis that she could write this letter.*“
>
> Mother

4.1.4 Gender stigmatization

Mostly, people in the society saw patients with autism or other disabilities as gender-less people for they cannot imagine disabled people having lovers. Disabled people are sexually discriminated in general. In this thesis, I would like to raise some awareness on this discrimination. My personal experience has shown that disabled people also have puberty and desire to have lovers.

When I studied in Grade three of primary school, I was about ten years old. My mother noticed under a shower that my breasts were starting to develop. She bought me sport bras to wear as undershirt. When seeing my doctor, my parents asked the doctor about my puberty. The doctor said that puberty is a good sign for me as most patients with metabolic disorder would have developmental delays in everything. They delay would worsen the patients’ health ash their organ systems would start to malfunction which in most cases result in short life expectancy, said the doctor.

My breasts showed that my development was going along with my age and menstruation could be expected soon. The doctor planned to arouse the cycle to begin as soon as it could. Having such cycle could strengthen my health without using too much medicine. After the cycle began, I had Estrogen, a type of hormone, which helped me with development together with his medicine. My knife-thin bones got stronger, as well as my legs. However, my mother was still worried that having such cycle might not be all good for me as I was so small, fragile, weak, and could hardly sustain myself. She was more relieved when the doctor said that I would be stronger as soon as I reach my puberty which meant that I could overcome the worst point of metabolic bone disorder.

My puberty brought along my body hair as well. My body hair was thick and dark like male body hair. My mother offered to shave me, but she was worried that she would cut me. Some other people admired my legs as they said it was described as "hot" and they wanted their legs to be as hairy as mine. My mother did not know that I also had armpit and pubic hair.

I would like to mention about my femininity here. When I was young, I was too weak to look after my own hygiene and my mother had to do it for me. After my puberty, I started to grow breasts, body hair, menstruation, pimples, body odor any my voice got bigger. My mother then realized that I was no longer a child despite my small body. I still went through puberty like other girls. My mother started to teach me about hygiene for women from wearing underwear, cleanliness and using sanitary pads. She also took me to see skin doctor for my pimples.

However, my mother is still the one who looked after my nails and my clothes. I have no interest in fashion includes how I look when I go out. I only wear clothes to cover my body. I think people who groom themselves so well want to impress someone which I have no one to impress. My mother tries to buy clothes that can cover my hairy legs to not attention to them. People always mock and criticize my leg hair and make me embarrassed. She has offered to shave my legs for me but she gave up as I did not stay still enough. Instead of getting rid of my body hair, I just kept hoping that one day it will just fall off which is impossible. I never hate my body for not being beautiful in men's eyes. I think that my lover should be the person who understand my conditions and accept my disabilities.

Four years later, my family and I took a week travel to Tokyo, Japan, for I successfully entered a secondary school. Upon returning from Japan, I began to notice changes in my body, the most obvious was having my first acne spot on my face. Then, my voice turned hoarse like a boy's and everyone could hear that from me. What worse was, I started to get smelly with undesirable odor.

4.2 Coping Strategies

Coping was a strategy used to endure issues while seeking a way to solve them. Coping strategies have been posited as one mechanism by which individuals respond to threats of stress, including stressors associated with parenting a child with autism. Based on the stress and coping model of Lazarus and Folkman (1984; as cited in Benson, 2010), researchers have often grouped coping methods into two general types, problem-based coping (strategies aimed at solving the problem or doing something to change the source of stress) and emotion-based coping (strategies aimed at reducing or managing feelings of distress associated with the stressor) (Benson, 2010).

Conversely, engagement coping or problem-focused coping, specifically support- and knowledge-seeking strategies, is also valued. Spousal support and knowledge-seeking strategies are also effective maternal coping strategies highlighted by Kuhaneck, Burroughs, Wright, Lemanczyk, and Darragh (2010; as cited in Dababnah & Parish, 2013). In addition, engagement coping, included a variety of ways of coping, such as planning and active problem-solving, correspond closely to the category of problem-focused coping as generally conceptualized in the stress literature (cf. Lazarus & Folkman, 1984; see also Hastings, Kovshoff, Brown, et al., 2005; as cited in Benson, 2010).

4.2.1 Problem-based coping: “Normalization” as my family’s Expectation

Normalization is the discourse from the medical system that tried to change the meaning of the disability into that of the normal (Horejsi, 1979). My family has the same belief, so they tried to take care of me by giving me the best medical treatment possible and tried their best in teaching me to be self-sustaining and independent. Normalization was an expectation for my family and could be considered as a problem-based coping strategy that used the reasoning to find a solution. My family made a research to get information about my conditions and treatment as follows.

Normalization in speech

My mother had the biggest role in my learning life. My process of daily learning began with the schedule my mother has made for my development. She said that the routine and repetition were the best tools to help me learn. She talked to me with short and easy phrases like take shower, dress up, eat your food, sleep, etc. She believed that I will finally understand the meanings of those phrases from repetition.

> *"I set my priority to your speaking ability because communication will function as a door through which you can overcome your autistic self. From wondering whether you were mute or not, today, you are wondering whether you used to be mute or not. Now that you study in Grade 5, became the presenter on the television and the inspiration to people who had autistic patients under their care."*
>
> Mother

My mother noticed that I especially liked to play with water when I was taking a shower or a bath, including those in other kinds of containers. So, the first word I could speak was "*nam*" (water in Thai) and I used that word for everything. Everyone in my family had to guess what I meant each time I spoke. Finally, they understood that, the word "*nam*" had the easiest pronunciation I could make back then and I liked to pronounce that word randomly without reason. Only they thought among themselves that I needed something or just wanted some attention when I said that word.

Normalization in behavior modification

Normalization is a key process to correct autistic behaviors and make it as normal as possible (Padmanabhan, Lynn et al. 2013). The narrative story shows that my family used normalization process on me to make me more acceptable to the society.

When the family was occasionally invited to a party, I would play with water in glasses without realizing that it was not polite in public. I enjoyed it even more if there was ice in the glass. I would put whatever was within reach, like paper, spoons, side-dishes, etc. into the glass until I was satisfied, before I went to do the same thing with other glasses. That behavior made everyone worried when they took me to a party. If I was forced to stop, I would slam myself to the floor and cry. My mother had to fix my behavior.

My mother had always closely observed my behavior so she knew that I liked anything that sparkled. She bought colorful wrapping papers and cut those into circles and stars. She used them as the reward to train me to stop playing water in glasses. When I reached for water in glasses, she showed those paper circles and stars to me and told me "*you'll get one if you don't put your hand in*". She always gave me the reward when I did what she told me. I put the given star, sometimes to my shirts or sometimes to my glass. She discovered that her distraction was a good trick to stop me from undesirable behaviors. She used the sparkling stars to stop my other undesirable behaviors too. Every time I followed her instruction, she gave me a star to stick on a board which she called "*the board of good deeds*".

My mother told me that making noises obstructs my socialization as often it is regarded as poor manner. I cannot refrain from making noise when I have extreme feelings even now. My mother said that my brother did not copy my loud noise behavior. The surprising thing was my brother could understand what I wanted from those meaningless noises I made, she said. When people followed my brother's instruction, they could calm me down, she said. My brother and I used be very close as we are only eleven months apart. We went to kindergarten together because my brother was strongly attached to me, my mother said. However, in primary school, my brother started to have his own friends who had the same interest as him.

My mother also noticed that I was afraid of the color red on anything including red clothes, red shoes, or red food. I used to cry and run away when I saw anything red. The reason for this could not be explained. On one Chinese New Year, everything was decorated red in my grandfather's house. When I arrived, I would not enter the house to join the celebration as I did not like red. I would not take the "red money envelope" everybody gave me as New Year gift. They solved the problem by giving me "pink one" instead. Red was also used to decorate some other Chinese ceremonies like Chinese festival, Moon festival, the death anniversary of the ancestors, etc.

My mother thought of a way to ease my fear of red by bringing everything red into the house to use them daily. The story my mother always told me was one with a pair of red shoes with flowers on them I absolutely refused to wear. She was not forcing me to wear them but put them beside my worn-out shoes which happened to be my favorite in order to lure me to try the red one. Everybody's new clothes were mostly red. Food or snacks she bought in had red packages. Most importantly, everyone would not tease me by bringing those things near me but rather leave me to cry whenever and wherever I saw anything red. What I remembered so well was my mother frequently took us to a car washing machine. It had a lot of big red brushing rolls rolling into the car in the center to clean it. I had to cover my face in fear and throw my face down to the car seat for I was scared that the rolls would reach me. Such procedures my mother was using, like the rhyme goes as "*klua-jim-klua*" (An eye for an eye, a tooth for a tooth, เกลือจิ้มเกลือ), took some time until I was used to the color of red. Nevertheless, with such a mild procedure, she could solve my phobia of the color red.

She said, she was confused about why I did not look at the people I was talking to but rather look at the moving objects. She had to hold my face to look at her every time she wanted to talk to me. She noticed that I would not make eye contact. My eyeballs would move around randomly, either upward, downward, left, or right. I was judged as having no interest in anyone who was speaking to me. Most of the time, they judged me as a person who did not pay respect to anyone speaking, even if that was not my intention. It happened automatically under a subconscious fear to avoid making eye contact to protect myself from them. My mother said she never thought that I would keep this characteristic up until now. She said it was the nature of people with autism to protect the patients themselves from being stared at, which was a sensitive matter. Everybody in my family could accept this so they felt that it was not an issue. They would not force me to have eye contact with them when they were speaking to me. Rather, they let me do it on my own by mimicking them from time to time. However, this characteristic of mine eventually improved in a positive way since I had got so much confidence in myself and my fear was lessened. There were just a few times I actually avoided the stare since the person talking to me had expressed too much stress on their eyes.

> *"I felt like the rolling eyeball looks so scary, while the other parts of the face are staying still without a blow of the wind. I clearly saw some red blood veins in each eyeball. Sometimes, I noticed that the pupils could change their size at will, and I didn't understand why. That misunderstanding led me to fear. Even now, I still avoid directly making eye contact.*"

The Researcher

My mother learnt from all the above about how to raise me. The most important thing for me was for a mother to take a continuously good care of me and I also needed to have my behavior improved. I also needed education equal to the others for a better future. Getting started, I must have trusted her first by sincerely giving love and help I needed. She had to do those things naturally and be kind, patient and frequently give compliments. When I trusted her, I would accompany her more easily to improve my behavior. She added that everyone in the family could understand and feel the same thing, that they should adapt themselves to the nature of the one with autism and one's limited capacity due to my bone metabolic disorder so that we could live together. They did not desire to make me feel abandoned by them. For example, giving educational support, help, advice, and encouragement to everyone equally, included going out and having lots of activities.

Since my brother is only eleven months younger than me, he was a good comparison of my delayed development. My parents noticed that my brother could learn, understand, and follow my mother's commands like other kids, while I could do them much slower than him. She even said that raising me was different than raising my other siblings. In other words, teaching my siblings to walk, they would steadily improve from one step to two day by day. In my case, I learnt a step one day, I might take a backward step later or stay the same or even worse.

My mother had to be extremely patient for she could not get angry with me or force me. She had to stay calm about everything I did because it took time before I could understand a lesson and could perfectly act as I was taught. I was the person who could not be forced at all. I must be persuaded to do something. If any behavior did not cause anyone trouble, my parents would let me do so, such as, the behavior of avoiding eye contacts, eating a whole big piece of food without cutting it into smaller pieces, dressing improperly, and scratching my face and my whole body all over.

When my brother could do something, such as looking at the others, flipping, sitting, crawling, standing, speaking, he became example for me to memorize and mimic. My parents felt satisfied that I had a similarly aged brother who had a really close bond to me. He also had an important role on my developmental stimulation, either directly or indirectly.

My parents also used the rewarding method in motivating me to try finishing a task on my own. The prize could be admiration, encouragement, praise, gifts, or money. My mother said that she and my father had to be aware of the promises they made with me since I took everything seriously. For that reason, my parents believed that my memorizing and mimicking from my brother were signs that I could develop like my siblings did. They tried to support me in every way to ensure that I would have a chance to study like others.

Raising me with my siblings did not make my mother feel that I had so much characteristic and behavioral difference since she knew and seen some resemblance between us three. Both of my siblings could speak at about one year and a half, which was considered slow. They did not like to take naps in the daytime. My sister was very active and naughty so she had a lot of accidents when she was in her nursery school to primary school. Her learning progress was a bit slow. The worst was she wrote letters backwards in English and Thai. My brother could not sit still. He rocked on the chair and stood every fifteen minutes when he was studying to walk to the fridge and eat some ice cubes. He did that until he was in secondary school. My parents had to work on some behaviors of my siblings too.

Autism, metabolic disorder, and asthma can be lethal diseases if the patient does not give good care. Taking care of me became an important task for my parents. Disease development turned me into a thin, pale, small body with big head and chest, crippled legs with both feet pointing at each other. I did not even speak. That made my life a struggle. I was always sick so I had to go to hospital frequently. Raising me needed more caution than raising my siblings who were healthier than me. My mother said that back then, my siblings were so young all they cared about was themselves, so they could not understand why my parents had to take care of me specially. Whenever I misbehaved like breaking things house, I would not get blamed, scolded or punished. My siblings, on the other hand, received no special treatment when they misbehaved since they were taught about manners and expected to follow social norms. When my siblings grew up and had enough maturity, my mother taught them about my pathology of being weak and fragile with very weak bones. I was always sick and I could not express my feelings into words so my siblings had to help me and never take advantage of me. In addition, my mother also taught us to love, to care, and to cooperate with each other.

Normalization with molecular biology treatment

Normalization using molecular biology was a modern treatment process to treat autistic patients to make them more acceptable in the society. (Corbett, Kantor et al. 2007) I was also treated with molecular biology technology.

At the medical center, the owner told my parents she was not sure she could completely treat me from autism since the study of molecular biology was about the treatment of live cells. However, she was interested in my case as she was specialized in brain. My parents took me back to that center many times to make the treatment plan with the center's owner. The owner did want to treat me without being sure that it will be effective as her treatment was very expensive.

Finally, she decided to treat me using some oral and injection medicine. The treatment course I took consisted of twelve injections together with the oral medicine. I had one injection every two days for the first course. During the first twelve injections, she asked my parents to take notes of any changes in behavior as accurately as they could to see the result of the treatment.

Right before the course ended, I could speak in sentences. At 5am one day when everyone was sleeping, my mother heard someone speaking outside her bedroom. "*Baan nee mai mee krai yoo sak kon lei ror*?" (Isn't there anyone in this house?, บ้านนี้ไม่มีใครอยู่ซักคนเลยเหรอ?) She woke my father up since she had never heard that voice before. She thought someone broke into her house. When she opened the door, she saw me repeating that sentence. Both parents happily cried and called the doctor as soon as they could.

The doctor requested to see me as quickly as possible after hearing that news. On arrival, I spoke another sentence, "*Baan nee mai mee tee wong tee wee sak kruank lei ror*?" (Isn't there any television here in this house?, บ้านนี้ไม่มีทีวงทีวีซักเครื่องเลยเหรอ?), that made the doctor so glad she jumped and hugged me. She told my parents she would do her best to treat me.

I cried in pain when I got the injection each time. Before that, I had no reaction to pain either inflicted my friends or ant bites. I started to speak in sentences though I did not make much sense. I spoke what I wanted to spoke. I could answer some simple questions like “Are you hungry?” “Are you sleepy?” “Do you want this snack?”. Though my answers were just yes and no, it meant I knew what I wanted. When I was alone, I spoke to myself all the time. My mother used this opportunity to train me to speak by inviting me to talk and to make questions like I was taught to speak for the first time. My mother found out that I already understood many things, even if I could not tell any of those stories. She also found out that I became calmer. I continued the treatment with that center until the next semester began.

> *“Just to think about it, could it be fortuitous? We, the parents, were worried about how could we fix Jib’s behavior and teach Jib before her next semester in primary school came. I could remember that at that time, we were teaching Jib day after day without going anywhere. I even thought to myself that if I could make a wish from a sacred item, I would wish for 25 hours a day for only 24 hours weren’t enough to train Jib to be as good as I wanted her to be. I felt like being pressured that we promised the head teacher about this, then one day, Jib went to get treatment from the Private Center. We didn’t even research for a place to give Jib treatment. If you asked me, I strongly believed in that associate abbot. Listening to his story, I saw a brighter way in Jib’s life. I did not hesitate to take Jib there even if the payment may be high. Yet deeply, I was afraid that there would be some risk. Even though there was danger and even a chance there would be no effect at all from the treatment, I still wanted Jib to try it. I didn’t ask for somebody else’s advice because I didn’t want them to stop me. At last, the treatment turned out so worthwhile compared to the price, since her first sentence made us parents so delighted we couldn’t stand still. We were so excited that the words cannot express our true feelings back then. (*I noticed her wiping tears from her cheek.*) When she could speak, she spoke in sentences. Even if she talked in a parrot’s manner, it was the voice we wished to hear Jib speak for a long time. It was delightful to hear it. We kept on teaching her to speak correctly. Our hopes then were above the limits.*

We helped teaching her to read and write before her next semester in the first year of primary school came. Oh... I was thinking about back then. If Jib didn’t go get the treatment from that Private Center, Jib’s life might be the same as other patients I saw. They could only sit at home and needed somebody to take care of them all the time for life. They could barely speak of their need. Furthermore, people out there who had no idea what autism was would badly gossip about it.“

Mother

“When there was new information about a doctor who used technology from Germany, which was a new way of medical treatment, we were so highly interested in it that we suddenly decided to take that chance. The current technology used by the doctor of the hospital in the city could make this far, even thought it was the treatment to the end solution. So, if there was a doctor with the technology from Germany known as stem cell, which was the treatment to the cause, the brain, that was our hope we thought it was something we ought to try, and we decided to progress to the Private Center to get the treatment for Jib’s brain which was the main cause.“

Father

During school semester, I received injections and medicine from the private medical center and received asthmatic treatment from the hospital nearby. Most importantly, I had to go to the hospital in the city for my regular checkup. My life was chained to hospitals as if they were my second houses.

My doctor at the hospital in the city decided to make appointment for my leg surgery early than he planned as were getting to misshape. At first, he wanted to wait until my bones are fully grown. He made the appointment for the next summer-break. This time, I cooperated with them unlike when I had my back surgery.

Figure 4.4 Normalization with the Surgery

The surgery was to reposition my thighs. After that, I was in a half-body cast with four iron bars inserted into my legs to help bend the bones inside. The lesions must be left open under each bar for easy cleaning for a month before the bars were removed. Upon seeing me, nobody in my family wanted to directly look at my lesions. My mother was the only one who always took care and cleaned the lesions' blood and pus carefully and gently.

> *"It was a hard thing to accept, to see Jib affected by disorders that could only be treated with surgery. It hurt me every time I saw small and skinny Jib lying there in a cast and her legs pierced by iron bars. I know she was deeply suffering from that condition, so I took care of her closely. When she smiled, I was happy. I told myself, if she was through it she would be able to walk again like others could.*"
>
> Mother
>
> *"As I remember, after the surgery and as I woke up from the anesthetic, my legs were separated by a white, hard, crotch-less trouser-shaped cast. Its length was from my ankle to my waist. My cast had four openings for each of the lesion on my legs. Each of them had an iron bar inserted as a marker for cleaning as someone had to clean them continuously. No one wanted to directly look at them. There was only my mother who had her courage to clean them for me. One day, my aunt visited me, as soon as she saw me, she said: 'Hey, Jib with iron bars on her separated legs reminds me of a grilled chicken in a som-tam stall.' From a person who was so used to containing myself, I became dependent on the surrounding people. I did not like to be like this at all, so I prayed 'Please, don't let me suffer in the fate like this one ever again' whenever I was reminded about it. I do not know how I survived that moment. The only thing I remember is, I received all the encouragement from my parents who took care of me and consoled me that I would recover and be able to walk and run once more.*"
>
> The Researcher

My mother said that our relatives visited me to give me moral support to overcome this big obstacle of illness. They even said "Jib was so tolerant. She is just eight years old but she already underwent two events of surgery. Instead of crying when she sees us, she gave us a sign of victory."

After recovery from the leg surgery, I lost my ability to fold my knees to the squat position. I cannot stand up or sit down on the floor by myself. My mother had to take care of me at school since she was afraid I would face more obstacles or dangers that I could not overcome. When my mother was there, I had no problem living in the school. When she could not be there, I did not even want to step outside my classroom.

I needed to depend on her for using the toilets at school as they only had squat toilets for students. Since I cannot squat anymore, I had to directly sit on the base where people step on it when my mother was not there to help me. The toilets in school were not clean since there were so many students using them all day. The base of the toilet I sat was full of human waste which was not washed properly from the previous users. My mother did not know that I was doing that on my own. My hands and buttocks were covered with scars and pustules from my unhygienic way of using the toilet at school. My mother found out later that those pustules on my body were from school toilets. She was surprised and sad that she left me alone in the school. This taught her a lesson which also emphasized on my physical and congenital misfortunes that led me to face such story on my own.

When I was in grade five, the school had built modern toilets in the kindergarten building. As soon as my mother heard the news, she asked for the permission for me to use those modern toilets. I wrote my squat toilet story with tears on my face from self-sympathy. This is one of the most unfortunate tales for a person who have limited movements like me.

During the year, I kept going back to the private medical center to receive continuous treatment which made my health much stronger. The medical center asked me to be their presenter in a seminar about children with autism. I had many chances to be on television with this medical center. More people knew about me and liked my story so the medical center kept using me as their presenter. About this, my mother and I kept on giving counsel and advice, including sharing my story in the filmed program and the seminars. My mother saw what I was doing as a good thing to help me become more talkative, more assertive, and brave enough to socialize. She also hoped that, in the future, all these things would benefit me in getting a better life.

According to my narrative story, normalization is a method to adjust the life with abnormalities caused by disorders to become normal. I was also treated with such normalization. My mother was the main person who tried to normalize my autistic behaviors, such as my fear of color red. I had two surgeries to normalize my deformed back bones and legs. Normalization helps reducing stigmatization which is necessary for a disabled person like me.

4.2.2 Emotion-based coping: The Strong Mind and the Self-believing

My innocence from my autism kept me happy and self-contained. On the other hand, my deformed body made my life in school a struggle. I could keep on studying when I had my mother taking care of me and coping with the stigmatization against me at school. For instance, there was once that the school's lunch caused diarrhea for many students so my mother decided to pack lunch for me to eat in my classroom. This was also a topic I was mocked about. This time, I understood that they meant negative things, because I sometimes see them writing it in my textbooks. They liked to mock me about my walking style, which were "cripple", "gimpy", and "waddling duck" for example. When my parents saw them in my textbooks, they erased them for me. I asked for their definition and the relation to me but they did not answer me. Instead, they complained about my friends' bad habit for they liked to dirty other's textbooks.

My mother said the reason she chose not to answer me was because she did not want to emphasize the mocking words on me. Besides, my friends might have just wanted to make fun of anything as kids without aiming to mentally hurt me. She taught me to ignore this mocking because if we told them not to, there would be more mockery. If we normalized them by ignorance, everything would end.

In my experience, the students who always mocked the others were mostly boys. They liked to mock quiet students who never replied to anything. Two of my quiet friends including the cap boy were also mocked by boys. They would pick on weak or embarrassing points as their mocking topics for fun. When they targeted me, I lowered my face down because I did not like it and I did not want to look at what they are doing. At least mocking was not scary like physical abuse.

I adopted silence and ignorance as my coping strategy like my mother told me which worked for me in primary school. However, in secondary school, those strategies were not as effective with male friends that did not like me. They mocked my physical appearances, movements, and speaking habits as they laughed, as if I was their clown. Their mocking words were getting more intense and became scolding blames, and then become verbal bullying. For example, they could not accept that I ate my lunch in the class, urinated on my skirts, or ate my nails. At worst, they could not accept my physical appearances as they said I was dirty, making the class dirty, too. Having me studying in their class would make them look bad in front of others. For another example, I then was compared to an ugly mango tree's parasite. Later, I was also compared to a monitor lizard. They stopped calling me by my nickname, but they started calling me "*e-yae*" (according to them, it means an ugly parasite found on a mango's tree, อีแย้) or "*e-here*" (the monitor lizard, อีเ*ย). When they showed their behavior of rejection by scolding me with rude words, they joyfully laughed whenever I was verbal bullied. I understood the meanings of their eye movements and their actions as they bullied me. I also understood their bullying words as their hatred for they did not want me to study with them in their class. Such behaviors and bullying words happened daily and I could not ignore them anymore. However, I could not tell my mother what happened. Their bullying and actions made me felt ashamed, pressured, and such deep sorrow that I ended up crying. When I met my mother after school, I started to cry and ran to hug her tightly without saying a word. Even if she asked me, I could not answer or tell her anything.

> *"Those so-called friends in my class saw me as a student with bad physical characteristics and actions, so they made them as their mocking topics and they heavily scolded me. Now that I understood their meanings, I felt horrible since I also perceived their hatred toward me via using those words. Both 'e-yae' and 'e-here' that they used to call me with were as painful as being pierced through the heart with a sharp needle. I went to study there but I also felt pressure from being mocked and scolded. They might have noticed that I was mentally sensitive so they aimed to*

attack my mind, but I couldn’t react to them so I always ended up crying from being frustrated and sad. However, I also had another group of friends who gave me better feelings and did only good things to me. They also protected me from those so-called friends and helped me scold them in return. Those good friends encouraged me so I didn’t give up on studying there.“

The Researcher

“(As she was interviewed, the researcher looked at her face and listened to her gentle and familiar tone of voice she used to talk with the researcher with kindness.) Mocking and teasing naturally happen to weak people, but that doesn't mean that those weak people don't have any value within them. If you know who you are and what good things you have, those mocking words will become meaningless as if they are just words coming into and going out of your ears. Their behaviors shown to you told you their mental weakness and some other weak points they had in possession. You have to normalize your feelings towards mocking words, Jib. Ignore it. If you're mentally strong enough, all these words will not be able to mentally hurt you. Anybody who says and acts with rudeness to mentally attack others, you have to see them as people with bad basis of lives or had experienced them beforehand, so they could say those words to harm others without any feelings.“

Mother

I had dedicated myself in studying for three years. I felt like I was more accepted by teachers and friends with my good grades and probably my image change. Most of my male friends stopped verbally bullying me. Only two of them still bullied me but they were scolded by the others when they did so. My other friends protected me by saying that at least my study result was better than theirs and their time might be better spent on studying than bullying me. I have already stopped caring about their verbal bullying since it was the only way those two friends could express their anger and displeasure.

When I started to go to university, I fully became my true self. I expressed everything according to my own thoughts. Those behaviors caused me many issues. For being careless, I had expressed and shown some improper behaviors which caused misunderstandings among a group of friends. The head student of the Department of Biology was one of the people who did not like me. He verbally harassed me on a social media platform for students in the Department of Biology. His action stressed me out and embarrassed me. The reaction from my friends was more severe than normal teasing because I really felt helpless and my apologies were not accepted. It was the saddest story I ever had in my whole life in facing the issues caused by my careless character of autism to express and show the autistic nature repeatedly. I deeply wished to improve myself to be like normal people who could successfully communicate without any misunderstandings like I had then. However, it was beyond my capability to turn it into reality since I could not fix or change anything about my disability to make it better. The best thing I could do was to control my autistic nature and prevent it from causing even more issues to me and the others.

One day, my mother saw me crying after I read their last text. Finally, I had to tell her the whole story because the last text was "We will punish you in our kangaroo court". Mostly, they were men. When my mother knew the whole story and saw the text, she decided to report them to the Education Department of the Faculty of Science. Finally, the Education Department had summoned this group of people to ask for their reasons to do so and find a way to stop it for good.

> *"I felt sympathy for Jib about this since it was difficult for her not to show her natural autistic behavior. I also understood her friends that had never experienced people with autism who had steadily developed by the stimulation so they could learn in the university like Jib did. There is only a way to soften the issues of her carelessness here. Jib has to control herself with concentration to lessen her carelessness as much as she can. I wanted to give her my encouragement about this that it was a very difficult matter. However, I was so proud of her that she understood her nature well that she tried to ignore this issue. Moreover, Jib has fairly decreased its necessity. I want her to keep trying, so she can live happily*

> *without bringing up her disabilities to embezzle with the other good things in her. I want to be Jib's encouragement.*"

Mother

> "*At that time, I was scared by the threatening words from those friends. I was stressed and I blamed my autism for causing the repeating issue. I heavily cried in front of my mother after I read the text. When I felt I could not deal with the issue anymore, I told her what happened. After telling my mother to vent off my feelings and got some soothing words in her sympathy, I left a lot better. My happiness returned for knowing I had a lot of good things in myself. Just the lack of communicating skills should not make me lose all confidence in myself. When I thought about it this way, I could comfortably accept my autistic nature. I realized that I should use more effort in controlling my conversation and expression. That was how I happily studied and lived in the society.*"

The Researcher

In my senior year, there was one subject that I and almost every student in the Department chose for having the reputation of giving students good grade. However, the class was not big enough for all the interested students. In a meeting for this class, I asked the lecturer whether I could register in his class. His answer was shocking. He said, "I guess you should die and reincarnate before attending my class". His words made my face go numb as I heard loud laughing echoing form wall to wall.

> "*I felt really bad, so bad that I didn't want to stay in that room. I had never thought that he would use such horrible words with me. Had he ever thought that his words had mentally hurt me? It's not my fault that I was born a handicapped. Why wouldn't I want to be as normal as everybody else? I shouldn't have to tolerate such insulting words. If I didn't go ask for advice from other lecturer, I might end up misunderstanding that lecturer for my whole life. Other lecturers told me that the lecturer has always been like that and I should not care about his words. Other lecturer also told me that I do not have much time in the*

university and I time would be better spent on getting good grades. I, then, understood that those words are not worth thinking about at all.”

The Researcher

Apart from constantly being mocked in the academic institutes, I was also mocked by people in the societies. When a stranger mocked me, I could not understand their reason behind. My mother has taught me a very good technic for coping with mocking from strangers. When I started to talk, I was interested about those strangers I saw when I went out. They were whispering to each other about my physique. Many times, I heard children’s voices talking to their parents about my health and appearance. Some other times, I heard adults’ voices showing their hatred when they glanced at me. Those whispers usually are “What’s wrong with her? Why is she so small?”, “Is she an adult already? But why is she so little?”, “Don’t get near her”, “Don’t look at her”, “Don’t talk too loud or she can hear you”.

I used to get shocked when a stranger just mocked me. Some just shouted “shorty” or “dwarf” at me. I asked angrily my mother “I’ve never know them before, but why did they talk to me like that?” She was silent to my question which needed an answer. She admitted she did not like it either and tried to explain that people like looking down on those who seem to be less fortunate than them. That took me many days to understand.

She taught me to cope with those words by saying that” *We never knew those people before. You don’t have to care about what they say. After saying those things and walked away from you, they already forgot what they said to you. Therefore, you should just leave those words there too. If people say mean things right in your face, you should just smile back at them as people with strong minds will smile back to deal with the situation like this. Moreover, you must at least know that good people don’t speak with others that way.*“

I think that my mother adopted her preaching words from the monk that she respected. My mother interpreted his words into a simplified version for us. I remember that my mother liked telling me stories about heaven, hell, good merit and bad karma while driving us home from school. She made those stories up to teach us to only do good things physically, verbally and even mentally for other people and for ourselves. She believed that good merit will lead us to happiness.

I was not the only victim to verbal bully. My mother was also subjected to the verbal bully. My mother told me that my classmate in university bullied her verbally by saying, ”You have a disabled child. Why don’t you keep it at your house instead of putting it to the school? It’s troubling the others. Even if it graduates, no one would hire it anyway, etc.“ My mother heard those unbearable words, yet she could listen to them peacefully without any response.

> *“I can remember clearly that I was extremely angry with this friend of yours but as an adult, it was in appropriate to react. That’s why I tried to control my emotion. At that moment, I repeatedly asked myself that I just heard them scolded Jib for the first time and I was that angry. What about my daughter? Being teased, called, and reviled for her whole life, yet she had a strong, persistent mind which could overcome all the negative obstacles, actions and words to this day. So I have to emulate you by being tolerant with the scolding instead of immediately react like I previously did. There was one thing I want to tell you. You were my model of tolerance to overcome the obstacles.* (After talking with the researcher, she smiled in tears.)*”*
>
> Mother

My mother’s strong mind and confidence has always been the coping strategies. One day, my mother received an anonymous letter. That letter aimed at attacking my mother by saying that she has a disabled daughter because she is a bad person. The letter described me as deformed as useless. There were other details that my mother can no longer remember. She told me that after reading that letter she showed to my father and her parents as well. People who saw that letter mainly pitied the person who wrote the letter as it showed that the writer must be mentally ill. My mother also had the same opinion. My mother and her family were well aware that she was not like what the letter said.

From the narrative story, my mother taught me to cope with mockery by ignoring it instead of reacting to it. These strategies were effective for me as I was too innocent and too weak to fight with other people. Avoiding any conflict is the best strategy for me. She also taught me about self-value so the mocking words could not mentally hurt me. She also became silent instead of reacting to the stigmatization to cope with the moment when people stigmatized her.

4.3 Resilience

Resilience is perceived as a personal characteristic in some studies, but in some others it is considered a quality that can be learned and a process that can be established. The accepted view is that resilience was not a personal and innate characteristic, but it is a process revealed as a result of the interaction of several factors in the case of one's experiences in difficulty (Erdogan, 2015).

Luthar, Cicchetti and Becker (2000) defined resilience as a dynamic process encompassing positive adaptation within the context of significant adversity. It was essential to understand what factors place teenagers at risk, as well as what protective factors might be nurtured in order to develop and support resilience (Anghel, 2015).

Negative stimuli, such as stress, can severely damage a person's feelings. To fix such damage, resilience is needed. Resilience is an acquired factor among each individual, one which gradually restores their feelings after being stressed out. An individual who has a stronger mind has more resilience, and thus recovers faster mentally, than others.

Positive family adaptation in response to, or despite, social stigma and the stressors associated with bringing up a child with disabilities and behavioral problems might constitute evidence of resilience. Early theories posited that family resilience was determined by intra-family factors. McCubbin and McCubbin (1988), for instance, defined the study of resilience as the search for “characteristics, dimensions, and properties of families which help families to be resistant to disruption in the face of change and adaptive in the face of crisis situations” (p. 247) (as cited in McConnell, 2014). More recent theories place greater emphasis on social-ecological factors and transactional processes (i.e., the family's interaction with their environment/s). Ungar (2011), for example, suggests that “resilience is more dependent on the availability and accessibility of culturally relevant resources than individual or within-family factors”. Similarly, with respect to individuals, Masten et al. (1999) observed that, if reasonably good resources were present, outcomes appeared to be good, even in the context of severe stressors. There was evidence to support the contention that the positive adaptation of families bringing up children with disabilities in general (i.e., with or without behavior problems) was at least in part influenced by intrinsic, within-family factors. A number of studies have found that positive maternal and family adaptation was associated with better family functioning, and psychological variables such as parent-carer optimism, positive affect, internal locus of control, and the use of meaning-focused and problem-focused coping strategies (Baker, Seltzer, & Greenberg, 2011; Bourke-Taylor, Pallant, Law, & Howie, 2012).

4.3.1 Resilience by contestation with medical discourse

My father refused to let himself drown in his suffering after knowing that my illnesses were incurable. Instead, he tried to educate himself about those illnesses to make me better. He always had hope in improving my conditions and curing them.

> *"In the sense of medical treatment, it's impossible. The only thing I could do is to make it less severe. But that wasn't what I wanted to hear. Being impossible to treat wasn't in my mind. The only way I knew then was to find a way to solve the problem, and by that word solve, it was to make the condition better. I didn't really need her to fully recover, she has to get better, and however little it would be. So, the doctor's answer wasn't what I wanted to hear."*
>
> *"To completely fix Jib's external appearance wasn't in my idea. I already knew that it was impossible. I didn't need to go see any doctor to learn that. Yet I still went to see one because I wanted to know how to relieve, prevent, or slow down condition from getting worse. I already knew that it couldn't be cured just yet. If I kept on thinking about the reasons things had happened to Jib, my feeling would end up blaming the misfortunate without thinking of a way to solve anything, and I couldn't proceed to any better way. There would likely be neither magic medicine nor a special doctor which could completely cure Jib. It was just impossible, no doubt. No one could even dream to have her back to normal. That's why I had to accept the truth. This meant we had to accept*

it the way it was, so our hearts would be opened. That's also the conclusion after talking to my wife."

"In summary, we had to bear the truth and think of ways to make Jib live as happily as she could. So, I made a plan for that with her mother. We knew that we had to take better care of her. Thinking this way, we could find a solution to this problem."

Father

4.3.2 Resilience by renaming as "Special Child" and "a Person with an Optimistic Mind"

People who are obviously the odd one out in the society face difficulties being accepted in the society. Overcoming stigmatization is important for those people to live happily. I was always stigmatized as well as my family for being my family. We tried to overcome the stigmatization by using optimism. For example, instead of calling me disabled, my family called me "special child" which has positive connotation.

"Jib was a special someone of the family. Nobody could really blame her if she was doing anything wrong or breaking stuff. Everybody tries to ignore her wrongdoings. There were just cheering, encouraging and good stuff for her."

Mother

"Jib is the one who needs special understanding since Jib has a lower level of reasoning compared to others."

Father

"Jib would be the one who was always forgiven from everybody else in the house. We aren't angry at her for not being responsible for the household and no one is actually arguing about this. Everybody can forgive her in sympathy, but we forget that people out there won't forgive Jib like we do. So, it ends up that we spoiled her too much."

Sister

"(He slowly given the interviewing, showing that it is the first time he has a chance to speak about this to the researcher.) *I felt that P'Jib*

> *was an exception. I admit I did neither feel good nor feel bad about it. On the other hand, it seems like she's got too much attention, and I sometimes felt neglected by that. I'm not sure. I felt like I was under her. She must be the weakest one in the house, but it appeared that I am inferior to her... There must be something that can be a lesson to her that being small and walking badly isn't an excuse to live comfortably. Back then, however, I was too young, so I must obey what the adult said so. If they said I should help her get that thing she herself couldn't reach, I did help her at last, so I felt that it was the thing I should do."*
>
> Brother

I tried to keep my positive thinking whenever I was stigmatized. I tried to look at the bright side of any story as shown in the narration about having to give up my scholarship below.

> *"I was so sad that I had to give up my scholarship. I was discriminated for looking so weak. I didn't understand why my image must be viewed as lacking in standard and capability, or why they didn't try to look at the capacity of my brain. However, with my fate and the confidence I got from my family made me realize that there are many other opportunities waiting for me out there. That thought help me stop blaming myself and the way I was born"*
>
> The Researcher

4.3.3 Sexually Resilience

My mother told me something interesting about my father's concern that my brother was becoming too feminine when he was little. My father was often for his work afar from home and left my brother to be the only boy in the house. My brother was imitating my mother and his two sisters' characteristics which worried my father. My father tried to get my brother to do more masculine activities every time he was home, for example boxing, biking and table tennis. My sister was interested in those activities too while I preferred being an observer. My father also asked my mother to teach my brother to speak more masculine by using male pronoun to call himself *pom*

(ผม) and male ending word *krub* (ครับ). I also used those male words like my brother for a long time as I did not understand the meaning and usage of those words.

From the previous help of doctors and nurses at the hospital in the city and at the private center, I had my first menstrual cycle when I was twelve years old .My health has improved majorly after my puberty. My parents thought that even though I was going through my puberty physically like any other girls, I still behave like a child. I was too immature and innocent for my age. My mother had to help me with wearing sanitary pad and lady personal hygiene at first. My mother started to see that I was going through my puberty physically but not at all mentally. She was worried that I might get sexually abused or assaulted from being too innocent for my age. My parents had to take care of my very closely to avoid bad incident. They agreed that they had to teach me about sexual threats and the fundamental lesson about how to avoid and deal with such situations. I also remember that my mother was even more restrictive on my hygiene, safety, and transportation. I was not frustrated by what she was doing for me back then. My mother took two years before she could trust me to look after my personal hygiene but she still does not trust to look after my own safety.

I was going to be 15 years old that year. My mother said she saw me as a young girl. She entrusted me on taking care of my hygiene, either on or under my clothes. Having menstrual cycle reminded me to be aware of my dirtiness from leaking out of my underwear, led to the end of me being ignorant to taking care of myself. I tried to take care of my hygiene on my clothe, appearance, body smell, and hand nails, because as I looked at other female friends who had males paying interest to and noticed that they had clean and attractive appearance. Thus I tried to be like them. In the past, I did not care about these things before without knowing the reason I did not. When my mother took care of them, I refused and got annoyed. At present, I begged her to take care of everything that made me become more attractive for me.

When I liked some guy, I would express it by drawing or singing. I would not do anything more than that as I did not want that person to feel awkward or run away. My parents also did not want me to waste my time on having boyfriend which might affect my study. They taught me to fulfill my duty as daughter and student first. They also told me to prioritize on studying and working in a good job before thinking about having a boyfriend. I do not think they know that I did not believe in every word they said. I am trying to be a good daughter and a good student but I cannot stop having feeling for guys that I like and hope to have a good spouse one day.

My female friends and I shared the same idea as we learned in high school, for instance, we felt good to some of our male classmates. They started to flirt with the opposite sex, however, I did not have enough courage to flirt like others. I sometimes had a feeling for boys and my mother just laughed when I told her about it. I did not like my mother laughed about my feeling like that when wanted to get some useful advice from her. At the end, I just stopped telling other people about my feelings toward opposite sex. When I could not have any “lover” in real live, I started to flirt in the online world instead. I feel more comfortable talking to people and express my feelings in the online world as I do not have to see their eyes or facial expression. I have more control with relations in the online world as I can change or stop it at any time. In the real world, no guy shows their interest in me so I started to unknowingly feel more bonded with the online world.

4.3.4 Resilience by being faith in Buddhism - The Core Belief for My Family

Many Thai families use temples and monks as their life consultant including my family.

Our family received many life advices from him as Thai people believe that monks can be spiritual anchor and life advisor. My mother said that looking after a sick monk is a big merit according to Buddhist belief. My mother said that once I went to pay respect to him with my siblings when he was in our home and I was the only one trying to grab him and his belongings. My mother had to stop me from doing so. My mother also said that listening to his kind preaching in our home made her and the rest of the family very happy. He said that everything in this world has its time and nothing last forever, therefore we should not hang on to any emotion that we have. Instead, we should try to do only good things for us and other people, he said. A family can be happy only when everyone share the same morality, he said. My mother said that he said something interesting about me. He told my mother that we cannot chose how or where to be born but I was lucky enough to be born into such a supportive family despite my unhealthy body. That enabled be to grow and develop with other people in my family and to contribute to the society, he added. I also have a strong mentality which would help me in pursuing my happiness, he told my mother.

From my mother's belief and faith in Buddhism, she voluntarily brought the monk's lessons to apply to her family's daily living. One of the preaching examples was, "All livings are destined by their karma". This made her believe that the reason I was born with disabilities was because of my karma from my previous life. This belief also was the main reason my mother was so determined to raise me, treat and correct my disorders for me in order to make sure I could study with my normal peers, according to her answer as follows.

> *"I believe that Jib has to study no matter how she is. I feel that her conditions are the result of the karma from her previous life. Jib might have done something wrong in her previous life. Now that she has a chance be alive again she should use it to make it up to whatever she might have done wrong in her previous life. I believe that by giving her the knowledge, wisdom, and good deeds that she has done in this life time will an asset for her next life, therefore I am giving her whatever I can. I hope that her next life will be much better than this one that she has to struggle so much with the asset I am giving her. This idea gave me encouragement to push her to learn as much as she can regardless of her conditions."*
>
> Mother

I think that my mother adopted her preaching words from the monk that she respected. My mother interpreted his words into a simplified version for us. I remember that my mother liked telling me stories about heaven, hell, good merit and bad karma while driving us home from school. She made those stories up to teach us to only do good things physically, verbally and even mentally for other people and for ourselves. She believed that good merit will lead us to happiness.

My family also had *belief and faith* in Buddhism as everyone could notice from my mother that had belief in the lesson about karma and her respect and obedient to the monk who had his consulting about the issues she could not solve on her own and resilient her mind, making her relieve from her sorrowful suffering and see the solution for the issues of her family.

My mother had a strong belief in Buddhism. She used Buddhist teaching to teach her children to be good people. Through my mother, my family had a very close tie to religion.

CHAPTER V

MY ACADEMIC LIFE: EXCLUSION AND RESILIENCE

This chapter is portrayed the narrative story that aimed to answer the research questions which continued from Chapter 4. The answers is about the learning life, the stigmatization there and my resiliency within the school or university I studied in.

5.1 Stigmatization and Exclusion from education system

5.1.1 Accusation, Punishment, and Rejection from the Academic System

Figure 5.1 My Academic Life

Normalization with the Surgery

Even though the perspective of the society toward people with defectives and disabilities is they should not be in the public area with others, my parents never agree with such perspective. They have foreseen the importance of me in joining with the society via studying to give me chances to correct my drawbacks and to steadily improve with my normal peers in my age. My mother took me to kindergarten at the age of 3 with my 2-year-old brother to the same school as my sister. At that time, I was not very strong and got sick often. I was thin with a big head with my legs bending inwards. My health was obviously in bad conditions.

> *"I believe that Jib has to study no matter how she is. I feel that her condition is the result of the karma from her previous life. Jib might have done something wrong in her previous life. Now that she has a chance be alive again she should use it to make it up to whatever she*

might have done wrong in her previous life. I believe that by giving her the knowledge, wisdom, and good deeds that she has done in this life time will an asset for her next life, therefore I am giving her whatever I can. I hope that her next life will be much better than this one that she has to struggle so much with the asset I am giving her. This idea gave me encouragement to push her to learn as much as she can regardless of her conditions."

Mother

My father also agreed with her for his following reasons;

"A basis of learning is necessary for children, especially for Jib. Speaking of children that needed to study, Jib has no excuse not to learn. If one day she grows up and has no learning experience at all, how can she live on? So, learning is a must for Jib to take. Jib needed more development on her remaining parts of the brain to make sure they will be stronger, which can be done by having an education. In youth development, the brain is a part that needs to be developed, too. The brain could be developed by many factors, either from education, socializing with friends at about the same age, or using EQ and IQ together. So, to those who said we should keep Jib at home, where would she get the development? If somebody was kept at home, where they didn't use their brains in communication, no socializing, no stimulation with friends, parents, or teachers, but just have meals and stay idle at home, how could IQ and EQ or the development of the damaged brain parts improve? To get Jib developed, Jib needed stimulation and needed to learn. On the other hand, if us parents decided to tell her not to go to school, when the time comes and 'special needs people can apply to work', yet she said 'I don't have the rights since I didn't study', we can't go back in time and fix the past. That's the reason for her. Another one is, I never thought that she will be cured or not, but we can't go back in time and redo anything if we didn't give her the rights to study, but if we gave her the rights and its necessity becomes apparent in the future, well, we will never know what will happen next, what a person's life ended up to. We must fight on. We must work to help people in some ways. That's why Jib needs to study."

Father

At first, my life in kindergarten school with my brother was as normal as it could be. Even though I would not speak and would always play naughty, I did not rebel against the teachers. I was actually excited with everything new to me. There were a lot of toys to play with. We classmates grouped together at school to play, listen, nap, and drink milk every day, as if we were at our own home. However, my autistic behavior back then became apparent when everyone was taking a nap. That was, I refused to take a nap with them but rather stood up and walked around the room. I left the room, quietly played with things, or made a loud noise so the classroom teacher brought me out of the room where my mother was to prevent me from causing too much trouble at school. The event my mother would, and will, never forgets was, she said, when friends were taking a nap and I left the room as I usually did, no one could find me except my brother since he knew where to go look for me when I went missing. I usually went to play with water in the bathroom or hide myself behind the bedding mattresses leant beside a wall.

At that time, I also had some urinary health problems so the teacher was the one responsible for taking me to the bathroom. I also could not listen and write well like my friends could so I had to take all the schoolwork to continue working on at home with help from both parents' training. They had to train me writing things for years by holding my hand and guiding it on the exercise books my father brought home. My first year's result was at average, but in second year, my development had not improved much from the previous year when my friends were found to obey and follow the teacher's instruction. Yet I still needed further training in reading and writing from my parents. I had no responsibility for taking care of my books, stationery, bag, shoes, and even the dress I wore like I should have to. I had no interest in packing my bag or pulling needed items out of it without help. My mother frequently bought me new colored pencils because I took no care of them so they went missing. She even helped me change my clothes when I urinated or defecated on my underpants, because either I had told the teachers when it was too late or the teacher forgot to take me to the bathroom. I usually got bite marks on my arm but I could not tell who has bitten me.

The teacher in both first two years was the same one, so she complied all the problems I had with my mother. Including the fact that she was always present in the school, I could pass to the third year of kindergarten. However, I still had those behaviors with me on that year. The school has set its standard to test its students in the third year of kindergarten on their capability to learn in primary school by adding more subjects like Thai, math, physical education, and English for them. At this point, my parents realized that it would be the hardest struggle to teach them all to me. The teacher was not the same one as the past anymore. She tended to report all the problem I had, like my behavior and my lack of interest in studying, to my parents. She even told them: “Your child interrupted her friends’ concentration in study since she could not stay still and follow my instructions correctly. During the class, she usually stood on the desk and waved her arms vertically like a flying bird, interfering with my students’ concentration. Sometimes, she dug herself under the desk and made screeching sounds. Sometimes, she played with the pile of shoes at the back of the classroom. Those mentioned behaviors caused problems in the classroom.” Finally, when I finished the kindergarten school, the school staff told my parents that “The child couldn’t attend in Grade 1”. They were asked to put me in the special school for the disabled, like Prachatham School (Let’s name), instead.

> *"As long as I can remember, N’ Jib wasn’t a healthy girl, she couldn’t stand or walk for a long time. Her hand muscles weren’t strong. She didn’t like to stay still. She could somehow serve herself on using toilets. Yet teachers needed to take a special care of her. N’ Jib was a jolly girl who could make friends. Her down sides were being easily offended, selfish, and didn’t obey the school’s rules, yet she could be cooperative in class activities, talk to friends and teachers, happy, be able to talk and listen, reasonable, could somehow join friends’ group works. For studying, she didn’t seem to have her interest in it. She didn’t give attention to teachers but rather stay alone. She didn’t have the concentration in listening. She didn’t like to study. She didn’t like to write or read yet she likes to do art works. She could read a little. She was not motivated in working. She didn’t know how to ask or answer the teachers. The teachers needed to help her working all the time.*”
>
> Teacher in Kindergarten School, Year 3

My mother could not give verbal interview about this, so she rather expressed her experience and feelings via writing.

> *"I somehow knew that the head teacher called upon us to talk about Jib, but I have no idea that she would talk about how sub-standard Jib's study report and behavior was compared to other students that we needed to take her to a different school for special needs. The head teacher's speech made my motherhood mind hurt and suffered to feel that Jib was discriminated against by the word 'sub-standard'. I could understand if it was about the vegetables, but when the head teacher used this word on her, I thought it meant that Jib was poor in quality that she wasn't suitable to study with the others in this school and she needed to quit from this school? The head teacher didn't talk about this with us beforehand to build any understanding about Jib's case. She didn't even offer us parents the choices, solutions, or chances to think about. The head teacher's intention was to have our signature on a letter showing we had resigned from them. Clearly, we didn't let the head teacher determine Jib's future since she never know or feel our struggle to fight the obstacles in hopes that Jib would have a chance to study there like her siblings. I dedicated my time and strength to keep my eyes on Jib during the three years she was there whereas her father spent his evening each day to teach Jib to read and write. The head teacher spent just a few minutes to speak. How could she know better than us parents? We asked for some time to talk about it from the head teacher. Finally, we chose to beg for her mercy, that both her siblings were already studying there. If she were to attend at another school like the head teacher said, I would have to deal with harder life in driving for my children. We promised the head teacher that we would try our best to help improve Jib before the next semester came. The head teacher finally accepted the offer with a condition. They wanted to keep an eye on Jib when she was studying in Grade 1 for a semester."*
>
> Mother

My father, however, slightly understood the head teacher, yet he refused to obey the teacher, for he believed that education could help improving me from my condition Thus, he opposed to her that;

> *"I understood the school's constraint that they didn't have specialized staff in taking care of the children with specific needs like autism. The teachers had to look after so many students. In a class, there would be 30-40 students per one teacher. I would be easier for teachers if there were no special student like Jib in class. She was viewed as burden for teachers and the school. That's what the head teacher was trying to say, yet it was unclear and we didn't understand. She was using the standard that Jib could not meet as the main reason but I knew that they just didn't want to look after her."*
>
> *"My feeling might be different from my wife's here. I was not so surprised when the head teacher asked Jib to drop out as there were signs about this for long time. I knew the head teacher's intention right from the start that she wanted to talk about Jib's drop out. I didn't give her any reply, but I asked her to think about it."*
>
> *"I have already visited the school for mentally challenged children, but I didn't see any educational goal from such school. The students in those schools seem to just be there to pass their time day by day. We decided that this was not the place for Jib. If Jib went there, Jib's condition would be even worse than before."*
>
> *"My wife and I have decided to put her through formal schools for normal children. My wife would help Jib at school and I would dedicate my evening after work to tutor her and improve her brain in ways that still can be improved."*
>
> Father

In the kindergarten, I remember that I was unhappy compared to when I was at home. I did not really like my peers there. I could also sense that teachers did not like me because I was always hit and I did not understand why... I was called "Thief" by my friends and heard the order "to be punished" from the teachers so often that these two words got stuck in my mind, even though I did not understand and know their meanings. An event I could remember was when I was hit and told to stand outside the class until I could not stand anymore, for my both legs were severely sore. I was sitting when I cried so the teacher told me to return to the class. I did not feel like going to school since I did not get hit and get punished like that at home. Moreover, I remember that I could not study well because I did not understand the meaning the teacher was trying to teach, and my hands were not very strong, so I ended up playing with toys in the class until my mother took me home. I felt that I did not get the encouragement from the teacher there. I was lucky that my mother stayed there to take care of me and be the one who encouraged me. That was the reason she knew what bad situations happened to me. Back then, I could not study on my own. My father was an important person who helped teach me every evening after school. If he did not, I might have ended up in the special school as the head teacher was suggesting.

When my grandparents knew about this, they had their words with my parents.

> *"Don't make Jib study too much, we feel pity for her. It's already bad being like that but why must she struggle with learning? She doesn't have to go to school! We can take care of Jib. Let Jib quit the school and stay comfortably at home. If she goes to school, she might be teased or be a burden by peeing herself in the school."*

My mother understood well that they were pitying me so they did not want me, who was their granddaughter, to have such a living but wanted me to live in a comfortable place. That was their point of view. However, my parents said: "We decided to keep her studying. If she is left at home, she doesn't have anything to do and will be all alone when her siblings are at school studying." Thinking that somebody was impaired in both body and brain and telling them to only stay at home was equal to denying them their rights of studying like their siblings. My parents were strongly against this. My father said: "We raised her because we saw her potential to do many things. Considering her brain, she can attend school." And both of them even insisted me to study.

According to the narrative story, growing up with my little brother made us very close to each other and going to Kindergarten together made us even closer. He was there to be my friend and to help me as I was not very healthy.

From my mother’s first speech, she said that she wanted me to study because she wanted the knowledge obtained from the Kindergarten School to compensate my physical abnormalities. She believes in next life and hope that the knowledge I gained in this life time will a good asset to my next life if not in this life time as well.

My father’s answer to the same question, on the other hand, showed that he had prioritized education believing that every child should have equal rights to education despite their conditions. His reason was education can help stimulate and develop the children’s brains. Such stimulation and development would be extremely important to their chances in the future. This is the main reason he fought very hard to keep me in school.

Life in the Kindergarten School started normally for me. However, my autistic symptoms obstructed my daily life at school, such as being noisy, running away during nap time and refusing to study in class. I was punished for what I did but I did not understand that. The punishment made me hate school and prefer being at home. I usually skipped classes and hid in the restroom or behind the pile of washed mattresses to avoid further punishment from the teachers and classmates. My family had to help me and school cope with each other. My mother and my brother helped me at school while my father helped tutoring me at home.

As seen in the teacher’s quotation from my third-year kindergarten’s learning report, the teachers judged me as a poor-health student who was slightly naughty and had no interest in studying. The head teacher in kindergarten implied that she did not want to let me pass to primary school with the reason that I was sub-standard and not suitable. However, in grade six, my teachers began to see that I paid attention to my study.

The head teacher’s judgment that I was sub-standard and not fit in formal education system hurt my mother’s feeling very much as did not understand the struggles that parents went through to give me the same education as my siblings. They refused to let her determine my future that easily. Instead, they negotiated with the head teacher to help me fit into the school system within a semester.

As shown in my father’s final answer, my parents coped with it by negotiation for more time for me to adjust in school. My parents went to see the schools that the head teacher recommended for me and decided not to take me there. They persisted keeping me in the same school and ensured that I meet the standard to stay in school.

For me, I did not understand the punishment and being labeled as thief at school as I did not have that experience at home. I could not understand anything taught in classroom and my father had to tutor me so many times until I understood it. The only encouragement I got in school was from my mother who was at school for me.

I also understood my grandparents' concern about me being rejected and mistreated at school and their desire to take me out of school. However, my parents insisted that the education was important for me and that I stay in school. My parents believed in my potential and felt bad to keep me at home while my siblings got to go to school. They viewed such action as depriving my rights to education. My father persisted very strongly to put me in formal school and deconstructed the belief that disabled people should be kept at home away from all harms and judgments.

Figure 5.2 My mother then took care of me in the school and at home,

5.1.2 Sick Ape in the School

When severe sickness is causing to someone, that person will face to obstacles and issues in living in the society. This case was me who was affected with 2 severe diseases which was necessary to constantly get the treatment in the city's hospital and the private center along with studying in the kindergarten then. My parents hoped that intensive treatment from the medical centers so that I could study in the primary school. Although the medical experts and my parents corporately helped taking care of me, I was still mocked hardly for my character was defected and differed from the others. My mother then took care of me in the school and at home, so she was also stigmatized by other parents and adults in the society. She taught me to ignore the stigmatizing words like she did, but the ignorance sometimes made the misunderstanding to the reason I had to study in the academic system. To provide me chances to study, she had to explain to everyone.

My mother told me that she could only imagine me dressed in a primary school uniform as she was not sure that she could help me stay in primary school. However, after four months of treatment with a private medical center, my parents were more confident that I could go to primary school.

I was excited and eager to go to school with my siblings on the first day said my mother. I was very active and sometimes naughty in classroom. I liked walking around the class and making noises. When I walked out of the classroom, my mother would guide me back to my seat. It happened several times until I understood that I had to stay put until the class was over. My brain development had steadily improved thanks to the injection course by course. My hyperactive behaviors had lessened in intensity day by day until I could sit through a class. My mother noticed that I concentrate on studying but I did not like to talk or answer questions.

Ma parents always checked my homework at home and got me to some extra reading. My father always used more than one textbook to teach as he saw that repetition was good for my learning. He tutored me more intensively during the examination time to make sure that I will pass the exam. However, using pencils for me was difficult as my fingers were rigidly bent. When I wrote, my handwriting would turn out thin and almost invisible, so it was barely readable. My father solved it by getting me darker pencils. Finally, my study results had steadily improved which pleased my parents and my class teacher. My class teacher confirmed with the head teacher that my physical, congenital and behavioral development met the standard so I could still go to the school.

In grade two, I went to school in stroller with big bandages on my legs. Everyone could not avoid staring at me. However, I did not care or understand why people stared at me. I remember that I did not want to go to school. I was not happy going around the school in my stroller or having my mother carry me to the toilet and feed me lunch. I tried to tell my father "*noo mai yark pai rong rean*" (I don't want to go to school, หนูไม่อยากไปโรงเรียน) as frequently as I could. He always replied "Illness and disabilities are not excuses for not going to school". My father really put his effort into getting me educated.

No one wanted to be friend with me apart from one boy who was openly friendly to me. He always wore a cap even in the classroom as he only felt confident in it. He was a quiet boy who was always mocked like me so we understood each well. He always called me by nickname and never mocked me with the labels others gave me. He helped pushing my stroller and chatted with me. When I trained my walking at school, he was there to cheer me up. The most impressive thing he did was to hold my hands as I walked like my mother did for me. So, he was my very first friend in school.

My mother said, I did not like writing down my homework that the teacher gave on blackboard. She said that I could remember all the questions but sometimes in the wrong order. However, I did not submit my finished homework to teachers and all of them told my mother about this issue. My mother solved the problem by submitting my homework for me. She also took care of my stationery, books, and backpack. In grade two, I still had all my repulsive behaviors, especially eating my nails. I did it until my fingers bled. My mother tried stop me by pulling my hands off my mouth but I still did it in my bedtime.

> *"When I took Jib to school, I had to take her to her classroom in stroller. Everyone watched Jib, who was so small yet was wearing her primary school's uniform. I felt pressured by the stares from everyone looking at my family, especially at Jib. During the day, people interrogated me about Jib when they saw me looking after her. The frequently asked questions were 'What happened to her? Why does she has to use a stroller?' Some gave very harsh comments like: 'A child like this shouldn't be taken to school, in my opinion. It is as if you are torturing her.' 'I think your child is ill. You must treat her until she is fully recovered before bringing her back to school.' Or: 'She couldn't even hold in her wee or poo. Why must you insist on taking her to school? "*
>
> Mother

My mother felt those questions and comments were very discouraging but still she persisted in taking me to school. Some people might disagree with what my mother was doing but she thought that those people did not understand what she was trying to do. She felt that it was not her duty to explain or answer any questions from anyone, but she thought that having people's understanding would be better for me and her.

> *"That's why I tried to tell them everything to make them understand the necessity of why Jib must study to receive academic experience. I made the understanding like this since the primary level to the university level. Sigh* (she sighed for a long period of time). *But if the teachers were asking, I was willing to explain to them about Jib. That's what I had to do. I had to talk with teachers because they directly taught Jib. They had to understand her. It began when Jib didn't hand in her finished homework as the teachers asked her to, I had to explain the reason why she didn't take responsibility on her homework, that she was an autistic child. She came to school because her parents wanted her to study. She was not very responsible with her homework which I had to help her with that. I helped Jib as much as I could so she could study at ease and understand everything like her friends did. I made such understanding with every teacher of every subject and every year level since she entered school to when she graduated from the university. I explained to the teachers that I would take responsibility for her transportation and her homework, until they understood that I was there to help them and Jib because I wanted her to be able to study."*
>
> Mother

When I was studying in Grade four, the private medical center contacted us to let us know that the medicine for my bone treatment was available. After a few injections, I felt that my legs become stronger. I also took injections for other organs in my body and I became healthy enough to walk for ten meter. However, I still had to use stroller to prevent myself from falling.

Unlike other people, the cap boy brought his lunch from home to eat with me. This year, he was way taller than me but we could still be good friends. When either of us got teased, the other would call for teacher's help. The cap boy and I were this kind of friends until we graduated from the school.

> *"My friend was a quiet, clean boy which was the opposite to me who was dirty and active. Normally, I didn't speak to anyone. This*

> *friend really likes to talk to me where I rather smiled as I quietly listened to him, so we could become good friends for each other. I wish that more people could be to be like him.*"
>
> The Researcher

That year, my arms and legs got hairy which surprised me because they were so dense that my arms and legs turned black. My friends mocked my hairy body as they called me "ape" and laughed. My school uniform could not cover my hairy legs. Some people even approached me just to see my body hair. I did not feel anything about my leg hair, but being mocked about my body hair annoyed me. My leg hair was the source of my irritation, so I prayed for them to be gone. Finally, I understood that it will not just go away, so I prayed to be taller instead as I thought I still had chance for that.

After reviewing my experience about friends in primary school, I found out that I had very few friends. The reason could be that I only remember friends that I liked. I can remember a boy that always wore a cap and two girls as friends. All of them were teased and bullied daily just like me. I chose not to remember other things around me especially if it was not my routine including friends that were not close to me. I focused on remembering my homework instead because I did not want to note it down in my homework book. Therefore, I cannot remember other events during my primary school.

My autistic conditions have improved so much that I could study with the same capability as my friends thanks to my parents' devotion. As a grade six student, I had to focus on studying for entrance exam to high school so as my friends. My father visited many schools in Bangkok and asked the principals about accepting a student who needs a wheelchair and has autism like me. Some schools denied accepting me right away with a reason that they do not have specialist to take care of me. Some schools agree to accept me and allowed my parents to stay at school to look after me. One of them agree to accept me with an interesting reason that they grade their students based on their cognitive brains not on their physical bodies. If they can pass our entrance exam, we will accept them as our students, the school added. My parents were very impressed with that school and wanted me to go there though it was far from home. That was the attitude my parents were searching for in school.

> *"N' Jib had an interest in her studies. She also had creative thinking and was bold enough to show herself. However, she wasn't too tidy. As long as I remembered, she was a good child generally.*"
>
> Teacher in Primary School

I went back to school though I was not fully recovered from the leg surgery. My mother had to take special care of me at school as she was the one who understood my conditions the best. Having my mother looking after me at school made us the odd one out because other students went to school by themselves. I was mocked for having my mother with me at school in addition to my obvious disabled body. When my mother decided to pack lunch from home to avoid diarrhea from school lunch and to save time commuting to cafeteria, I was mocked for my lunch as well. Any difference can be a target for mocking when you are that age.

Even though the school let me study there, I still had to face with stigmatization from my friends due to my repulsive behaviors. The treatment from the private medical center only helped with my study not my behavior or socialization skills. My friends mocked me for those behaviors but I was too affected by my autism to understand mocking or stigmatization. Therefore, I laughed with mocking instead of feeling bad about it. I laughed with people who laughed at me because I wanted to be happy with them. My parents coped with this problem by teaching me proper manner in public.

From the narrative story, my parents adopted teacher roles at home to enhance my study to be on the same level as my friends. However, my academic performance did not meet their expectation. After receiving the treatment from a private medical center suggested by an abbot of a temple in Pathumtani, my performance has improved by far. My father noticed that I performed much better when he taught me with textbooks and exercise books. On the other hand, I still had problem with my handwriting as my hand muscles were too weak to write solid lines. My father solved that problem by giving me darker pencils. My parents needed to prove to the head teacher in primary school that I can meet the standard to stay in school. With their hard work and devotion, the head teacher let me stay in school.

Not understanding the stigma kept me happy and kept me going back to school. When I finally understood the meaning of the words, I was no longer happy.

My friends used those words to attack everything that was perceived as wrong about me. They mocked my behaviors, how I walk and my body hair. I coped with mocking by trying not to think negatively about myself. When they were mocking me, I looked at the floor instead of their faces in trying not to acknowledge what they were doing. When they did not get reaction they wanted from me, they escalated their mocking by writing those words in my books. When my parents saw those words in my book, they erased them for me. When I asked about those words, my parents avoided answering my questions by complaining about my friends making my books dirty. My parents taught me to ignore people who mock me or stigmatize me and they would stop in the end.

Apart from helping me get around, my mother had to help me with my study as well. My mother helped with my homework. She made sure that I did all of them properly and correctly. My mother also handed in my homework for me when my teacher told her about not receiving my homework. She was worried that not doing or handing in homework might become another reason for school to ask me to drop out.

My mother was also stigmatized from being at school with me by other parents. People asked her about my abnormalities. Though some questions hurt her feelings, she tried to answer them all to raise understanding about me. She paid more attention in making my teachers understand me as they were the ones who had to take care of me at school.

I did not feel ready to go back to school after a major leg surgery during summer break of my first year in primary school. I told my father that I did not want to go to school but he made me go back to school anyway. He said that illness was not an excuse not to go to school. His words implied that education was his priority.

I noticed from the story that many high schools rejected me with a reason that they did have specialized staff to look after me. However, the school that accepted me did not have such staff either. The school did not need to have any specialized staff to take me as their student. They only needed to understand my condition and allow my mother to help me with my special needs.

5.1.3 The Odd One Gets Pushed Out

Figure 5.3 My adolescence life in the high school

My adolescence life in the high school could be a happy one for I had become a teenager. However, I was mocked and ashamed by my male classmates for I had distinctive and ugly appearance. Coping with such mocking using my mother’s strategy of ignorance did not work anymore. When she saw me cry, she chose to teach me to see that people who bad things to mentally hurt others must be seen as the ones with poor fundamental mind who experienced hose bad things beforehand. I also agreed with her yet my issues kept occurring to that my teachers and some other classmates did not fully accept me and forced me to quit schooling. So, I had to form my new personal self, as the one with potential, by dedicatedly studying to get the acceptable studying grades, for everyone was accepting that.

The computer took on a major role in learning in the High school in the city. So, my father gave me one for my personal use, yet my usage was still under his supervision. I sometimes could use this computer to communicate and work with my friends, yet I could also use it to play games in my free times, not knowing that I began to become addicted to playing them. However, my parents allowed that within their given time limit for I did not have any outdoor activity like my siblings did. Personally, I preferred to live indoors for I was used to the house’s atmosphere. I could talk to and understand people in the house more than those outside. I could do anything I pleased without being scolded. That was the reason I did not want to go to anywhere if it was not necessary.

My daily life in high school started early as the school was quite far away from my house. My brother and I had to have breakfast in car. I refused to sit in my wheelchair at school by telling my mother that I wanted to walk instead of sitting in wheelchair. My mother walked with me to my classroom and helped me carry my backpack including my lunch and water bottle. My classroom was on the fourth floor which I could use an elevetor to get to there easily. The elevetor was another reason that my parents choose this school.

The students had to study very hard in my high school as the curriculum there was intensive. The school wanted their students to be admitted into top universities of Thailand to build the school's profile. I discovered that most of the students there had excellent grades and results from their primary schools. I enrolled in bilingual course which was just opened with foreigners as the teachers. I liked the course very much. The teachers were kind and I could keep up with my classmates. My grade was among the top ten in my class.

> "*When I moved to a new school, I was always stared at by the surrounding people for their disbelief that I could actually study, since I looked weak and I looked as if my brain was slow. However, as time passed by, my grade results had proven that I had the same capability as everybody else in my class.*"
>
> The Researcher

In the second semester, I had to use my wheelchair again to help me travel between buildings. I could not walk fast or long enough to attend my classes in other buildings. The teacher had to assign my classmates to push my wheelchair. Most of them were kind and considerate enough to help me even when I did not ask.

However, there were some classmates that did not like me. They mocked my physical appearances, movements, and speaking habits as they laughed as if I was their clown. Their mocking words escalated to scolding, and verbal bully. Some of my behaviors were unacceptable for them, for example, eating my lunch in the class, urinating on my skirts, and eating my nails. Some of them said I was making the class dirty as I looked dirty in their eyes. They felt that having me studying in their class would make them look bad.

I was call *“e-yae”* (according to my friend, it meant that the parasite of the mango’s tree) and “*e-here*” (water monitor) as they compared my appearance to those reptiles. However, my friend understood that Yae was a mango parasite which he drew a picture on the whiteboard to explain to everyone in my class about Yae. When one of them shouted bad words at me, the rest of them would laugh. I understood the meanings of their eye movements and their actions as they were bullying me verbally. I also understood that their bullying words were from their hatred for being in the same class as them.

I could no longer ignore daily verbal bully which made me feel ashamed, pressured and cry. Most of my classmates disagreed with people who bullied me. They tried to protect me from the bully and told the teacher to help me also. Some of them tried to console me when they saw me crying. They understood that I tried so hard to be accepted in school. I agreed to have my lunch outside the class to end everybody’s dissatisfaction. When my mother picked me up, I started to cry and ran to hug her tightly without saying a word. When she asked me about what happened, I was too emotional to tell her the story.

At home, everyone in my family would take turns mocking each other. My sister was mocked as "*yai-hua-thork*" (wide-forehead, ยัยหัวเถิก), my brother as "*ai-naa-leam*" (square-face, ไอ้หน้าเหลี่ยม) and I as "*yai-tea*" (shorty, ยัยเตี้ย). However, the mocking at home was totally different from the verbal bully at school. At home, I felt the sense of love and acceptance when we mocked each other. At school, the mocking was done in hatred and was intended to hurt my feeling.

> “*Those so-called friends in my class saw me as a student with bad physical characteristics and actions. They mocked me about those things and scolded me. Now that I understood their meanings, I felt horrible. I could sense their hatred toward me via using those words. The words ‘e-yae’ and ‘e-here’ that they used to call me hurt me a needle piercing through my heart. I felt pressure from being mocked and scolded at school.*”
>
> “*They might have noticed that I was sensitive so they tried to hurt my feeling. I couldn’t react to them so I always ended up crying from being frustrated and sad. However, I also had another group of friends*

who gave me better feelings and did only good things to me. They also protected me from those so-called friends and scolded back at the bullies in return. Those good friends encouraged me so I didn't give up on studying there."

The Researcher

"*Mocking and teasing naturally happens to weak people, but that doesn't mean that those weak people are worthless. If you know who you are and your good points, those mocking words will become meaningless. Those behaviors show their mental weakness and some other weak points. You have to normalize your feelings towards mocking words, Jib. Ignore it. If you're mentally strong enough, all these words will not be able to mentally hurt you. You have to see rude people as people with bad basis of lives or had experienced them beforehand, so they could say those words to harm others without any feelings.*"

Mother

I also interviewed my brother and sister in this matter. These were their reasons.

"(Her voice shook during this interview session.) *I don't like to see someone else tease you or bully you. They use very strong words to mentally hurt you and that hurts my feeling too. Unlike people in the family who have been helping you and looking after you, they have no right to abuse you like that.*"

Sister

"(He was calmed and collected in this interview session.) *I had no idea since I never knew that you had problems at school. I only knew it when you told us about it in the car. I could not see that in primary school. … I don't know … If looking to the topic of mocking, most of us get used to being mocked no matter who we were. As a child, we mocked others for fun and for entertainment. We laughed with it. If you were short, you'd be mocked as, shorty, shorty like this. I had a friend who was affected by the condition of kidney disorder but no one mock him as, kidney-boy, kidney-boy. Nobody had the intention to mock others to get attention. They were*

> *all mocking each other for fun. Mocking wasn't an abuse because you also mock someone else at some point just to exploit our fun.*"
>
> Brother

My physical appearance kept causing more problems for me. This time, it did not relate to the study, some parents and the principal did not want me to study in that program. One day, the principal met my mother and tried to convince her to take me to another school for the following reason.

Principal: "*As you can see, your daughter is a very weak child with autism. When she was outside the class during lunch break, I saw many students running through the hallway, they have to avoid running into your daughter. I'm afraid she will get in danger if someone runs into her by accident or even fall over on her own. I'm afraid she is going to die here. Who is going to be responsible about this? I mean, are you going to blame the students who run into her? Or blame the school? I don't think we should let it happen at all. So, I think this school isn't suitable for her. It may be better if I look for a new school for her, the one that as good as this one here. Will it be possible?*"

Mother: "*Thank you for your concern. If something does happen to Jib, I'll be the one taking the responsibility and I will not blame anyone. Moreover, I have nothing against you finding a new school for her, but I would rather choose the school she is going to on my own. I would like to choose that well-known demonstration school. If you can register her there, I will be happy to take Jib out of this school.*"

Principal: "*Must it be only that well-known demonstration school? I have picked another one for her.*"

Mother: "*That well-known demonstration school or else, I will keep Jib here.*"

My mother told my father about the principal and later on told the director. He decided I could keep on studying there. I passed the school's entrance to be in this program on my own therefore the principal could not deny my right to study in her school. During the semester break, there was a field trip to Chiang Mai by splinter train. The principal used her power to exclude my name out of the student list for this trip. My mother knew about this when it was too late to solve it. She made a complaint to the director for she wanted him to help but it did not work. The principal said that the reason she did not want to take me was the splinter train was too dangerous for me as it was too fast and had too much vibration. Although my mother wanted to buy a ticket for a normal train for me to follow them to the destination, the principal did not allow her to. She said, "I'm afraid that she would get harmed by the activity we are going to have." The director could not help me in this case since the principal had the authority to make decision in this field trip.

> "(The interviewee looked unhappy and spoke so fast that the researcher could barely catch up.) *Jib could pass the entrance exam to this school so the teacher's claim that Jib was not suitable for the school made me feel uncomfortable. Sickness can happen to anyone. If a sick person can smoothly study with no problem, there is no reason for him or her to quit the school. I felt sad that this teacher had a negative attitude and was so narrowed-mind. She has done dirty tricks to tease Jib and pressure her. She made her feel like an unwanted part of the school. I had to be strong to fight for Jib's rights to study there without mentioning her health as an obstacle.*"

Mother

When the principal talked to my father about her desire for me to transfer, my father was very upset. He told me about the event as follows.

> "(The interviewee was knocking his pen on the table while giving the interview.) *I felt upset because what the teacher said meant that she didn't want Jib to keep on studying. She even claimed a variety of reasons and predicted the worst scenario possible. The truth was, being a teacher or a principal meant she must have some mercy to find a solution to Jib to continue her study not predicting the worse out of Jib. She didn't want Jib to study there because she didn't want to take the responsibility and she was scared that she couldn't take it. That was why she tried to come up with those excuses to make her look good."*
>
> *"My feeling toward that teacher wasn't anger, but it was more of a disappointment. I wasn't pleased with her being so selfish and didn't even see Jib as a student. I didn't think that all the teachers in that school were like her. I believed that teachers with teaching spirit outnumbered*

her in that school. I told my wife that the issue with the principal might be brought up to her supervisor. I didn't believe that the principal had the power to expel Jib. Removing a student's status from a student who was able to pass the entrance on their own must have more procedure than just telling my wife to take Jib out of school."

"I strongly believed that there were more people on my side so I seek help from the director. Also, I didn't want the principal to get things her way so easily."

Father

"When I knew that I can't join the field trip with friends, I was sad and displeased that the principal had denied me of my rights and opportunities. I had done nothing wrong and I didn't understand the principal's discrimination? Why didn't she even try to solve the problem so I can go join the trip with my friends? I asked those questions to myself repeatedly, but when I knew the answers from my mother that the principal did it on purpose, I stopped feeling sad about myself."

The Researcher

My brother also had his opinion about the principal.

"There is nothing at all. I think that the principal was just a normal person who didn't have power to do expel you. Wasn't that the reason she said "don't study"? Finally, she didn't have any power to stop P' Jib from staying in the school. Wasn't she just a normal teacher who had no right to order anyone to get out? Yes, she could say it, but we didn't leave like she wanted us to. Moreover, P' Jib had showed that she could study and even got good grades at the end. That's how we humiliated her... Since then, we had joined the school righteously."

Brother

I took a long time to recover from being excluded from the field trip. To help me feel better my mother took me on vacation during the semester break. Time helped me feel better. In addition, everyone in my family thought that thing like that was not a big deal and I should not soak in sadness from such incident. I agreed with everyone. Moreover, my friends were sympathetic to me for not being able to go to Chiang Mai with them.

When I was in grade eight, my brother attended the same school as me again. He said that he did not feel awkward or frustrate about having a sister like me. He might be used to it already.

I felt like I have adapted to the environment of learning and to new friends by the time I was in grade eight. However, the boys who bullied me still have not stopped. I tried not to cry and ignore them as my mother told me that people who bully others have mental health issue. They might have their own issues since I saw them having troubles with teachers and other friends.

In that year, my health has improved majorly from the treatment with private medical center. I finally stopped peeing my skirt. I could walk to and from each class without getting tired. I could use the stairs from one floor to the next. Those made me so happy. Sometimes, I felt free from using my wheelchair. My parents told me to keep my academic performance up as that was what the school was looking for in their students.

During the first semester of my grade eight, I had a chance to join a scout camp with my friends. My mother came along to look after me. All the administration teachers joined the camp as well. Joining the camp made me become acceptable by everybody since I could participate in the assigned recreation activities like my friends did there, and could live there with everybody without causing troubles. From then on, I could join any activities the school had without any interruption from the principal since I have proved to everyone that I was capable to join any activities.

My problem in grade nine was group work. Even though everyone was nice to me, they felt that I was an inflexible person who could hardly understand the others. They did not want to be in the same group worrying that I would be a difficult person to work with. To solve this problem, I asked teachers to find a group for me or asked to work alone. I prefer to work on my own since I could fully use my ideas and capacity to create each work without listening to anyone. On the opposition, when I worked in a group, I had to listen my friends every time and it was so annoying that they did not want me to do anything myself for my ideas were either “invalid” or

”unaccepted“. From then on, I always asked the teachers to work alone because I could fully use my capability. My friends never asked me to join their group.

> *“I felt like I had nothing interesting for my friends since when we were in class, I was quiet as if I was a listener only. I only spoke when teachers asked question. I was almost the only one who answered teacher’s questions. That behavior annoyed my friends and they said that it ruined their concentration in class. At lunch break, my friends would sit together and eat snacks while talking. I wanted to join them, yet I didn’t know what I should talk about because their favorite topics were too hard to understand. Mostly, they talked about famous superstars, T.V. dramas, fashion, and the newest versions of toys. Those topics weren’t in my interest because what interested me were academic topics especially science, Japanese comic, animation, and languages. My friends and I did not have the same interest. I wanted to have a lot of friends too but that is almost impossible for my personality”*
>
> The Researcher

My health has improved by far after receiving treatment from the private medical center and from the hospital in the city. At the hospital, I noticed that people with Bone Metabolic Disorder at my age were facing so many health issues. They could not walk and their bones were so fragile.

In grade ten, I felt proud of myself that I got to wear senior high school uniform. I have told my parents that wanted to study in science-math plan for I was very interested in nature and biology. My mother said she and my father used to believe that students with autism would have their interest in art or subjects that require memory skill. However, my parents let me make my own choice when to come to study despite their worry that I might be able to handle it.

To study science I needed to be able to analyze and think logically which was a challenge for someone with autism. However, my parents also thought that having those challenges can be good for my brain development. I was also willing to take on the challenge. The relations with my classmates has improved as we knew each other better and were too busy studying to care about little things like before. With my good health, my life was very happy. One day when my mother came to pick me up from school, she could not find me. Finally, she was surprised to know that I have climbed to the top floor which was the fourth floor of a school building to watch the school's concert. My parents realized that they had to be more aware of my development as a teenager.

That year, my mother let me take care of myself more at school. She only drove me to school and picked me up from school. Also, my mother started to feel sick and noticed irregular menstruation which lasted two weeks at a time. She was so sick that my brother and I started to notice as well. She came to pick us up late and looked so pale and tired. My father was not aware of this as he was working in another province. When my aunt and uncle saw her condition, they immediately took her to the hospital.

The doctor told my mother that she was at risk of uterine cancer. He performed a hysterectomy to remove her uterus and told her to rest for at least one month or until she was fully recovered. Two weeks after her surgery, she started to drive her children to school again against the doctor's suggestion. She said she that did not want to stop doing her duty for too long.

In grade eleven, my academic performance has fallen no matter how hard I tried. My father decided to send me to a tutoring school in the city with my mother taking care of me there. Going there made me feel nervous from being stared at and being gossiped about. I went to that tutoring school until I finish my high school and was accepted in the university.

However, at my school, the situation has improved so much. My teachers and my friends encouraged and supported my study. The teacher even assigned me to join my friends as the school representative to compete with other school in academic competition. The assignment made me accepted that the school trusted me to be a representative despite my physical condition. Even my friends who liked to tease me had already accepted me for that.

I was a happy eighteen-year-old girl thanks to my parents and the doctors. On average, patients with metabolic disorder have life expectancy of about eighteen, yet I could still happily live on. For me, my parents said nothing was more important than to see me happily living in the family. It meant that I had overcome my metabolic bone disorder. From then on, my life was to follow my goal I set, which was to study as much as I could.

From the narrative story, I tried not to use wheelchair in high school but the teachers noticed that I needed help to walk to another class in time. I had to use wheelchair again to go around school. I understood that wheelchair caused more stigmatization therefore I tried not to use it.

Computer has become an important tool for my study. The higher I studied, the more important computer became. My father had to buy me a computer for my study. Apart from using computer for my study, I also used it to communicate with the outside world on the internet and used it to play online game.

My family accepted that I had some limitations which could be fixed or improved. For example, they accepted my autistic conditions and had a plan for me to study in language plan. They thought that my lack in analysis and logical skill would be a major obstacle for me to study in science-math plan. However, they let me make my own decision to study in science-math plan and saw it as an opportunity to overcome those challenges I had.

When I was sixteen years old, I was almost as healthy as my friends. I could do things that I wanted without having to ask for help. I could even climb to stairs to the fourth floor to see a concert. My family was surprised to find out that I was interested in my surrounding and became a teenager like others.

My classmates and their parents used to stigmatize against me. Bully came in many forms. My friends verbally abused me while the principal and parents used their power to discriminate from school activities. They aimed at pressuring me to resign from school. I could understand the stigmatization already but could speak for myself as a result of my autism. My mother understood that ignorance was not enough to cope with bully anymore. She trained me to communicate better to be able to at least tell her the story of what happened to me at school.

Like in my primary school, the principle in my high school asked my mother to take me out of the school. This time the reason was I was too weak and she was afraid that an accident at school might kill me. My mother told the principle that she would not change the school for me and asked the director to help me. The principle abused her power by denying my rights to join the school activities with false safety reason like the train vibrated too much for me to ride. My father was upset about this incident too.

In the end, the principle could not make me resign from her school as she had no authority to do so. She also could not continue to deny my rights to join the school activities since my mother and I have proved that we were capable to. This story has proved that most people in the society are good to disabled people like me despite the minority that tried to discriminate or stigmatize against me.

When I could speak better than before and observed the environment, I noticed that the stigmatization did not limit itself only within the educational aspect. People in the public also stared at me. This is the stigma and discrimination given to me by strangers. Their method of stigmatization was gossiping. Sometimes, they did not realize that I over hear them. No matter how sad I was then, I had to forgive them for they did not really know me.

I had to go to tutoring school to keep up my grade after choosing to be in science-math plan. Being in a new environment meant I had to face with more stigmatization and had to flight to be accepted again. People at the tutoring school stared at me and made me feel uncomfortable again while in my high school, people were already used to me.

I have noticed that every time I transferred to a new school, I was always viewed as someone who could not study. The stigmatization and discrimination started again like a cycle. I coped with it by putting my effort on studying to show that my grading result could be as good as everyone else. In addition, there were always someone that understood me and tried to help me in every school.

As time passed by, my classmates had lessened their mocking until it was no big deal to me because most of them became my good friends. Even though my friends stopped bullying me, they still did not want to do group work with me. They had the impression that I was hard to work with. I coped with that problem by asking teacher to work alone or help putting me in a group.

I have also learnt that I was mocked at home as well. However, at home the mocking was more about to make joke and laugh. Unlike at school, the mocking was aimed at embarrassing me. From my observation at school, I found out that people who liked to bully me were not happy with their life and could not get along with teachers and friends. I started to feel sorry for them instead of hating them. I learnt to ignore those people and focus on more important things like my study.

5.1.4 Exclude from Education

From getting good grades, my parents saw my academic potential. They decided to fully support my education to maximize my potential. The applied for scholarships and took me to do entrance exam with many famous schools. I had to face with stigmatization in the process for appearing weak and unhealthy. I was asked to drop out of the process. My parents were upset by the injustice and the discrimination. The events traumatized me and caused me to stigmatize myself. I needed help from people around me to make me feel better.

In the first Semester Break of grade nine, the school gave me a chance to join in a Scouting Camp named 6th Scouting to Develop Youth Qualities camp, which would feature many scouts from various countries joining in. I was a representative of the Thai students to welcome the Ministry of Education in English, and had a chance to form some relationships with foreign scouts joining this camp.

When I was in grade nine, a teacher suggested that I should apply for a scholarship to go on an international student exchange program. I was really interested in spending a year in Japan as an exchange student. I applied for the program and went to take a written exam. I passed the exam and my parents took me to sign documents at the exchange student agency. There, I was asked to drop out of the process. They explained that they did not allow students with medical issues to join the program.

My parents and I argued with the agency that the details of my conditions were included with the application along with the letter from my teacher and they have already seen me on the written exam day. We did not understand why they let me come this far if my conditions appeared to be an issue. The staff could not any explanation and only apologized to us. My parents tried to convince them to allow me to have that oral exam but a senior staff insisted on me dropping out of the program and gave the opportunity to a more appropriate person. We finally had to drop out of the process on that day.

I was so sad by the incident as I really hoped to be an exchange student like my sister, I cried right there. My parents could not stop me from crying. That was the first time I was sad and hurt about myself being born as an incomplete person. I had to face so many obstacles and discrimination from my conditions. I did not have a chance to even try to pursue my dream.

Though I was hurt, I had to focus on finish grade nine and move on to senior high school. Many of my friends go to join that exchange program and I had to quietly look at them being happy. I tried to suppress my sadness deep inside my heart and turned that into hard work and study. I was awarded for my excellent study results and earned a certificate for a student with a desirable morality from my hard work. My parents awarded me by taking me to Osaka, Japan during that semester break. They said the trip was a consolation and my reward for getting into the science-math plan as I wanted to. They wanted me keep up my good work.

> “(She slowly gave the interview, afraid that it could trigger the researcher’s bad feelings about it.) *I felt so sorry for Jib about this as she has invested so much feeling into being an exchange student. She has already passed the exam but was asked to drop out. It shouldn’t have happened since she rightfully took the exam, yet we couldn’t argue with the agency when they had so many excuses. They asked us not to keep going since we couldn’t go anywhere with it. It also sounded like they tried to warn us of bad outcomes from our persistence, so I thought we should stop right there. That showed them we were understanding. All that we could do was consoling Jib, which was our job from the beginning. We didn’t want her to give up on her dream. If she was so determined about this, she should keep going. There would be more ways for Jib to take steps to achieve that dream. Jib had to move on without giving up. Someday, I believe she would be able to do it and fulfill her dream with pride. That’s what I believed.*“

Mother

My father’s opinion was not that different from my mother’s on more academic. He wanted to compensate this incident with something equal to the exchange program.

> *“I was sad that things like this happened repeatedly, leaving Jib in a state of sorrow. I thought this sadness was hard to compensate*

since Jib had a high hope for it. I believed that Jib wasn't the first one who was asked to drop out. Therefore, they should be more efficient or systematic about dealing with cases like Jib. If not, they should have let Jib tried until we could not further in the process. I felt that the agency did not put in enough effort in to this."

"However, I would never let Jib go abroad alone anyway. Her mother must accompany her. That's my condition. I thought it might sound troublesome for Jib. Moreover, her sister had good connection with this agency so didn't want to push things too far. This mustn't be the end of Jib's dream. There are so many more opportunities to choose from. Remember, passing every test showed that Jib was a student of quality. If Jib tried, of course we parents had to try with her. I believed there must be a scholarship suited for Jib in every way. That's why we couldn't be so full of sadness that we forget to look forwards to the future."

Father

As a former exchange student, my sister was well aware that I could not join the program but she did not want me to blame myself.

"*In this case, the exchange student agency was wrong for letting Jib take the exam from the beginning. They should have told her that her conditions were not appropriate for such activities. They might have thought that Jib couldn't pass the exam, so they let her take the exam."*

"As a former exchange student, I can tell that you cannot handle this activity as you have to be alone in new environment with strangers. That challenge can be very hard to overcome even for people without any disabilities. It can be extremely stressful for an autistic person like you. In addition, this program will not allow your mother to accompany you. They even discourage the parents to visit during the program. Being asked to drop out early might be the least horrible thing that can happen to you in this case."

"I don't want you to look at it as the fault of your abnormalities that forced you to drop out. Like anyone else, Jib has to learn and understand

her abilities and her limitations. Jib's abnormalities had already given her some sort of prerogative or advantage. They also gave her the attention. Being a disabled person in academic world gave Jib a lot of spotlight already. Jib could use this attention to her advantage in many ways. I wanted her to focus on them rather than being sad about her limitations. I believed there would be other organizations that want to Jib a scholarship. I want Jib to prepare herself for those opportunities instead."

Sister

My brother also gave his opinion about this based on his feelings about it.

"(He gave the researcher his interview with a normal expression.) *I felt bad about that incident. I didn't have to be her brother to feel about it. Being asked to drop out after passing the exam would make anyone sad. They should not let you join the program from the start."*

"Anyone could feel like she was being discriminated against. No matter whom my mother told this story to, they would feel the same. Even if I wasn't her brother, I could sense that it wasn't right. If their criteria were to prohibit the people with disabilities, they should tell us so from the beginning so it wouldn't waste our time and money, which wasn't refundable. Maybe they just wanted our registration money."

Brother

After coming back from Japan, my father wanted me to try the entrance exam to the best high school in Thailand. He wanted me to at least try the exam since my grade has always been so good. On the date of registration, I was waiting in the queue in my wheelchair with my parents when a teacher approached us. He told us about a blind girl who has got to study there and could not stand the pressure since everybody was for themselves in that school. She had to resign in the end, he said. Even normal students felt pressured from how hard and competitive the study in that school was and quit as well, he added. He expressed his concern that I might not have a happy life there.

My parents viewed his action as trying to convince us to drop out of the process. My parents were upset and disappointed for having to face situation like this again. They did say anything to that teacher as they were fed up with the discrimination. In this case, they decided to drop out from the process of entrance exam to that school for being disappointed with their staff.

> *"I thought this teacher was used to having those excellent students, both in learning and in self-improving gathered in this school. When he saw Jib, he thought the worst out of her future in that school. His words made us so disappointed in him. We talked to another teacher and told us about our point of view but it also seemed that he was no different."*
>
> *"I told my husband that I didn't like the atmosphere in that school. This teacher's welcoming was really bad. Despite the fame of this school, Jib's current school was already a school with good standard. Jib was already used to almost everyone there. So, let's not waste her time taking the exam there. Jib didn't want to transfer to another school, anyway. I just want to say that, famous schools only want perfect students without considering morality, ethics, or mercy to create even more fame for the school. It's good that we decided to cancel the registration since I believed that Jib was a student, and a student was the one who gave the fame to the school he or she was studying in. In other words, Jib could also be a valuable asset to her high school as well."*
>
> Mother

My father was really disappointed in that school as shown in his interview.

> *"This teacher didn't speak with the spirit of a teacher, but he spoke with the feelings of those businessmen from the agency who wanted only perfect students for his school. He was discriminating Jib and tried to scare us away from the registration process. The story of the blind girl who had to quit made me think."*
>
> *"Imagine if Jib could pass the school's entrance exam, a higher level of discrimination would follow. No one would take care of her or have any mercy for her. We had to decide. We shouldn't let Jib face the heavier pressure. That pressure didn't come from her own physical problems dealing with the study but came from the teachers."*

> *"I decided to drop out of the process and stopped the problem there. My feeling told me that not only did the school have the right to choose the students, we had the right to choose the school, too. We had the right to choose what suited Jib the most. Jib already studied in a very good school. Her high school was more suitable for her than this famous high school. The facilities in her high school were better and more suitable for Jib."*
>
> *"Furthermore, the famous high school would be much more competitive. Jib might have no friends to take care of her there. We have no need to put Jib in 'the best high school in the country. Jib should be in a school that was suitable for her. She did not need to go to the best high school to be able to get into a good university. She has proved that."*
>
> Father

My sister has been abroad so many times as she always looked for opportunities to do so. Every time she won a scholarship or a chance to go abroad her confidence improved and her vision was broadened. The first time was when she was in grade eight; she was a exchange student to Australia for six weeks. In grade eleven she went to Costa Rica for one year as an exchange student. Right before she finished high school, she went to Japan for ASEAN youth meeting. In university, she went to Mexico with her friends to join Model United Nations activity. For her postgraduate degree, she won an Australian government scholarship to study in Sydney. My father also won the king's scholarship to study at AIT.

My family was very supportive when it comes to education. My parents encouraged their children to compete for scholarship and to always find opportunities to go abroad. With my conditions, looking for scholarship was more difficult for me. I have been stigmatized and discriminated so many times but that never discouraged me from trying again. My family also encouraged me to never give up and convinced me that the right opportunity will come along.

In grade twelve, I was determined to study about biology in university as I was passionate to learn more about diseases. My parents helped me choose where to study by taking me to the universities I was interested in to meet the lecturers and staff. They wanted to make sure that the university and the faculty can accommodate my conditions.

In my last semester in high school, I tried to apply for scholarship again. It was a scholarship for students who want to be scientist or work intensively in pure science field. I passed the written exam and got to have an interview with the scholarship committee. When the result was announced, all the candidates' names were on the list with their score and result of scholarship application. However, my name was the only name missing in that list. My mother asked the staff at the university about it and they only told her that the announcement was final and nothing can be changed.

When my dad knew about what happened he called the university and a committee to ask about it. The committee explained to my father that they had the right to choose the candidates and Jib was not suitable for the scholarship. The scholarship was meant for people who can work intensively in science field which the committee could not see Jib doing so.

However, my parents have later on found out that I had the rights to be interviewed by a special committee for handicapped candidate. They felt so bad that such information was withheld from us. However, the process was done and there was nothing we could do about that scholarship anymore. We only hope that it will not happen to any other handicapped students.

> *"I think we just had to accept what happened to Jib with that scholarship. I didn't understand where Jib's name had gone to. No one was willing to give us any explanation about it. They might have a very high standard that we couldn't even reach for it. The committee of that scholarship might be looking for something that Jib did not have. That's how I concluded the situation for myself. We were sad about it but there was nothing we could do."*
>
> *"However, not winning that scholarship didn't mean that Jib was not good enough since Jib was accepted in many other universities and one of them had number one rank in Thailand. Jib was good enough and had the potential to study. I wanted Jib to understand the truth of life that people have to face both success and failure alternately. No one could always succeed in everything. What happened to Jib happens to other*

people too in different forms. I wanted Jib to understand that it could happen to anyone.”

Mother

My father looked at that scholarship incident as deprivation for disabled people.

“I tried my best to help Jib in that situation. However, we had to accept the truth and respect the decision of the scholarship's committee since the scholarship had its objective. I already asked everyone related, including the scholarship's committee and the university about why you mysteriously excluded from the process. The explanation I got was the scholarship’s objective was for the recipients to study until they finish doctoral degree and become lecturers for the university and further promote science in Thailand. They wanted someone who can work intensively in science filed which they couldn’t see that from Jib.”

“My question was why they let Jib register in the first place. This kind of situation keeps happening to Jib where she is mysteriously excluded from the process. The answer was the committee had the power to choose the most appropriate person for the scholarship. That answer did not really answer my question anyway.”

“I couldn't meet him in person because he denied me the chance. He only agreed to talk on phone and that's how he answered me. It was clear that he didn't want to have further issues that you might demand for anything and just cut you out as soon as he could.”

“I felt bad that you were discriminated for your physical appearance. If you had looked like other people, you might have got that scholarship. People will not quickly judge that you are less suitable than other candidates. Since the committee had to right to choose whomever they wanted, we just had to accept the verdict no matter how painful it was for us.”

“You have been rejected to stay in the selection before but this time the explanation from the scholarship committee was very direct. It was so direct that it hurt my feeling. I felt helpless. There was nothing I

> *could do to help Jib. I felt that you weren't given the chance to even try. You were blocked out from the beginning. Since it happened repeatedly, I felt that it was a pattern of the society to discriminate people like Jib."*
>
> *"Finding out later that you had the right to be interviewed by specialized committee made me feel even worse. I didn't understand why we were not informed about this. The discrimination had gone far worse than I thought. Again, people in education system were thinking like a businessman not educator. It is hard for me to explain my feeling about this. This injustice was truly unacceptable for me."*
>
> *"I was saddened by the incident but I cannot stop encouraging you to keep on. I put the scholarship issue aside but I never forget about it. Since then, I was more careful about having all the information necessary to help you.*"
>
> Father

When I graduated from high school, I had a chance to compete for an opening quota for handicapped students at another university. I chose the Faculty of Public Health there. I passed all of the exams there. When I met a staff member, she gave me advice that I should be the one who choose what to study since the study in university will be hard and requires passion to graduate happily. I took that advice and chose to study biology with the university that I graduated from.

I was inspired by my father and my sister to get scholarship and to go abroad. However, as a handicapped person, I had to try harder than normal people. Despite all the discrimination I have faced from applying to go abroad and for scholarship, I persisted on trying again with encouragement from my family. My father wanted me to have a good career and he thought that winning scholarship and going abroad can help me.

When I was asked to drop out of the selection process by the student exchange agency, I stigmatized myself for being born handicapped. I was discriminated from having disabilities. I was so saddened by the incident that I had to cope with my feeling by crying. I was sad to see my friends go abroad on that exchange program. They had the chance to do what I did not even have the chance to participate in the selection process.

I faced with stigmatization and discrimination again when I was registering for entrance exam to the best high school in Thailand. A teacher came up to our family and told my parents about a blind girl who dropped out from his high school. He thought that all handicapped students cannot study in his high school from one example. When we talked to another teacher there and he had the same attitude, my parents decided that the best high school was not the best school for me.

I was discriminated again when I applied for scientist scholarship. My name was missing from the result announcement without any explanation which can be considered a double standard treatment. While my mother and I just accepted what happened, my father tried to get answer from the university and the scholarship committee. My father was told that I was not appropriate for the scholarship and the committee had to power to finalize the selection result. There was no argument to make against that answer and left him feel helpless about it.

The scholarship committee made us feel even worse when we found out later that I had the right to be interviewed by special committee for the scholarship. My father that felt that discrimination against disabled people was a common thing in Thai society after many incidents that happened to me.

The science scholarship incident did not hurt my feeling too much as I was accepted in other universities. I was able to study biology in another university like I had hoped for. However, my father’s feeling was far worse since he felt that the society was against me and he could not help much.

5.1.5 Trophy of our Struggles in Education System

Figure 5.4 I became a student of a famous university in Thailand

I became a student in the faculty of biology of a famous university in Thailand from my hard work. My mother gave me more freedom in the university.

However, without her intensive care, I had to face many problems caused by my autism and my appearance. I was stigmatized by classmates and lecturers which had become more severe than the stigmatization in high school. I was extremely traumatized and distorted. I vented my feeling by using my phone in class which distracted me from my study and led to bad grade.

After reviewing my problem, I have found out that I did not put enough effort into my study. I needed some help to reduce my stress. That person might be my mother or my advisor. The advice I got was to change myself by keeping on managing my nature of autism so that I can be accepted by others and could live among others. I was also encouraged to focus more on my study.

My parents celebrated my success in getting into the faculty and the university that I wanted by inviting the extended family for a party. Everybody congratulated my success and blessed me to be successful in my study. From a hopeless child, I could pass the entrance exam into a good university.

Before the semester began, I my parents took me to the campus to survey the buildings and the surrounding to make sure everything was accessible for me. They bought me a motorized wheelchair to help me get between buildings quickly. During the first year, I had to study in the campus in Nakhon Pathom. I was living in an apartment with my mother. Since I did not live with my father anymore, he could not tutor anymore.

There was a dog in this campus that everybody loved. The dog has been there for about ten years already when I studied there. We called the dog “Happy”. Though the dog was really nice, some people still did not like it and tried to chase it away or kicked it. I felt so sorry when the dog was poorly treated and compared the dog’s feeling to mine.

The motorized wheelchair facilitated my life at university and gave me more freedom. My parents wanted me to feel more matured and able to look after myself more. However, I was not used to move around by myself and often ran into people. My mother had to look out for me and train me how to use it at first. She still had to prepare lunch for me as I was not used to the campus yet. My life was not so much different from life in high school. I asked my mother to try some food shops around and that was how I could talk to some new friends. I thought that I was going to be happy in university level as the students must be all matured.

All the students in the Faculty of Science had to study together in the first year. The first-year subjects were mostly knowledge from high school but more intensive. We also had some classes with students from other faculties. Those subjects were Thai Language for Communication and English. I had a chance to meet friends from different faculties there. Most of my friends in my faculty had previously registered in at least an Educational Olympic Competition so I believed they would be matured enough not to tease me. The lecturers were kind but the exam was very hard. I had to concentrate very much on my study to get good grades. I was happy with my friends and my health. I liked the atmosphere of learning among friends and joining a lot of activities together.

However, my personality was still a quiet person who did not like to talk to friends but rather ask teachers in class. My friends labeled me as “The Questioning Jib”, “20-question Jib“, and “The Curious Jib” so everyone knew me from those labels.

On the second year, I moved campus to the one in Bangkok, but there some subjects that I had to go back Nakhon Pathom campus. I have lost contact with many friends I have in the first year. I chose my major in biology as I liked the subject since high school. All the subjects in the second year was completely new to me. I asked so many questions in class and I was teased again. I was wrong thinking that smart matured people would not tease. I did not know how to break away from being teased. This issue disturbed me so much. I started drawing in class to distract myself from my teasing friends.

In a class, we discussed about the use of smartphone and its benefits. My friends agreed that smartphones must be used in the class so I begged my parents to buy me one by telling them what the teacher had said. My parents agreed and bought me a smartphone. Instead of using my gadget for educational research, I used it more for my entertainment. I could not stop myself from playing on my phone in class. My mother also noticed that I was not studying at home at all but was on my phone all the time instead. My grade has dropped from my lack of interest in studying. I tried to conceal this fact by lying to my parents that the reason my grades looked like that was because I did not understand the courses at all.

During that summer break, my parents had to fix out house after the big flood in Bangkok. During that time, I decided to start working on my senior project as my advisor suggested me to start early for good work. My mother spent her time helping me for I could not work on it alone. We worked together until the next semester. I was concentrating on working so I temporally forgot about the internet and games. My mother helped me make studying schedule to help me manage my time better.

My senior project was about Asian Open-bill Stork’s behavior. I chose two water ponds in the university to observe them. When my mother and I were observing the storks, we found out that the ponds were peaceful unlike in my class. I have never felt so peaceful before. When I was observing storks, I also observed people and animals around the ponds as well. Furthermore, I could spend more time talking with my mother. When I thought about that time, I could remember that I did not have any nostalgia about people or entertainment I had known on the internet. My mother dealing with flood and her sick father at that time was very stressed. She also liked the peace she got form observing the storks. We noticed that we like spending time at the ponds.

From reading books, I used to think that Asian Open-bill Storks only eat Golden Apple Snails. After the observation had done, I noticed that they also eat Periwinkles and some other aquatic animals. I would never had known such information if I never had spent any time observing the storks.

Comparing such observation to myself, people have many misunderstanding about me because they never truly knew me. I was judged upon the first impression I gave people. People do not understand what autism really is. I have come to a conclusion that only people who live with me understand me and my autistic nature deeply.

During the semester break, I kept on collecting the necessary data from the Asian open-bill stork and started to write a report about it. I was so dedicated to this senior project that I refused to let anything interrupt me, even when my parents wanted me to go outdoors with them for the relaxation.

I dedicated in this senior project to finish it in time for Science Project Exhibition. After that, I spent my time on my study. My friends were so stressed with their works that they did not have time to eat out on the same dining tables. However, we could still talk via the social media anytime we wanted to discuss our problems. My online sweetheart kept on giving me his encouragement as well. My heath was good from the medication and regular check-up.

The private medical center invited my mother and I to their television show more often because I was their first patient with autism who was about to graduate from university. They wanted to broadcast their success in treating autism to the public using my case.

During the semester, the faculty selected students to be candidates for the Institutional Royal Award of the Year 2013. One of my friends in the faculty and I had been selected. The result was, my friend got the scholarship whereas I got the certificate showing my prestige and virtue. That brought joy to me and my family.

On the Fifteenth Science Project Exhibition day, my senior project named "The Foraging Behavior of Asian Open-bill Stork found in Current University, Urban Campus” received interest from many students and teachers. After that day was the last day of me being a student there. I was so relieved that I could also graduate from the university like my friends. Before I went home, I visited my advisor for the last time to say goodbye to him and ask him to bless me. I bid farewell to my friends though I was not sure they wanted to do the same to me or not. However, many of my friends apologized to me for treating me badly before. Most of us then took a group photo as a part of good memories we shared.

Before the graduation day, I returned to the faculty to get my graduate gown which was smaller than usual. I was excited to see a lot of dresses hanging there, hoping mine would be as fine as those. I was so excited to try my gown although it was hot and heavy when I wore. I felt happy and proud in my gown. I was thinking about what happened in those four years in the university in my prestigious gown. My parents smiled as they took a photo of me in my gown.

On the graduation day, my family and cousins were proud of me. They came to congratulate me on my graduation. On the day I received my graduation certificate from Princess Maha Chakri Sirindhorn. My family and I were delighted. I had a chance to personally receive it from Her Royal Highness at the backstage so my graduation photo was unique. I wish more handicapped had a chance like me. I have come so far from a handicapped who could not even tell my basic needs. I could prove to everyone that being a handicapped is not an obstacle to study. With support from the surrounding people and society, they could be successful like me on that day. My intention from then on was to get a master degree to expand my knowledge. I wanted to use my knowledge to contribute back to the society.

My graduation is the success of my parent’s dedication to cure and encourage me to have a chance to study and to utilize my capacity. When I got my graduation certificate, I prostrated myself before my parents to thank them. I set my resolution to sustain myself as much as I can to lighten their load.

Figure 5.5 My graduation is the success of my parent’s dedication

Nobody in my family could foresee my academic future when I was young until I could pass the entrance exam to get into my university. My whole family was so happy and gave me their blessing. My parents tried their best to support my study, for example buying me motorized wheelchair and renting apartment for me.

My senior project about storks made me understand more than just stork life. I noticed that the information I read form book was different from the information I gathered from the observation. I then realized that most people only judge each other from appearance and information they have from other sources. People who truly know me is my family. During the observation, I also saw a stork with an injured leg. The stork tried its best to survive despite having only one good leg. I realized that every living on this earth has to surpass its limitation and keep on going.

My study in university required hard work and dedication yet I was so distracted by being labeled by my classmates. I was seen as someone annoying and asked too many questions in class. The labeling made me so frustrated that I started to sing and draw randomly to distract myself from my bad feelings.

5.2 Resiliency

My family and I had to cope with the stigmatization by the society who wanted to make negative pain to our mental minds. However, it was because we had the belief, faith, encouragement, value to the feeling of a mother to a child, and my father's overcoming sadness as our good armors, we could resilience to those stigmas back to our normal mental states.

5.2.1 Belief and Faith in One's Self

To resile one's self back to normal, a stigmatized person had to be implanted the self-belief and foresee the value and potential in him or her. My parents had understood that I have the disability, yet they chose to take a very good care of me, properly corrected my defected physical body, and stimulated my brain which helped me develop, in order to make me able to co-exist within society through educational system. Because of their belief and their faith, I consider they were the right things to do to help me as the narrative story goes;

I am proud to have parents that take a very good care of me, even when I was recovering from the surgery. Even though I was unsatisfied in the state I was in, I had my mother to by my side.

> *"As I remember, after woke up from the surgery, my legs were separated by a white, hard, crotch-less trouser-shaped weir. Its length was from my ankle to my waist. Moreover, my weir had 4 openings for each lesion on my legs. Each of them had an iron bar stabbing on it as a marker for cleaning as someone it needed to be cleaned. Everyone did not want to look at them. There was only my mother who had her courage to clean them for me. One day, my aunt visited me, as soon as she saw me, she said "Hey. Jib with iron bars on her legs reminds me of grilled chicken". From a person who sustained such disability, I became more dependent. I was an unhappy with my condition, All I could do was prayed "Please, don't*

> *let me suffer in the fate ever again”. Whenever I was reminded about my condition in that stage, I do not know how I survived that moment. The only thing I remember is, I received all the encouragement from my parents who took care of me and consoled me that I would be recovered and be able to walk and run again.”*

The Researcher

My mother was a housewife who look after me and my siblings. She did not have time for anything else besides housework and her children. As a result of her busy lifestyle, she didn’t even have time to make friend with our neighbors. And that made our neighbors think that we are arrogant and conceited family, so they harassed us by sending mail when I was born disabled. However, for having faith and self-belief that letter did not affect her much.

I had to give up my scholarship due to my disability. I was so despair as I had to give my faithful rights to a healthier person. I was comforted and encouraged by my family and they did make me feel better and stronger.

> *“I was so sad that I had to give up my scholarship and let somebody else replace me even though I have received from the scholarship center itself. I was discriminated because I’m an unhealthy person to them. I didn’t understand why my disability was judged as lacking of quality and capability, and I didn’t understand why they don’t judge me by my academic ability. However, with my fate and the confidence I got from my family made me feel that I’m hardworking person, and I my life can go on in many other ways. So, I no longer regretted my opportunity and stopped blaming myself for being born this way.”*

The Researcher

My mother fell ill due to her busy lifestyle and overwork;

The doctor diagnosed the risk of having uterine cancer. She had hysterectomy done to remove her uterus and she had to rest for at least one month or until she was fully recovered. Unavoidably, two weeks after her surgery, she had to return to her work looking after me and my brother. She said she is proud of herself to do her mother jobs.

When she took her recuperation and then recovered from the surgery, she hastily returned to work on her role including giving me her advice as I studied in the university.

> *"When I felt I could not deal with the issue anymore, I told her what happened. Yet after I told her to relief what was in my mind and got some soothing words with her sympathy, it made me feel a lot better that I got my sense of myself back for having a lot of good things in myself. Just lacking conversation and expressing skills should not make me lose all confidence in myself. And I realized that could comfortably accept my autistic condition, and that I should concentrate on trying to control my conversation and expressing behaviors. That was how I could be happy with myself in learning and could happily co-exist in the society."*
>
> The Researcher

Figure 5.6 Me in Social Events

My defected body and impaired mind were not excuses to force my parents to keep me in the house. Instead, they see the importance of me being introduced how to be among people as soon as possible so I could adapt myself to be co-existed in the society by constantly joining the social activities. Moreover, my parents also see the importance of training me to develop myself. So I could be ready to attend school. When I attended school, they supported my academic skills to pull out my academic potential and to make the progress, so the school provided me chances to attended the activities including the scout camp and competing in academic competition as a school's representative despite my physical impairment. In addition, I was the presenter of the private center I got the treatment for autism. As a presenter, I was filmed as I gave my encouragement to other autistic patients and their caretakers, as the narrative story went;

My parents never thought that my behaviors were unacceptable. All of them was the way I was express my feelings or needs. They did not want to suppress me or make me an aggressive child, so they tried to learn and understand my needs by observing my actions. They did not want to keep me inside the house away from the society as it would obstruct my development. My family ate out very often to take me out of the house. My mother said that I was excited and restless when we went to new places. I could not stay still but rather walked around the place. I would be calmer in places I have already been to.

Figure 5.7 I became the center's permanent presenter.

My parents worked together to plan where we would go and told me in advance which helped reduce my excitement. When we went to department stores, my parents had to take turn in taking a special care of my safety. Though taking me out was a lot of work, our family still really enjoyed it as it made us happy that I could not stop smiling. Eating out at the restaurants helped me learn about the new tastes and try new things since I usually ate the same thing all the time. Everyone wanted me to try new food and talk to new people so they took me to eat out often.

When I recovered from the treatment at the private center, the staff asked me to be one of the presenters to show my speaking skills.

I had to continuously get my treatments from the private center. That made me steadily healthier than the years before. The center wanted me to be presenter in its seminar about children with autism. Soon enough, I was also occasionally invited to film a television program with the center. The news about me got spread around, so I became the center's permanent presenter. My mother and I keep on giving our counseling and advices, including sharing my stories in the filmed and the seminars. My mother saw the improvement as I become more talkative, more assertive, and brave enough to be in the society. She also hoped that, in the future, all these things would benefit me in getting a better life.

> *“I set my priority to your speaking ability because communication will function as a door through which you can overcome your autism. From wondering whether you were deaf. Now that you studying in Grade 5, became the presenter on the television and the inspiration to people who had autistic patients under their care.”*
>
> Mother

And I was the center’s first autistic patient who was capable to study and going to graduate a Bachelor’s Degree soon, so they wanted to broadcast this to give encouragement to other homebound autistic patients.

When I was more outgoing, I had a brighter academic future. As I studied in the secondary school, I had chances to join the camp which helped develop my skills.

When I was studying in the first semester, I had the chance to attend a scout camp with my friends in the same grade in the same camping resort. There were the administration teachers joining in the camp. My mother also had a chance to visit the camp. Joining the camp made me become acceptable by everybody since I could participate in the assigned recreation activities like my friends did there, and could stay there with everybody without causing troubles. From that, I could attend the activities without any excuses from the principal.

Figure 5.8 Me as a girl guide in the 6th Scouting to Develop Youth Qualities camp

In the first semester break of the consecutive year, the school gave me a chance to join in a scouting camp named 6th Scouting to Develop Youth Qualities camp, which would feature many scouts from various countries joining in. I was a representative of the Thai students to welcome the Ministry of Education in English, and had a chance to build up relationships with foreign scouts joining this camp.

When I keep on studying, my grading report was clearly shown that I was chosen as a representative competitor to compete with other schools. This clearly shows my capability in academic and to utilize my capability.

When I was in the school, I felt I did well in making good relationship with my classmates and teachers. When I was a grade eleven student, my teachers and my friends willing to support my learning to ensure my results would be stable. In addition, the school's teacher had given me the chance to join my friends' team as the school representative to compete with other school teams. That made me feel like I was accepted and was treated equally despite my physical handicap. Even my friends who liked to tease me had already accepted me for that.

From the narrative story, the reason my parents tried so hard on introducing me to the society by taking me outside with them was to reduce my stress and to normalize my deprived skills. As said, they did everything they should do, such as the activities we did together and go out could improve my skills like I should have to keep on living.

The activities I had experienced were camping with the school and the scouts to prove myself as a capable one who did not cause any issues to the fellow camp attenders. Moreover, I was asked to be a presenter in each seminar the private center held and to get myself filmed. Thus led me to be more outgoing and become more confidence than before, as normal as majority people in the society.

Although I was more capable, I was still judged and stigmatized by other people as always. So, I had to use my academic capability to proof value through the academic competition and as my encouragement to keep on studying.

5.2.2 Encouragement from Family

The family is the first society unit for the newborns, family members are often willing to take care, help, improve, and protect the newborn so he or she can take care of his or her own self in the future. In case of disabled newborns, the family should also give him or her the encouragement in every possible ways to resilience the newborn so he or she can co-existed in the societies. In the narrative story, the family's outdoor activity is the good idea to calm everyone in the family, including the disabled ones, from the issues that led to many mental stresses, and they can affect everyone. They could also help stimulating the cognitive by the new environment the family goes to.

Figure 5.9 Taking a Break from Stigmatizations

My family usually does outdoor activity to relax ourselves. There was once I realized for the first time that living outdoor was not as fun as I thought, as the narrative story went;

My mother said, in the summer break when I was a grade 1 student, my aunt invited us to go to Pa Sak Cholasit Dam. I could still comfortably ride my old wheelchair that I have been using since I was a toddler. I was struggle to use the toilet as they didn't have a proper toilet for the handicapped individuals. The toilets they have got there appeared to be the squat type ones, and I needed aids from my mother in order to use one for urination. I did not enjoy the trip that much as there are some insensitive people and the place where they did not have facilities for the handicaps limited me to do things.

> "*Your aunt and your mother, Jib, took us to Pa Sak Dam. I also came along as well as you. We rode the kart service for tourist for sightseeing around the dam. The activities started early in the morning which wasn't that hot. I didn't feel sorry for you because you looked happy and did enjoy the trip. I was glad you did.*"
>
> Grandmother

I had traveled to various places in Thailand with my family to relax ourselves, traveling could resilience me. There was only once I did not actually happy. That was the time we traveled to Pa Suk Dam after the legs' cast was taken off. I lost my capability to sit in the squad position after the surgery, using squat type toilets there was an uncomfortable thing for me unless I was aided by my mother who took care and helped me.

Rewarded by Traveling the World

Apart from resilience by consolation and encouragement from my family, traveling inbound and aboard makes me feel happy, enjoy, and relax from mental stress. Including the change of environment that made me forget about my bad experiences. The warm welcoming and services also made me forget about the difference between me and majority of people. Traveling to many places was the reason I saw the living of the disabled people in that country that referred to the quality of the governmental basic health care that supported the disabled people to live in the public comfortably with less care-taker and more dependence. In contrast, I had to depend on other people still, as the narrative story went;

I had experienced traveling abroad the first time with my family in the summer break before I started my grade three. One year after my leg surgery, my parents decided to take me and my siblings to Singapore, which was the first time we travelled afar by my father's personal car. They were worried that I could not cope with it. However, my siblings and I were found asleep in the car until we reached our destination. We occasionally took our rest to comfort everybody. We rested for a night at Surat Thani. In the morning, we made merit at Wat Pha Moke before we start our journey, which took a day to get through Malaysia and reach Singapore, our destination. We chose to stay in a hotel in the capital. My mother said the capital of Singapore was clean and tidy. We visited China town, Little India, Orchard Road, and then paid our respects to monks in Wat Khieaw Kaew (the Temple of Glass-fang). The next day, we went to Sentosa Island by the monorail to take a picture with the Merlion (the lion statue with mermaid’s tail). Later, we visited Jurong Bird Park and Underwater World. Even though I was weak and was not capable to walk, I had no problems going around with in the wheelchair. There was specially accommodated and catered to by people everywhere we visited. About food, my mother added, the food we ate there had a wide variety so some of them were edible for me. There were no problems about food.

In the next morning, we took our trip to Genting Highlands, Malaysia. We stayed at a hotel near an indoor theme park. My mother said that I could not go around as free as everybody else, had made my way around the theme park and enjoyably played on some attractions with my siblings. She also added that everyone looked like they had fun with the variety of attractions there. However, there were some attractions where I, as a weak child, had to play with helping aides. I played some of them several times until my parents carried me from them. I then was too old to cry like a young child.

Finally, we headed back to Songkhla Province, Thailand, where we had a chance to do some sightseeing such as vegetarian ceremonies in Hat Yai. My mother said she kept on watching me to observe me whether I was startled or not by the deafening sound of firecrackers and the scene of people, who pierced through their bodies with sharp objects, walking on the street with others, I had experienced the leg surgery two years before. It appeared that I could sit still in my wheelchair, yet she never knew how my heart beat so loudly from the fear as I saw the scene there because some people on the street were bleeding from their lesions. It was a scene I would never forget, but I passed through such feelings without fear or showing my fear to my parents by trying to run away.

I could still remember the events during the trip to Singapore and I it was fun, even I could not freely move around like everybody else or having interactions with people apart from my family.

Figure 5.10 Me in Tokyo, Japan

Three years later, after I successfully entered secondary school in the city and my father had to go to work in Japan, he took his entire family with him. This is the second time I traveled abroad, but it was the first time I traveled by plane. My mother said, my siblings and I liked to watch Japanese animations, eat Japanese food, and had our interest in Japanese language. So, traveling to Japan would delight us for sure.

The extreme excitement I had was my issues on the plane in the midnight flight. I could not effectively adapt to sleeping and breakfast time, so I ended up vomited after I had my breakfast. Everybody scrambled to clean my clothes. At Narita International Airport, Japan, my mother took me to a restroom to clean me up and change my clothes as soon as our luggage arrived. Then, we were serviced by airport staffs who accommodated us to the nearest train station. The carriage has seat belt strap for wheelchairs. We took the train from the airport to Asakusa. Every time we transited the trains or carriages, either going inside or outside each cabin, there was a staff who placing a plate, for my wheelchair to get on and off inside the cabins and the platform's floor so I could easily access the train. For the motor train station that has no elevator, there was a motor carriage lift to carry me in my wheelchair up to the station's exit. So, although there were so many people taking services in the train stations, there were no obstacles or issues for wheelchair-bound people, so I did not have to worry about services in Japan's public train system.

On the first day, we visited the area near our hotel in Asakusa, Tokyo. My sister was the only one who could speak Japanese, so it was her task as a tour guide for the rest of us to go around in every way related to communications because most of the Japanese people did not speak English. My sister impressed me a lot, and I thought I would learn Japanese language as soon as possible. We traveled around Tokyo for eight days. We were happy and enjoyed our trip. My family took me to many places of tourist attractions. The attractions in Tokyo were Senseji Temple, Tokyo Imperial Palace, Ueno Park, Shibuya, Harajuku and Shinjuku districts, and Tokyo Tower. I could easily go to every place we visited. I also saw the disabled people out there on the street. Some of them used their walking canes, some were wheelchair-bound, some were guided by their dogs, and some had at least a person walking by their side as their accompanying aides. I noticed that every disabled person could live a normal life. I also saw those people using services in the train stations and other service places. Most of them could sustain themselves. There were regular and special facilities for disabled people, bus stops along the street. The restrooms everywhere in the public also distinguished by types of the users, for males, females, and disabled people. The restrooms for the disabled people had the automatic flush types to make it easy for disabled people to use. There was also the emergency button, to ring the emergency buzzer, installed in the restrooms. The place I was highly impressed is the amusement park called Tokyo Disneyland. My family and I could get through special gate accessed to the equipment, so we could play and admire to almost all of them in one day. I could play almost every equipment there and we had our free time to see the parade of mascots before the park's closing time. I was impressed by the park that it could support every type of visitors. I was happy to have fun with everyone there without worrying about my disability. Moreover, every staff there would extremely willing to assist disabled visitors' safety. For the food, I would like to try the traditional, Japanese one for a long, long time, and I was enjoyed trying them because its original taste was so delicious. Before heading back to Thailand, my family decided to make a trip to Japan again for at least one more time.

Figure 5.11 Me in Osaka, Japan

During summer break when I was grade nine student, my father kept his promise by taking us to Osaka, Japan in order to console me for missing the chance from the exchange scholarship earlier. In my sister's place, I took the translator's job because she could not join us. Osaka did not provide the same facilities for the disabled compared to Tokyo. That was the reason I had to rely on both my family and the service officers at the places we went to. However, I saw a lot of landmarks with the service for people with disability to serve themselves properly without relying to anyone else. I saw people with various types of disabilities, both children and adults, who could sustain themselves better than I do. I mainly relied on my family. I saw them lived independently and traveled freely with help of every disability-aid transportation. That made me look at myself as the one who still depend on others that I would not overcome some of my limitations. Studying then could also make me unable to surpass my various conditions and limits. Compared to my siblings, however, they could live more independently than I could in many ways. For instance, when I wanted to go anywhere, I have to ask my parents to take me there. That would depend on whether they are free or not at that time, too. This always made me feel uncomfortable and sometimes I have shown my displeasure about it to beg for the attention from my parents. My mother said, they have sympathy for me about my condition so they tried their best to assist me. In conclusion, coming to Japan with disability-friendly aides made me feel bad about me living in the country where disabled-friendly environment does not properly provided.

The first time I traveled abroad, I traveled there by my family's personal car. Me and my siblings adapted with it by taking a nap in the car until we reached the destination, so we did not feel irritate to traffic or to the noisy honking sounds. However, I feel like I've failed to adapt myself to when it was my first time traveling abroad by plane. It was my very first time so I did not know that a passenger should avoid eating anything before getting abroad to prevent plane sickness, so I ate quite a lot and messed myself up on the plane's breakfast. My mother quickly changed my clothes as soon as we reached the destination and our luggage was picked up. It did not happen again in my second flight, though.

Seeing both Singapore and Japan, I noticed that both countries had disability facilities around everywhere. So people with disabilities living there could help themselves when they are outside. If not, citizens there were kind enough to give the people with disabilities their "helping hand" to help them to access to every facility they would like to. Looking back to Thailand, however, I noticed that it lacked of a lot of disability aides and, even if Thai people were so "kind", they still refused to help people with disabilities and happily stigmatized them without any sense of sympathy.

From the narrative story, apart from traveling inbound, traveling abroad could also resilience the stigmatized me. After studying my hardest for the best grading result possible. My parents awarded me by taking me abroad, and we travelled to Singapore once and Japan twice. Travelling not only relax us, but also let us see the another cultures that different from ours, especially on taking care of their old and disabled population to make them capable to happily live in the society. Many disabled in Thailand, in contrast, were prohibited to live in large proportion of the public area, so they could only live in the place they known. The prohibition was considered as the discrimination to the disabled's right and completely deprived them to other society or their responsibility home without taking the academic learning like my parents hoped and dedicated to.

5.2.3 Encouragement from Cyber Society

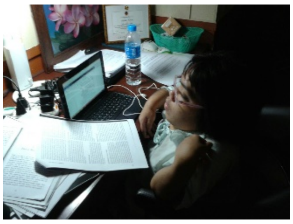

Figure 5.12 The Cyber World no One Aware of

My parents let me use the internet mainly for academic reason. And my internet access is under their provisions. Sometime, they allowed me to use it for entertainment when I am alone, if I could not join my siblings outdoors activities. In the other hand, I had to live on being stigmatized, from my impaired intellect and defected body, with normal people in the society. I used the internet to resilience myself by seeking for the entertainment on my own. This activity can be done on my own. Since they have their own separated, extended families to take care of, and also with my autism that can hardly controlled, my behavior of internet usage had changed from “to resilience myself” to “to solely entertaining myself”. Such behavior change was harmful to me as I studied in the university. As I abandon my study sometimes, my grade results turned out badly in the consecutive academic year. Although I promised myself to quit, I was asked to stay and I was too soft-hearted so I stayed as they wanted me to. Finally, my internet usage turned out to be addiction. Right after I had reviewed myself in my leisure time, I found out that I was indulged in using game applications. I had to change myself back to dedicating on studying, and try to lessen down such usage as much as possible to avoid the issues from reoccurring. I then could lessen the usage’s time down up to the recent time, as shown in the narrative story.

Regarding making friends with neighbors, I remember that I had few friends in the neighborhood and they liked gathering at my house as we had many toys. They usually played with my siblings. They fought sometimes but befriended again easily. My mother would tell my siblings to compromise. She said that compromise does not express weakness. All it does is reducing bad feelings in our hearts and their hearts and maintaining your friendship, she added.

On the other hand, I did not care so much about maintaining friendship with people. I was not attached to any friends since I felt that friendship is not a stable kind of relations. I felt that everyone is the same to me physically and only different in clothing. I was interested in those who are missing some parts of their body as I wanted to know what happened to them. I was only interested in people who affected my life either in positive or negative way.

I was more interested in more intangible things like cartoon either in books or animations. The reason is that, cartoon never made me feel bad. I do not have to control my emotion with cartoon which made me feel liberated. The imagination, colors and characters of the cartoons are totally different from those in society.

Even though I am not interested in having relations with people face to face, I have more interaction with people online. This is because I do not have to feel pressured from being observed or from the noise of other people. I am satisfied that we do not have to care much about relationship online as they are not stable kind of relationships. This is the main reason I rarely mention my friends in this narrative story.

The computer took on a major role in learning in the Secondary School in the city. So, my father gave me one for my personal use, yet my usage was still under his guidance and permission. I sometimes could use this computer to communicate and work with my friends, yet I could also use it to play games in my free time, not knowing that I began to become addicted to playing them. However, my parents allowed that within their given time limit. So I did not have any outdoor activity like my siblings did. Personally, I preferred to live indoors for I am more familiar and more comfortable in the house. I could talk to and understand people in the house more than those outside. I could do anything I pleased without being scolded. That was the reason I did not want to go to anywhere if it was not necessary.

Since then, I have been using the internet more frequently to do schoolwork, research, or for gaming. Three years on, my needed on internet usage had multiplying itself up.

My friends started to flirt with the opposite sex, however, I did not have enough courage to flirt like others. I sometimes have feelings for boys and my mother just laughed when I told her about it. I did not like my mother laughed about my feeling like that when wanted to get some useful advice from her. At the end, I just stopped telling other people about my feelings toward opposite sex.

When I could not have any “lover” in real life, I started to flirt in the online world instead. For I feel more comfortable talking to people and express my feelings in the online world as I do not have to see their eyes or facial expression. I have more control with relations in the online world as I can change or stop it at any time. In the real world, I could not do any of that for there is no guy showing their interest in me so I started to unknowingly feel more bonded with the online world.

Cyber world began to be a part in my life because I have my social life with people who understood me and ready to listen to me. For those reasons, I strongly connected to the cyber world, and kept on using the internet up until I studied in the university.

I was left alone at home as everyone else in the family had to look after my grandfather.

Usually, my parents always had activities for me to do during school break so I never had so much free time. For example, in high school, my parents enrolled in tutoring classing for me. However, this time, apart from not having activities to do, my siblings were all grown up and had their own things to do outside the house. Unlike me, I could not leave the house and had to eat frozen food from the refrigerator alone.

Not knowing what to do with so much free time, I indulged myself in internet for friends and entertainment especially Facebook and online game. I slowly got addicted to the online world to the point that I cannot survive without it. My parents were not aware of that and no one could foresee that my addiction would be a major obstruction to my study.

After that, there was a major flooding, I had nothing else to do. So I spent most of the time on internet gaming every day to entertain myself and not to get stressed out like others. However such usage brought about more issues as time went by.

The University turned to the semester 2 but I still addicted to using my new cell phone for entertainment for the whole semester. My mother had to travel to my house for several times to help my father repair the house after the flood so she could not take care of me all the time. That made my behavior gone worse. I had no interest in studying since I always played games on my cell phone. I refused to care of my mother’s words and I did not listen to any warning or advice she gave. At the end, my learning results returned as the lowest grading scores possible.

> “(She took some times to review all the situation above so she could express her most accurate feelings possible compared to those feelings in the past) *I felt sad for my own action, both about my friends and my overly addicted to playing games, including the worst studying results in my life. All the bad results affected me. I didn’t concentrate on study. I didn’t even know what I had done so I couldn’t fix the issues I have made. Finally, when I openly told every wrongdoings I made to my mother, my regrets that had turned to sadness would be healed up by the consolidation and the advices with kindness from her. I then aimed to correcting myself to improve my life in the University.”*
>
> The Researcher

During summer break, my parents hastily repaired our house so we could temporally live there. During that time, I decided to start working on my Senior Project because I wanted it to turn out well. My mother spent her time on helping me as I could not work on it alone. We worked together until the next semester. I was concentrated on working. I forgot about the internet and games for a long while. My mother also came by taking care of me and arranged my schedule so I could stay away even further from gaming.

My Senior Project related to the observation on Asian Open-bill Stork’s behavior. I chose two places (water bodies) in the current University to observe them. When my mother and I observed the water body, we found out that it was a peaceful place, which was the opposite from when I was with my friends in classes. I had never met such peacefulness before. When I was observing storks, I took chances to see the behavior of people and animals apart from the storks around the water body. Furthermore, I could spend more time talking with my mother. When I thought about that time, I could remember that I did not have any nostalgia about people or entertainment I know on the internet.

From the narrative story, internet usage had both positive and negative results. The positive ones were to relieve the user's stress and to use as the data source needed. The negative ones, however, were when the nature self was not self-managed, other aspects of user's life might gone bad, such as poorer grading results, poorer relationships, etc. When autistic users were using the internet, their parents could not abandon them, but rather spent more time with them and gave them the correct suggestions to prevent the issues as it happened to me in the narrative story to occur to them.

5.2.4 Valuing the feelings of a mother to a child

Figure 5.13 Me and my mother

People who had not experience to being stigmatized might not understand how the stigmatized ones live their lives while they are under pressure and pain from being mocked, accused, and scolded. When my mother acknowledged the feeling from being directly scolded by my classmates, she was so angry. As she looked at me later, she realized that my intense toleration was the key I used to survive all the previous stigmatization, she had to try and mimic me, as the narrative story went;

> *"I can remember clearly that I was extremely angry with this friend of yours, Jib, but as an adult, it's improper to react. That's why I tried to control my emotion. At that moment, I repeatedly asked myself that I just heard them scold Jib for the first time and I was that angry. What about my daughter? Being teased, named, and reviled for her whole life, yet she had a strong, persistent mind which could overcome all the*

> *negative obstacles, actions and words to this day. So I have to emulate you by being tolerate with the scolding instead of immediately react like I previously did. There was one thing I want to tell you. You were my model of tolerating to overcome the obstacles.* (After talking with the researcher, she smiled in tears)*"*
>
> Mother

From the narrative story, my mother directly faced the scold about my disability in which angered her a lot. On the other hand, she realized that I also faced the scolding and the stigmatization my whole life, yet I still could keep on living. That fact said I had more toleration than her, so she praised me as her tolerating model to tolerate on her own obstacles.

5.2.5 My father's Overcome sadness by giving chance

About this, my father also interestingly added *"I wanted Jib to have a chance to prove yourself that you can be acceptable from each scholarship you're going to take, because granting a scholarship will increase your confident to help benefit the society in the future. As the word we, I mean everyone in the family wants you to have the chance here for you'll no longer be the society's burden but rather become the society's benefactor. Receiving the scholarships mean asking the society the educational opportunities to learn and have a job. As soon as you get a scholarship, it will prove that it works as a laissez passer to guarantee you a job in the future. That's why we wanted to work on it since the beginning. At the same time, you will be more confident to work in the society. Now that you were previously rejected from the scholarships you applied. It can be referred as the society hasn't accept you just yet so it didn't give you the opportunities, but there's still hope as long as we don't give up. We will keep on believing that. And one day, the society will accept you. Even if it isn't Thai society who accept you, that's fine. If we have a chance, we will challenge abroad scholarships for the country giving opportunity to the group of disabled people, like Scandinavian for example. They are more possibility to accept us, and we may proceed our way there. I think the challenging for scholarships was also what I had been experienced to as an opportunity to get one for my Master's Degree's study. Granting a scholarship can be seen as a chance for a person to get the* *opportunity from the society he/she lives in. So, putting an effort to persuade one's self was a challenge. The example for this was Jib's sister who could grant the Australian's government scholarship. That's another chapter to prove that a person can persuade one's self to get chances for getting good careers. So, you might have her opportunity somewhere ahead for yourselves. In the meantime, your brother who had been graduated earlier might need a few years of experience. Then I will persuade him, too. So, granting the scholarships is an opportunity of life, especially of you in which having such a laissez passer like this will be more significant compared to the others, for normal people without granted scholarships or the opportunities from the scholarships would still get the opportunity from the society they lived in to make their career paths in the companies, department stores, or governmental officials where normal people are always accepted even though they didn't have their granted scholarships, right? On the other hand, the authorized people in scholarship boards should give more chance to the group of handicapped people. In other words, being handicapped people should be more acceptable as they can work like normal people could, and sometimes even exceeded the capability of those normal people. It will be your opportunity to step into the working society to help the society as a whole. As it can be concluded, the scholarships granted to this group of people can be even more significant comparing to those granted to normal people. An opening chance to the society, it gave more opportunity to this group than to normal people. It's because normal people had a lot of pathways to their opportunity, but the group of handicapped people had just a few chances to be accepted. Proving themselves via the scholarship's challenging means that they had enough capability to grant the scholarships. Here, scholarships would be good opportunities to this group of people. Getting the scholarships would be a good thing, and excellent thing indeed."*

Father

The impairments and the educational self-proof

I had proved that my impairments were not the academic obstacles. From a child with no future, I could study until I graduated a Bachelor’s degree and received the certificate because I was always got the encouragement from my family.

> *"How many handicapped people will have a chance like I did in the joyful day like that day? Think about it, from a child with invisible future like me who could not tell any needs even the most basic one like secretion. My parents could only hope that I could tell my needs. Today, I could prove to everyone that "Handicap isn't the obstacle to studying. If they get opportunity, support from people around them and general society, they could have the brightest day like I have today".*

5.2.6 Lesson from the Environment

Figure 5.14 Observing me aside the water

One day, when I was quietly observing the Asian Open-bill Stork's life, there was a stork arriving near the observing point we were at. That stork landed on one leg and jumped around the area. At the moment I observed it foraging for food, it immediately used its leg to jump and hide under the bridge because of a random startle. Having only one leg caused it to struggle to live on foraging and defending itself to avoid the danger. The bird's action I saw gave me an important remark,

> ”*Even the bird was refusing its own misfortune. No matter that it has only one leg, it tries to survive. Should I give in my misfortune for being born with a handicap? I have to try harder to be tolerant and overcome my struggles to successfully reach my dream.* "

The Researcher

CHAPTER VI

CONCLUSION, DISCUSSION AND RECOMMENDATION

This study, Just a Person Walking Slower than the Others, but can Reach the Intended Destination: The Narrative Story of a Person Overcoming Autism has the objective of portraying the experience of a woman with autism, to create a new meaning for and a new understanding of the word “autism”. It includes details of stigma, discrimination, and the strategies of coping and resilience as necessary life skills, including ways to overcome physical obstacles. This is a narrative study which aims to study the researcher’s story about the provision of meaning, stigmatization, coping and resilience as it relates to issues of disability.

The methodology I chose in my study consists of in-depth interviews, participatory observation, and narrative story-writing. I chose to conduct these interviews and observe the participants to collect the necessary data from my key informants, which are my four family members, before writing the data into my life narrative story. The whole process went on for six months from the beginning of the interviews until all the necessary data was collected.

6.1 Conclusion

6.1.1 My life: A person who lives with metabolic bone disorder and autism

My family and I can be considered a case study reflecting the experience and struggle with disability issues and stigmatization. They discovered my condition when I got my spinal surgery at the age of about two years. Now, I am 25 years old. My physical body has changed from a regular child who was skinny with an unnaturally big head and weak muscles, to a small-sized adult, compared to others. I have not grown any taller since I was three years old. I am weak and have slightly bent legs, due to the disease and treatment, am chubby and have breasts. My arms and legs are hairy and I have menstruation. Some of the symptoms are from female puberty which made me different from other people who have the illness, but without the changes associated with puberty.

At present, my disability management consists of medical, family, and social help. In order to make everyone in society able to accept me, I had access to the educational system because my parents wanted me to have the same experience as other children my age. They also wanted to improve my brain’s potential, since my brain was the cause of both my diseases. I have graduated with a Bachelor’s Degree of Sciences and I am studying for a Master’s Degree. I have had the chance to join the family’s activities like other members as much as my limitations would allow. My parents, including others in my family, had always supported me to live on by raising me, paying for medical care at hospitals, and ensuring I had access to the regular educational system. Meanwhile, my family and I experienced discrimination, misunderstanding, and prejudice from others in society.

6.1.2 The Experience of Stigmatization

With my obvious physical limitations, I have experienced stigmatization in various forms from society, including in academic and medical fields. This has featured examples of direct stigmatization such as using mockery and insults, disgusting expressions, deprivation, and devaluation. In the medical society, they said that due to the diseases I had, I might have a short life span and might fail to have a relationship with society, leaving me unable to live within it. This was not only a warning, but left me with the impression they would not make as much of an effort to help me because it was not worthwhile. There were times I saw disgust because of my “ugly” physical body, as they saw it, and I was rejected from their activities and competitions. This lowered my self-esteem, left me feeling unworthy and resulted in self-stigmatization. There was also courtesy stigmatization to related people which are everyone in my family, especially my parents who were also stigmatized by the society. I blamed myself for being born abnormal, and the letter detailing my disability was used a “weapon” to attack my mother’s emotion. I saw and judged my abnormalities as only the limitations and defects which could be improved, yet my family was also caught up in the “scandal” for having me as their child. This is despite the fact they were not actually related to my disability in the slightest, according to the theory by Birenbaum (1970, 1992; as cited in Ali et al., 2012) which said that stigma and stigmatization does not affect only the targeted individual alone, but also surrounding related people. So, the family of the disabled person was to be blamed and must be held responsible for the disability they were claimed to “cause”.

6.1.3 My Family’s Adaptation and Coping with the Stigmatization

My family and I adapted to the stigmatization by accepting the issues on my physical body and the sickness needed care. Meanwhile, we had to accept that, no matter how hard we explained to society, we could not change everyone’s attitude about people with unusual appearances and learning processes.

As the above truths were accepted, my parents would focus on correcting or working around my physical limitations, caused by the metabolic bone disorder, and the difficult relationship to society, caused by being autistic. They searched for medical treatment that suited me. They gave enough time to train me and learn about my limitations to correct them as much as they could. They assigned roles to increase understanding among the family members. The most important adaptation was the acceptance and belief in my potential, and that I could, if I had the opportunity to improve, live to the fullest and the best of my ability.

Regarding the autistic condition, before attending secondary school I failed to understand about stigmatization and the feelings after being stigmatized. Because of my reception problems, I did not have to cope with stigmatization in my youth. However, after I steadily became healthier and started to become clearer in my thoughts, in secondary school and university I could perceive the idea of stigmatization and realized when friends, teachers or others in society were discriminating against me. So, I had to cope with my feelings and changes, and also had to correct the issues from stigmatization. This was done with constant help from my parents, from their lessons to build my concentration to manage my feelings and from the lessons I learnt from the natural surroundings, so I could cope with each type of stigmatization and prove my own capability to everyone.

6.1.4 Positive Resilience

My parents tried to be optimistic by consulting with respected monks, researching medical and educational information, and teaching me to be optimistic like they were. Moreover, they rearranged their priorities; my mother resigned from her career to take care of me, while my father would dedicate himself to working alone for family, and they explained my abnormalities to my other relatives so they could help take care of me and solve my issues.

My own positive resilience came from being surrounded by supportive people's encouragement, such as that I received after surgery, my friend who always soothed me and helped me, the support from my family about the scholarships, the encouragement from cyber world, from my teacher, and from my close relative when I felt despondent and could not cope with the stigmatization on my own. Apart from the encouragement I have got from surrounding people, I also adapted myself with more methods like joining the activity with my family who constantly gave me their love, refusing to give up on me, and learning each lesson from the environment around me.

Believing that I have potential that could be improved to a positive person is one of the necessary resilience methods to make me feel better, and was a great motivating factor to support myself to live on.

Taking me outdoors and living like everybody else forged my confidence that, even though I am slower than others, I had the same capability as everybody else in the society.

6.2 Discussion

6.2.1 The Contested Meanings of Disability

From the narrative story of my life experience as a handicapped person, the meaning that can be ascribed to me can be categorized into three definitions; medical, social, and self-definition as followings.

6.2.1.1 Medical Meaning onto Disability

Medical definitions and meanings stated that patients with autism, caused by the malfunction in the part of the brain which manages the language usage and emotion, would have deprivation in communication and social living. Moreover, the patients would have delayed development, for they might not be able to speak but rather be childish all the time, have repetitive behavior and a very low interest in other things. Without rehabilitation, they could not live in society. Furthermore, such characteristics might lead them to be at risk of lethal danger. All these definitions agreed with DSM-IV's diagnosis criteria, stating that autistic diagnosis followed these orders of condition: 1) Abnormal behavioral expression, 2) No friendship reaction, 3) No interest in the surrounding environment, 4) Cannot use verbal communication or started to talk late, 5) Communication failed for they could not communicate in verbal language, 6) Lack of imagination, 7) Repetitive behavior, and 8) Developmental delays that are noticeable in the first three years of life (Pramote Sudpitch & Manote Lortrakul, 1997: 10; as cited from Gunvipa, Wajjanin et al. 2003).

Patients with metabolic bone disorder, especially with Skeletal Dysplasia type like I am, caused by the lack of calcium and vitamin D since the fetus stage, have porous, fragile bones. Bones would grow abnormally, making them shorter in figure than regular people. Most importantly, the progression of the disorder would reach the point that the skeleton could crumble down and apply pressure to the crucial internal organs, ending the patients' life sooner than expected.

So, from the diagnosis of my two disorders above, the doctor forecast my disorders might significantly shorten my life as they were impossible to cure and I needed to be under specific care and treatment from the medical experts for life. I also had difficulty in living my life and letting others take care of me. My parents had to face more struggles in taking care of me all the time. Most importantly, if I was not taken excellent care of and treated properly, my life span might be shortened or I might be at lethal risk.

From the narrative study of my life experience as a handicapped person, I found out that even if my family had accepted such definitions on the medical aspects, they refused to let my life be defined by this alone.

My parents had accepted the fact about the medical definitions that I was affected by autism and metabolic bone disorder, which led to further research for medical treatment by studying, researching, and finding alternative ways along with receiving regular treatment from the medical experts. By this, my parents were constantly forming a deeper understanding of my behavior and condition. They also agreed to change their life roles to make them synchronized with taking care of me. With my mother as a full-time carer, my father kept on searching for more details about the institutes that would treat both disorders to help cure them or relieve their symptoms as much as possible. Finally, we met the private center doctor who accepted to treat me and help me live as happily and healthy as I could.

I have defied medical expectations in several ways, for I am now older than the age doctors expected, and have good development on my bone metabolic disorder where I am capable to serve myself. Moreover, I had positive development with my autistic symptoms, better than those same doctors expected. Now I have graduated with a Bachelor’s Degree, am studying for a Master’s Degree, and am sustaining myself, which significantly deviates from what the doctor predicted.

On the other hand, my parents did not let my treatment depend on the doctors alone, but chose an important way to complement my medical treatment along with the regular one from the city’s hospital and private center. They gave their reasons that they had given close care to me so they understood my behavior, condition, and chronological progress of both my disorders. In some cases, they refused to let the doctors make a decision on my treatment alone. For example, when the doctors suggested my mother take me to the autistic rehabilitation center to treat my condition, she found that their treatment would not help with my development at all but would instead hinder it, she decided not to take me there anymore. The next one was when the doctor suggested me to undergo neck surgery to prevent it from lethally breaking. My parents had refused to allow the doctor to perform the surgery as there would be side effects and would not make me live happily.

During the time my parents took care and treatment for me along with receiving the constant treatment from the medical experts, the disorders kept on progressing and made my behavior, condition, and physical characteristic to be even more abnormal, thus leading to limitations and deprivations. They tried to help sustain me and correct me in many ways to make me able to live as smoothly as possible where my mother would closely take care of me all the time. They even sought a wheelchair to aid me during my daily travel.

This study showed that the medical definitions had benefitted us as to make my parents accept and lead to more solution seeking. However, such definitions were not the absolute truth, for my parents refused to let the doctor make the decision alone, yet chose to make more research about both of my disorders to help me and made the decision with the doctor. For these reasons, I could become healthy and live longer than the doctors' expectations. So, if a family has a child with multiple disabilities or defects as I do, they should research the disorders the child was affected with and cooperate with the doctors and medical experts on decisions. This correlates with Dr. Poonpit Amartayakul's (2012) study, which said in conclusion that ultrasounds for pregnant women could identify the fetus' abnormalities, make the couples accepting of the need to prepare for their child's disability in the future and help correct it to a positive person as much as the couples are capable of. Yet it should be noted the same study also said some of the parents would not want to bring their children who were at risk of autism for scans, for they were afraid the children would be claimed as having psychological problems or insanity, leading to late diagnosis.

6.2.1.2 Social Meaning onto Disability

Although the medical experts had already diagnosed and defined me as a patient with both autism and metabolic bone disorder, society just judged me by my physique as a person with disability. I was considered "a person who has limited capability to sustain him/herself in daily tasks or join the society, including having obstacles in various ways and specific needs", as it says in the Empowerment of Persons with disabilities Act, 2007, clause 4 (as cited from Poonpit Amartayakul, 2012). Although my family and I tried our hardest to explain that I am a patient, we could not change or correct the society that considered me a disabled person. The definition for people with differences from societal norms is to label them as people with abnormalities and/or disabilities. Such values had long been part of Thai society and cannot be changed, erased, or edited away. So, I could not avoid being given the negative definitions as a disabled person since my parents took me in the society.

From the narrative study of my life, I found out that my parents thought that the best way to correct and improve the drawbacks was to introduce me to society via education. Moreover, I would get a lot of valuable experience together with people around my age. They had never thought to leave me at home, which could add stress and turn me into an aggressive, bad-tempered child, but when I had a chance to join the society, either kindergarten, primary, secondary, high school, during my bachelor's degree, or even the society as a whole, I found that people in each group only judged me based on how I looked. They defined me in ways that could be broken down into three categories: as a person with disability that cannot live among the society; cannot attend school; and should stay home.

Society's meaning, based on my external appearance, can be split into three categories.

1) The Meaning of Commiseration which refers to the words and expression as "*Don't make Jib study too much, we feel pity for her. It's already bad being like that but why must she also struggle to learn? She doesn't have to go to school! We can take care of Jib. Let Jib quit school and stay comfortably at home. If she goes to school, she might be teased or be a burden by peeing in the school.*" "*A child like this shouldn't be taken to school, in my opinion. It is as if you were torturing her.*"

2) The Meaning of Fear as the expression of "*Don't get near her.*""*Don't look at her.*""*Don't talk too loud or she can hear you.*"

3) The Meaning of Hatred and Disgust which referred to the expression of

"*She couldn't even hold her wee or poo. Why must you insist on taking her to school?*"

For being a bad and evil woman, her child was born uselessly deformed. "*You have a disabled child. Why don't you keep it at your house instead of taking it to the school? It's troubling the others. Even if it graduates, no one would hire it anyway, etc.*"

Although my parents' introducing me to regular society via education would give me as much negative experience of such definitions, they instead saw the importance of the truth that education would help with my development, realizing my potential and making me a positive person. They then kept on supporting, helping, and encouraging me so I could cope with and struggle through the negative feelings from such definitions and meanings given by society.

The narrative study revealed that my family members could not change the society's definitions about me, since the definitions were constructed and would remain in the society forever. No matter how much my parents explained to people their reasons and the necessity of being in society for me, they still could not make people stop or reduce their usage of such definitions or meanings. So, they chose to teach their children, included me, to have a positive attitude to me, and encourage me to see my potential and how valuable I actually was. The society's definitions could not negatively affect me after I understood my parents' teaching. Having a positive attitude to myself, moreover, could lead me to my educational success in the future.

6.2.1.3 The Family's Meaning onto Disability

Normally, the society of single, small family would consist of a father, a mother, and at least a child. The larger family would include two grandfathers, two grandmothers, uncles, aunts, etc, within a single family's household. The definition and meanings to the relative, either among cousins or elder-youngster, within the same house would likely to have some special or dominant traits mentioned, which would be different from other members.

When my mother conceived me, she wished that I would be born healthy and strong without disability. After I was born, however, I began to fall sick so often that I had to frequently visit the hospital. I was so skinny and looked as if my head was big, had bent limbs and it was difficult to walk, and could not live normally like my siblings. So, my parents had to take greater care of me than my siblings. Moreover, I could not communicate to express my own feelings or understand my family's conversation, adding to the difficulty, so they had to help me until I was capable to happily and healthily live with family. The fact that the doctor had forecast that my life might not last long also persuaded my parents to take even better care of me. They also defined me in ways that were different from society, in ways that were based on their love. Their definitions were "*a special someone* (mother)" and "*the one who needs a special understanding* (father)". My siblings also gave definitions based on their love and understanding. They helped take care of me in every way and always forgave me each and every time I did misdeeds or refused to do any household tasks. Their definitions to me were "*the one who was always forgiven* *from everybody else in the house* (sister)" and "*an exception* (brother)". Everyone in my family, grandparents, uncles and aunts included, tried to understand my condition in order to peacefully live with me and my family. Everyone also helped look out for and solve my drawbacks as much as they could. In addition, my parents also taught us siblings to love, forgive, cooperate with, and accept the differences of each other. As time passed, I was positively developed, became able to live among my family, became capable of sustaining myself in daily tasks and help lighten other's burden in household tasks. My family also saw other dominant characteristics of mine, so their definitions were used less and less until they completely disappeared.

The findings showed that the meaning was giving in the beginning by my family members would refer to the sympathy for my weak body and different manner But as time passed, the such meaning would fade and eventually disappear to find my aptitude then improve and support then I can fulfill my potential even I am disabled person. This study contrasts to the study of Prof. Dr. Poonpit Amartayakul (2012), which said that, multiple disability, such as deaf and blind, is an obstacle in education. When a child was unable to hear, the family would transfer that deaf child to another school for the deaf. When the same child went blind, the family withdrew the child from the school and let them stay at home, as they did not see any benefit for this child to study further. The deaf-and-blind child's family support in terms of education ended then. In another case, neglecting the child who could not do sport until the medical experts were met later, led to the diagnosis of the unexpected bone and muscle weakness which was hidden for a long time; the conditions eventually caused the disability to him. If the parents took better care of the child who could not do sports even if he looked healthy, they had to keep an eye on him since the beginning to prevent such tragedy from happening.

6.2.1.4 The contested meaning between social meaning and family meaning

The contrast between social definitions and self-definition is clear from the comparison of the family's given definitions and those of society. During the study, I found out the social perspective and self-perspective, as portrayed by close relatives, significantly contradicted each other as seen from the definitions and meanings, including to the acceptance of me living among society. For the meanings, it pointed out that the society gave me the negative ones. They gave me the definition as a handicapped, poor, scary, and hated person, which contrasted with the positive definitions given by my relatives as "*a special someone* (mother)", "*the one who needs a special understanding* (father)", "*the one who was always forgiven by everybody else in the house* (sister)", and "*an exception* (brother)". Moreover, people in the society still did not accept me to live among them, which also contradicted my family who accepted me no matter how abnormal I was. Despite my abnormality, my family would help me correct it in any way possible.

The narrative study of my life experience as a handicapped person pointed out that, the meanings given by my family were the important causes and factors that brought benefit to my life. I had better development until I became who I am at present, which completely contradicted the meanings given by the society. Society's constructed meaning did not accept me and wished to categorize me among the marginalized, unwanted society no matter how high my potential was since the society's defined and discriminated against people based on their looks alone.

6.2.2 The Experience of Multiple Stigmatization

Erving Goffman had defined stigma as a phenomenon whereby society rejected an individual with an attribute which was considered deeply discredited. The effect of being stigmatized, when known about or apparent, spoiled a person's social identity, cutting them off from society and from themselves. They stood as a discredited person facing a world which did not accept them (Goffman, 2009). Compared to my narrative story, this definition was not completely true, because even if I was stigmatized and devalued by the definitions and meanings from the society, saying that I, as a handicapped, was not allowed to live among the society or to study, but should stay home, or was stigmatized by mockery to devalue me into non-human animals or objects, such as "*e-here*" (the monitor lizard) "*e-yae*" (according to my peers in secondary school, it means an ugly parasite found on a mango's tree), ape, or stigmatized by teasing to devalue me by giving me negative nicknames, such as "cripple", "stinky", "*yai-tea*" (shorty), including to the stigmatization to completely devalue me into nothingness, no value left, saying "*I guess you should die and be reborn before attending my class*" and the struggle of depriving in communication so I had just a few friends at the end. Finally, I felt as if I was left isolated from friend's society as said, "*At lunch break, my friends would sit together and eat snacks while talking. I wanted to join them, yet I didn't know what I should talk about because their favorite topics were too hard to understand… That's why I didn't have any good friends with the same taste.*" All the stigmatization stated happened when I was studying. It could be inferred that the school's societies tried to devalue me, but when I proved myself by passing each grade with a satisfactory result, the devaluation decreased until it was completely gone, for I have been accepted as a capable, positive student.

6.2.2.1 About Three Types of Stigma and the Effect of Stigmatization

The concept of stigma by Goffman (1963) had given the definition as an individual with unpleasant characteristics or differences. It was used to explain a person or a group of people who were weak, slow, imperfect, horrible, and powerless. Moreover, Goffman also categorized stigma into three categories; 1) stigma from the physique, such as disabled people with amputated or incomplete limbs, 2) stigma related to mentality, such as those with psychological illnesses, criminals, and jobless people, and 3) stigma associated with nationality and religion, referring to the third-world population, including the minority group of people in any country. The severity of each category of stigma depended on the context and the constructed meanings in each society. When there were more than two types of stigma overlapping each other, both stigmas would become more severely negative, resulting in the stigmatized person to feel sorry, regret, shame, self-reject, and then rejected by the society (Pimpawun Boonmongkol, 2012). Comparing the concept to the narrative study of my life experience as a handicapped person, I found out that one category in that concept agreed with my story. That was category 1) stigma from the physique, for I had the abnormal and malfunctioned body, resulting in the fact that I could not happily live as my bent legs made me unable to walk as freely as others; for my weak arm muscles, I could not use my arms as freely as others; for being shorter as if I was a dwarf, I could not reach the tall shelves and struggled when I lived with taller people; for my failure in communication and understanding, I would misunderstand people in the conversation; and for being so weak, I always needed wheelchair to help me with transportation. The results from the progression of my disorders made me continuously affected by the society's stigmatization. These were my defected abnormalities that were called "stigmas". So, it could be said that my story had agreed that I had only one type of stigma as categorized in Goffman's concept. People in the society could clearly notice my stigma by their bare eyes that saw me, and stigma could affect the stigmatization for people in the society could not accept me, either in educational deprivation, disgusted expression, harassment, insults, rights loss, or discrimination. Sometimes, I could not cope with the strong effect of my own stigmas and society's stigmatization anymore. At last, I felt sorry and regret to my own stigmas that I self-stigmatized. Yet I still had my understanding family who always helped turn my heavily distorted mental state back to normal, giving me the positive point of view to myself and be capable to cope with the next stigmatization that awaited me.

This findings show that Goffman's theory can be applied to my case and other cases of people with abnormalities. The guilt and stigmatization does not affect me as much when I have a better vision of myself. Stigmatization cannot hurt my feelings anymore.

6.2.2.2 Appearance and Stigmatization

Most people do not want to socialize with people who are abnormal. Abnormal people are stigmatized, devalued and treated unequally. People who socialize with abnormal people are also devalued and stigmatized and might also receive unequal treatment. People pass on stigmatization and devaluation to their descendants by telling them to socialize with people who are similar or better than them, not with those who are worse or abnormal. Social animals normally reject one in their own species if it happened to look different from the others and expel it away from the tribe. So, I think it is the natural instinct in human society, too.

From this study, I have also found out that my body is a great disadvantage for me with all of the illness and abnormalities I have. This resulted in people not wanting to socialize with me as they will also be stigmatized and devalued. Together with my impaired socialization skills from autism, the stigmatization and devaluation is worsened. These are some samples of stigmatizing and devaluing words: "Cripple", "waddling duck", "ape", "gimpy" Moreover, they think that people with disability should be kept at home as they could not study, making trouble the other and no one hire though they would graduate.

Therefore, my abnormal physical condition has been causing stigmatization to me my whole life. If I accept this stigmatization, I will feel guilty, inferior and finally isolate myself from society. On the other hand, when my family and I understood social stigmatization, we tried to improve and correct my behaviors that contributed to the stigmatization. My family also enhanced my potential to make up for my limitations and overcome them. I was able to build a better identity for myself to be better accepted in the society.

This study reveals that appearance has a direct effect on stigmatization. People who do not have the desired appearance like me are stigmatized. This finding is the same as the finding in “the Studies on Disabilities according to Health Society Concept” by MG Ubonpun and Assoc. Prof. Penchan (2007). Their studies stated that the concept of stigmatization is based on differences and reflects judgement and evaluation of people who does not have desired appearance for the majority. The studies further stated that the more different the stigmatized person is the worse the stigmatization became. The same studies also added that healthy people claim that they are more capable and faster than those with disabilities, therefore, feel superior and try to make disabled people feel devalued.

6.2.2.3 Forms of Stigmatization I have Experienced

The lives of people who have undesired appearance are stigmatized. If those people also have undesired behavior, they will experience more stigmatization. Those people finally feel that society has devalued them.

From this study, I have found that my undesired appearance caused stigmatization in many forms.

- Verbal stigmatization by calling names, ”teasing words for example Cripple”, “Gimpy”, “Wadding duck” “Ape”, “*e-yae* (according to them, it means an ugly parasite found on a mango tree)”, “*e-here* (the monitor lizard)”

- Observing stigmatization by judging me from my appearance. Every time I change school, many teachers thought that I cannot study judging from my weak and slow appearance. My mother felt uncomfortable every time people looked at our family.

- Criticizing stigmatization by talking about me when they see my appearance. For example, “What’s wrong with her?”, “Why is she so small?”, “Is she an adult already? But why is she so little?”

- Discriminating stigmatization by not letting me study in their school, join their program or receive scholarship though I passed the entrance exam. This is a form of discrimination by not letting me have what I have the right to have.

- Marginalizing stigmatization includes emphasizing the disabilities and devaluing my dignity by saying that I should die and be reincarnated before I would able to study.

The stigmatization I have experienced conforms to the study about the stigmatization to people with intellectual deficiency (ID) by Werner, Corrigan and colleagues (2012), which stated that people who are mentally challenged may experience bullying, being stared at and being ignored by people in the society (Pratt, 2010), the deprivation of social services, including being made fun of or shamed by poor medical services, such as public bathing, losing privacy, and having limit on environment that non-approved for people with intellectual deficiency (Jahoda & Markova, 2004). It also agreed with the study about the specific schools for disability in Thailand by Vorapanya and Dunlap (2014) that teachers related to this study said that children with intellectual deficiencies were deprived of study in regular schools, pushing them to study in specific schools for the disabled. And the reason the teachers ended up teaching here might be because of the bond of “destiny” between them and their students since the “previous lives”, so the teachers had to help them in turn. Lastly, the study of the situation in the development of the quality of life of women with disability in Thailand by the Office for Empowerment of Persons with Disabilities, National Ministry of Social Development and Human Security (2013-2016), stated that women with disabilities were prevented from studying. Women with disabilities tended have lower educational qualifications compared to men with disabilities. So, they lost their opportunities to study, had occupations, and work for sustaining their lives. These women worried about their safety and sexual abuse when they were outdoors, tended to be unable to access reproductive services and treatment, had no capability to get pregnant and nurture their children. Moreover, the expectations of the patriarchy had deprived them of many of their rights since they could not meet the expectations of the socially imposed role as wives and mothers. Finally, even if their capabilities were equal to normal women's, the attitudes of people in Thailand resulted in women with disabilities being hidden or erased.

6.2.3 Coping and Positive Adjustment Strategy

When parents have a child, their main responsibility is to make sure the child survives. However, if that child has disabilities and needs special care, the stress and the burden will be worse. Parents have to find ways to adjust positively to raise that child with special care. Therefore, parents have to find ways and methods to look after their child to reduce stress. However, just bringing up someone to be able to survive does not complete the life of a person. The family needs to educate the child to socialize as well.

However, the disabled child will experience obstacles in socialization due to stigmatization and labeling. The more visible disabilities the child has, the more devaluation, stigmatization and labeling that child will experience. Socialization will cause tremendous amount of stress for the disabled child and the family has to help that child and cope and adjust positively. Positive coping and adjustment will help reducing stress of family members and the disabled child. In the end, the family that can cope and adjust positively can socialize and live in the society again.

The coping methods can be compared with the individual strategies and mechanisms to cope with problems and stress of bringing up an autistic child from the book "Stress and Coping Model" by Lazarus and Folkman (1984; as cited in Benson, 2010). The researchers categorize coping strategies into two main groups, problem-based coping and emotion-based coping (Benson, 2010).

Positive adjustment is another component in coping. Positive adjustment process is revealed to be the consequence of the interaction of various factors from individual hardship experience (Erdogan, 2015), and more details were added in Luthar, Cicchetti and Becker's group (2000) which gave definition to positive adjustment as "a dynamic procedure covered with positive adaptation under significant suffers". It was necessary to know the factors causing adolescences to fall into stress, as well as defensive factors that cause improvement and supportive for positive resilience (Anghel, 2015). Therefore, my parents upon knowing that I have two disabilities which contradict each other and compound the problems, obstacles and difficulties in raising, caretaking, and treatment. To survive, my parents have to cope with all the problems I have no matter how much stress those problems cause. My parents adjusted by searching for information and solution to my illness. They incorporate their caretaking with medical treatment to relieve my symptoms and illness as much as they could. The coping procedure and mechanism that my family adopted to help can be described as follows.

6.2.3.1 Coping with disabilities: Emancipatory Process

A) My family Coping

From the narrative study, I have found out that my parents have to dedicate so much in raising me. They also have to consider my needs more than my siblings' as I have metabolic bone disorder and autism. I have to go to hospital often. They have always been observing and learning about me. They have also been adjusting the environment around me to be appropriate for my conditions and development. During their research, they found out that a private clinic can cure the source of my illness and took me there. Moreover, they constantly study about my conditions to solve and cope with prospective problems. I think the way my parents raised me is good as they could respond to most of my needs and keep me healthy until now.

I have also found out from my narrative story that my parents had negotiated with many teachers who did not want me to continue my study in the same school. They also tried to explain the importance of education to my development to other teachers and parents. I think trying to keep me in normal school was the right thing to do as we have equal rights to education to develop our abilities.

Moreover, I have found out that my parents tried to develop me without expecting any return. Their method was developing me through education which is the stage that I can prove myself and give myself value. They also pushed me to get scholarships to prove my abilities to the society and improve my employment opportunities. Planning to have a good career is the right way to build a good future as it provides value and stable life for a person.

The way that my parents coped with their emotions are blaming other things, ignoring negative feelings and controlling their feelings when they cannot ignore them. I think that their methods only work in short term as they can solve their emotional issues at the time but not in the long term.

This study revealed that the methods my parents used to cope with my conditions enabled me to be able to live life like others. Their methods conformed to the study of adaptation and positive resiliency of families having a child with disability by Summers, Behr and colleagues (1988). The book said that a good method for a family to cope is more about personal perspective than the actual situation. It also said that the family can cope the best if they can explain the reason for the situation, control the situation and enhance their confidence when they can respond positively to that situation. This is because the challenge management for people who have abnormal child is communication and negotiation skills. The support from the society or network can respond to feelings that these families have in common and encourage each other to give better care to their disabled child (Summers, Behr and colleagues, 1988). In short, parents use the same method in raising normal and abnormal children. The only aspect that my parents do not have in common with this book is the book said that when parents can accept the disabilities of the child and love the child for who he or she is, they will not have to change anything. My parents, on the other hand, accepted my abnormalities but still try to improve and develop me.

My parents tried to protect me from stigmatization in order to avoid negative impact on my mental health by not telling about bad stories from the past. Many of the stories written in this thesis I was not aware of before or could not remember it. However, to write a good narrative story, my parents had to tell me everything though that was against their desire. They could not avoid getting emotional during the interview. They sometimes cried or needed a break during the story narrating.

On the other hand, my parents seemed to more relaxed and relieved after those stories were told. They were so worried that I might not be able to handle some of the stories. Furthermore, I was able to analyze the stories and turned the thesis writing process into emancipatory process from social stigmatization. Such process cleansed all the negative feeling after the stories were narrated to the public via this thesis. I hoped that this thesis can help families with disabled members to cope and free themselves from stigmatization.

From the narrative story, I have proved that I could emancipate myself from social stigmatization. In primary school, I emancipated myself by proving that I could study like other children at the same age. In high school, I proved that I could do field trip and camping with friends with my mother’s help. In university, I have proved to the wider society that I could graduate from a top university in Thailand.

B) My Self-coping

This study showed that I have had the chance to study in many institutes which is important for my development and a chance to prove myself to the society. I believe that Regardless of my disabilities, I have the right to education and it is the right method for me to gain equality in the society.

I have experienced changes my whole life which affects how I live and socialize. My changes are physical and social. I was born a normal baby but grew up to have disabilities by social definition. My social change includes my parents who tried to take me to socialize by having activities with people outside family and schools. I have to cope with many obstacles all the time including my sad, stress feeling.

My coping strategy for my sadness is detachment from my feeling. When it cannot be ignored, I have to control it. I also found out that when I cannot solve the problems or control my feelings, I would cry to let out my sadness or become quiet until the problems are solved by other people, which is mostly my mother. She will try to comfort me from my problems. In short, I need encouragement from people around me to cope with sadness from different situations. I think this is the right method as it helped me emancipate myself from the social stigmatization and restriction. I also think to can help me become a stronger person and able to cope with the same situation in the future.

Moreover, I have also found out that my coping strategy with my stress is to do relaxing activities, such as drawing and reading novels. My favorite activity is playing games. It can help with my stress the best. However, when I cannot relieve stress by myself, I would get help from people around me including my mother and teachers to help me solve the problems and to listen to me.

Finally, I found out that using things that I can find easily around myself to relax is the method that other disabled people use as well. For example, I only need pen and paper to draw or read novels that I have any time. Support from people around them is also important when they cannot relieve the stress be themselves. Once the stress is relieved, the disabled people would be able to cope with labeling much better.

6.2.3.2 The Positive Resilience of People with Disabilities

A) Family's Resilience Strategy

I have found that my parent have never given up to me who was diagnosed by the doctor that I would probably has a short life. One of their coping was seeking help from different sources and information. I found out that consulting the respect monks my mother did could help. She felt relieved when one of them told her that "the child would be freed from Karma". This is the moral support which will help someone who do not know ways to solve with the hard situation. Moreover with the help from the monk suggestion, my parent could find significant medical treatment which can help me to prolong my life until now.

From the study, I found out that after knowing the reasons for my developmental delay, or autism, my parents then created a learning group to share their knowledge they got from their separate studies and to observe more about me. My father sought information and facts from various sites' database to adapt them to his care-taking methods, both from library books and from medical expertise. Moreover, he also told my mother to accept the truth of what actually happened to me no matter how bad it was, and told her to keep on taking care of me. They had to accept it and train me in accordance with the conditions I had. When I had grown up, I could show my mother that I could be her tolerance model. I think that, observing and understanding among my parents were good actions for children with delayed development tended to have specific needs of care from their family members. So, the family needed to acknowledge and understand the same things as they are very important for a family with a member having developmental delay. When they knew the reasons I had developmental delay, they could know my specific needs. When they knew my specific needs, parents like mine could more easily research about taking care of me to make me happier. When I grew up, I could be their models for some topics.

Moreover the study illustrates that a mother would be the best person observing and learning about, then improving her child, for the mother of a family takes her role on taking care of the child and be the one who understands the child the most. So, my mother who was close to me, and understood me the most would be the best one observing me, learning about me, and improving me. She also believed that, every child needed education no matter how abnormal they had become, and education was necessary for life's chances in the future. For that reason, she resigned from her career to take care of me at school, to make sure I could study there smoothly without being hindered with obstacles. She would talk and make people understand, then give the value to my capability to communicate for communication would be the gate to overcome my autistic self. Furthermore, choosing a secondary school for me had a lot influence on my development for my parents did not want me to attend any specific school for the disabled. They did not see any academic lessons being taught there, so they chose a regular school for me. In the secondary school, I participated in the bilingual program, so it taught me and improved my skills in a second language. I think that, rearranging my parents' priority for having me as an abnormal child was what they should have done, because children with abnormalities needed special kind of care. Their parents then should prioritize their children to take care of them and make them happy, resulting in them being happy as well.

I found out that my mother had created positive value to her feelings toward me. Moreover, since I learnt at a slower rate than normal children, she taught me with patience, calm, and understanding. She also sought chances to manage each issue before it was too late and the issue would be too hard to solve. When I encountered a problem at school, my parents would turn themselves as teachers to teach the problematic lesson to me at home and to feel my struggle to persuade me to get the chance to study at school. For example, they refused the principal, who knew me for only a short time, who was determined to get me to study somewhere else. They had dealt with the principal to make her change her decision into letting me stay under her conditions. Later, they took me to get the treatment at the private center, using the newly discovered remedy which had a high cost compared to regular medicines. That center was providing the treatment that could eventually improve my sickness from both disorders. My father voluntarily paid for high-cost injection type medicines for he wanted them to keep on treating me. Furthermore, they were also interested in my femininity, especially my natural reproductive health. In the time of major flood, my family had to greatly adapt themselves to guide every member to overcome that critical time. I think my parents took care of and taught me the correct way. Therefore, the results from their teaching made me a person with good quality of life.

Moreover, I also found out that my parents believed a thing about sickness. They believed that every sickness could be improved despite the fact that some could not be cured. From the Buddhist’s belief about reincarnation and karma, they, as Buddhists, also believed that doing good deeds in the present life will help make better in future life, even if no one can alter the previous one. With all their beliefs, they were determined to seek good academic institutes that suited me to support my development on for they believed that I also had the same right as my siblings had. Finally, my parents also trusted themselves not to give in to people’s disdain, and had faith in themselves that they could make my life better. I think all the beliefs they had were good factors to bring about their adaptation to my disorders. When they believed those things, they would have their encouragement to continue taking care of me.

The narrative study of my life experience pointed out that, the methods of resilience my family used as stated above can be compared as the self-encouraging they used during the care-taking to me, their daughter with abnormality. The methods consisted of using religion, changes within the family, and their beliefs. It agreed with the study about the resilience of the families having a child with autism by Van der Walt (2006), summarized as, support from relatives and friends, quality of communication within the family, and reliable seeking were the best methods of resilience for families having a child with autism.

B) The Self Resilience

I found out that my family was a group of people giving me their encouragement each time I was under treatment. The encouragement from surrounding people after taking the leg surgery and taking the body cast off; either my relatives, good friends, or my own family. Cyber society I visited in my leisure time, especially when I was left alone, also have a group of users who gave me their encouragement. Telecommunication allowed me, who struggled to travel, to contact my friends, who worked in the same group as me, from my own home. At school, I had a group of good friends consoling me and helping me when I was mocked and teased by the group of bad, so-called friends. I had my family's encouragement on taking scholarship competitions to use the grants as proof of my capability. The encouragement from the society of the cyber users, teachers who taught me, and my own family, were so important to my positive resiliency in order to restore my distorted mental state back. Accessing the cyber world gave me the chance to meet and know each society of users there. When I wanted encouragement to soothe and heal my broken mind after I faced suffering and stress, I would seek for it from people closest to me at that moment. The most important one was when I was about to graduate my Bachelor's Degree. I bid farewell to my colleagues who passed all the happy and sad times in those four years with me, not expecting the positive response. Yet I saw some of them, who used to do bad things to me, apologizing to me in that day, so I acknowledged that they wanted to tell me how sorry they were before they missed the chance. I think that the encouragement I had got so far will be the significantly important factor to my resiliency, as it was stated above that it could heal my mental state.

From the study of the narrative story, I found out that I had received love and understanding from my family each time I met or lived with them. For example, my grandparents loved and had mercy for me. My grandfather even took me to the market almost every morning I stayed with him. Moreover, I had joined festive holidays and vacation with my family, then I even traveled abroad with them to see more of the world, which made me really happy. Furthermore, everyone in my family had been mocked at some point in their lives, so they taught me how to cope with mockery by ignoring to end my friend's mockery. I think love and understanding between the young individuals and their families occur by instinct, when it occurred in families having children with abnormalities, it would be a really good moment.

I believe that the Royal Award I received was proof of having faith in myself. Moreover, my defectiveness was my persuasion to prove myself all the time. The study had shown that my parents had given me their support. I think that my effort which originated from my faith in myself was a good thing for it can lead me to success.

Previous teachings to me in my life also had their effects in my adaptation and resiliency. I was taught by my parents to choose the beneficial and harmless information. They also taught me that people who mocked me were unhappy people and to not worry about it, but to keep concentrating on learning at my best to yield the best results possible. Lesson and moral I got from the natural environment's observation made me think about the struggle of life living in solitude to in order to survive. I think that the lesson from my learning might benefit me.

6.2.3.3 Factors of the Handicapped Person's Coping and Resilience

From the study, it is demonstrated that crucial factors of my positive coping and resilience was a family who always sought knowledge to take care of me. My parents searched for more information about my disorders and treatment. My mother would observe and learn when she was taking care of me to seek the best care-taking methods for her. Meanwhile, my father would research from the library and various doctors. When they did not understand nor had a question about taking care of me, they would consult each other and share the information they found. It pointed out that their knowledge seeking for sharing among themselves when they had a question about care-taking was a very good factor. For I had the abnormality, so I needed a different kind of care compared to regular children. Moreover, the consulting they made helped encourage them to take care of me, which agreed with the study of the relationship between each of the care-taking factors and maternal happiness of Thailand's mothers having a child with autism by Chayamon and Renu (2005). This said that many of the mothers in the study had their husband and close relatives helping them take care of the autistic child, giving them encouragement and support physically, mentally, and emotionally.

From the narrative story of my life experience, I found out that my parents had understood that my disorders were not be able to be treated, my father said when the truth was accepted, they would be able to seek the method to take care of me and actually do it to make me live as happily as they could, and that would give them happiness in return. This points that the truth acceptance to make a care-taking plan was a very crucial factor, as it agreed with the qualitative study in families having an autistic child in Canada's urban area by Hoogsteen and Woodgate (2013). This found that, according to the sample in the study, an autistic child would be the family's center, and the parents in the sample would do everything they could with everything they had to support their autistic child's needs without considering their own. However, this contrasts with a study about families having a child with high-functioning autism in Australia by Gray (2003), which said that the fathers would not have a major role in care-taking for they worked outdoors as their tasks, and taking care of a child was the duty assigned to the child's mother. So, mothers of autistic or Asperger's children would be responsible to take care of each issue relating to the children, either at home, at school, or at hospital. Fathers seldom would join mothers and children in the activities, yet they would for the activities that required no social participation.

I found out that my mother wanted me to get the exact same experience as my siblings. Later, after seeking information about autism, my father believed that if my brain was treated, my autistic condition would eventually be cured. He also believed that having an education was a method to improve a student's brain. For that reason, they tried to persuade me to keep on studying as much as I was capable of.

The study demonstrated that, my parents wanted me to have the experience of joining the society to develop myself and improve my academic and career opportunities in the future, so they persuaded me to join the society and gave me their support to study. These desires were good, for the desires that would lead to persuasion to me to form a better future. They agreed with a study about coping with stress and maternal living of mothers having autistic child found in Massachusetts, United States of America by Benson (2010) that had a sample consisting of autistic students. From the total of 142 students, 76% of them studied in the regular class and 24% were in the specific class. A consensus study of Ireland's population by Gannon and Nolan (2005) revealed that the education level of the patients with chronic diseases or with disabilities depended on how severe the diseases or the disabilities that interfered with the living life were. The more severe the disease or the disabilities of patients were, the lower the educational level the patients.

6.2.3.4 Changing the Attitudes and Perspectives

From the narrative story of my life experience as a handicapped person, I found out that, I in my childhood did not have a good perspective, yet I had people, which are my parents, help adjusting my attitude and perspective. As soon as they noticed that I began to express my feelings and began to think on my own, they were afraid that I would perceive the society's stigmatization upon myself and would feel down because of what I perceived. So, they implanted me with their good attitude and perspective, and also taught me to be optimistic, to make me be able to live happily.

Even sometimes, after I was implanted with their attitude and perspective, I could barely cope with some of the stigmatization on my own, so I needed to rely on my parents to help me solve the issues from the stigmatization for me. Their help would be their encouragement and support to correct my behavior.

The narrative story of my life experience as a handicapped person pointed out that, changing my attitude helped me to get the better perspective, which led to the correction of my behavior to make it agree with social norms. The study agreed with a secondary study of the study about the resilience of families having a child with autism who had the behavioral issues by McConnell, Savage and colleagues (2014), saying that the child's behavioral issues would agree with economic issues but contradicted social support, which found contradicted with family's quality of life.

I also found out that, after I had enough stigmatization experience so I could think on my own, I began to perceive the stigmatization and started to regret, then I even self-stigmatized. My parents were the first group of people who helped me adjust my self-perspective right after they realized that I could think on my own. So, to prevent me from feeling bad about society's stigmatization, they taught me to think positive, that I actually had my own value and potential hidden within me, to bring out my value and potential, and also taught me about the perspective of people in the society. I then adapted their lessons to my strategy of resilience and coping with stigmatization, as I had them helping me solving the issues from the stigmatization from afar. Later, my life's affection with stigmatization was eventually decreased for I had developed self-immunity.

My attitude about myself after I adapted it with my parents' lessons was, I was not a worthless person, but I had my self-valuation. Moreover, if I brought out my hidden potential, I could show people in society that I had enough capability to bring myself out of the society's stigmatization.

This study designates that, an autistic individual's attitude would be formed from helping onto the mental state by the most important group of people for the autistic individual, which were the father and the mother.

6.2.4 The importance of the family for People with Disability

Base on the narrative study I found out that even though I have been disheartened and fell into despair, love and understanding from my family were the important encouragement I have got that made me keep on my struggle on and cope with many forms of stigmatization by the society. From my experience about the stigmatization by the society for my entire life, I learnt the method to cope and be resilient, so I could cope better with the stigmatization.

It is showed that encouragement from the family was an important factor helping the stigmatized person with disability to be able to live on in the society that stigmatized him/her. So, the family was the most important group of people for people with disability to "heal" their affected mental selves caused by the stigmatization each time.

6.2.5 Empowerment in Opposing the Stigmatization

The society had decided to stigmatize the disabled people as those who lacked of capability that could not live among the society, but belonged to another part of the society where the disabled were.

The characteristic of empowerment to the stigmatization meant that when the group of the disabled people and their parents tried to give their reason in opposition to the society. If someone set their opposition by explaining to the society that the disabled people also had rights to live, learn, and stay like normal people had. Explanation would empower the opposition to change the stigmatization in two aspects. The first aspect was to deconstruct the stigmatization by opposing struggle, and the second one was to directly reconstruct the stigmatizing structure by disobeying and replacing with the new activities to set the new stand points in the society without considering the succession outcome whether success or not success.

Although the opposed one was alone, despite the outcomes, the empowerment would be with its usage when we opposed something. Even if we were alone or the usage was going to be difficult, but we did try to oppose without considering the outcome whether success. Without your effort to struggle, you would not be success.

From the study, my family had been successful at certain level that we could change some society structures, such as, I studied in the regular schools since the kindergarten to the Bachelor’s Degree, even though this could not be considered as a perfect success. From this narrative story, the result had shown the possibility to turn out positive if a person tried to oppose, but the results might turn out differently for other families with a disabled member that might not as successful as we did. Nevertheless, opposing with using the empowerment to change the social structure did not consider the outcome, yet if the disabled and their family opposed to seek for their comfort zone, social structure may positively change, no matter how small the change would be.

6.3 Recommendation

6.3.1 Recommendation to the Families with a Member with Disabilities

1. I suggest the families with a member with disabilities to oppose the stigmatization in order to change the social structure without considering the outcomes. If the opposing attempt did not conduct, the social structure would not have a change. If you see this story, I suggest you to oppose your society for a positive change for you. You can also choose the stand point that suits you and your disabled members in order to live among the society comfortable. However, the opposition was not an opposition solely for yourself and the disabled’s rights, but this was an opposition to deconstruct the old structure that marked the old role of being deployed

on the disabled people and reconstruct the structure to provide easier living with the society for the disabled, just the same as me in this narrative story you read.

2. Every member in my family deconstructed and destroyed stigmatization. They also understood that I was not a disabled person. Wherever they went, the society would recall them "You have a handicapped sister/daughter". The society stigmatized me, but my family did not stigmatize me. Instead, they called me "their special member", as the new meaning they gave to me. Refusing that I was a handicapped person but instead, I was a person who needed extra level of understandings. They deconstructed the social structure into "handicapped people and their families do not have to follow the procedural the society gave and forced them to follow". As said, my family took me to everywhere that normal people went; to travel, to eat and to feast. Even to some attraction sites, such as on the mount summit, my father did not give up to take me there. Even people asked him when they saw him with me on the summit "How dare you bring her up here?" As if the society stigmatized me, "She is a disabled person. Bringing her up here is too dangerous for her. / Don't this / Don't that". But my father did not share the same thought with the society. This was how my family deconstructed and reconstructed a broken structure for me into that "Jib is a special one, not a disabled one". Therefore, a special one should be treated especially. In travelling anywhere, if someone said, "a handicapped shouldn't be here", my father would reply, "She isn't a handicapped one but a person I took an extra care to, so I can take her here". Therefore, the families having at least a member with disabilities, this is a suggestion to you to not stigmatize that he or she is a disabled person but should change the definition into something positive meaning that you would like him or her to become. You may call him or her as a special member who needed extra level of understanding and care like my family did in this story. No matter what, you have to change the definition into that you would like him or her to be, from negative meaning to be positive one, for family and society, to make a society that provided the benefit to living in harmony with the disabled people. This is how to deconstruct for family. The outcome is not being considered to, but we acted nonetheless. From the narrative story, alter the family gave me the new meaning, we would never blame that disabled member made us become this or that, or having one made travelling even harder for one's limitations. When we did not regret, we just did

it, so we go everywhere we wanted to, but if we thought, we might not go anywhere. If you do not think that our handicapped member is disabled, you can tag him or her along to anywhere for he or she only had the limitations. Having limitations for a special member did not mean that the limits cannot be fixed out. So, this is the close relative society that the structures were deconstructed and reconstructed.

3. My father's extended family stigmatized me from the beginning of my life. They claimed that having a child like me would not make the family succeeded. However, this extended family had spoken, to adjust their understanding, with my family already, for my parents were opposing, deconstructing the old structure that stigmatized and limited me, for me. The new structure was, I needed to study and I am not the one hindering my family from being successful, but am the one that is capable to learn at certain level. From my observation, this extended family did not understand much about my disabilities, for they only saw my physique, but my family explained them about my disabilities, but not explain with too hard medical terms. My parents explained about the act of deconstruction together that they had to destroy the stigmatization on me and they had to reconstruct a positive meaning for me. As a result, the extended family began to have their positive point of view about me. I was even more accepted that I could tell when I visited them and I felt drastically better. Each member in that family has the positive opinion about me. They even congratulated me when I graduated a Bachelor's Degree, even though their family head had to rest from his recent surgery. From that point on, their points of view to me had drastically changed in the positive way.

4. My mother's extended family was also stigmatizing me. They stigmatized in the form of unintentional kindness and depended on the social stigma from their societies. They also accepted the given stigma without any opposition to their societies. So, my mother's extended family had their opinions affected by the assignment of the society. My parents, however, explained and deconstructed the meanings. This deconstructing attempt was the complex deconstruction, because my parents deconstructed indirect to the society that my grandparents lived in without my parents' direct involvement. In the past, they deconstructed the meanings from the society they lived in; their friends, their families, educational system, and people interacted to them. Deconstructing from the society

my grandparents lived in, however, was even more difficult, for my parents did not interact with my grandparents' friends at all, thus they could not explain them. So, my parents could only explain their reason that I needed to study to my grandparents. When my grandparents met and talked with their friends "Her parents thought so. They are just like that". The conversation was full of disappointing as they thought that their children would disobey adults like them. Later, their conversing moods improved since I could actually study. They started to see that I could actually study. So, deconstructing the meaning in my mother's extended family yielded a good outcome. When their friends met me, they had a positive idea about me, especially when I entered the university and when I graduated a Bachelor's Degree. That family's social structure has been greatly improved. So, I suggest the extended family of the disabled people that the social structure that stigmatized the disabled members could be positively changed by deconstruction, new definition giving, and reconstruction.

6.3.2 Recommendation to the Medical System

1 Patients and parents who interact with the medical society are not necessary to follow a single doctor's recommendation which may consider as an assigning treatment for a patient with a disorder which is the stigmatization and limiting given by the single doctor's opinion. What my parents did in the story was not to rely on only a single doctor's opinion. They rather sought for "second opinion" as much as possible, study from the actual situation, and plan the treatment schedule accordingly. Their moral precept was, as long as there was a way to further study on something, they would keep on studying. Finally, they would use the knowledge that they gathered from various knowledge resources, in this case were from the libraries and various doctors' opinions as their empowerment in opposing to choose the treatment way in the field of medical treatment and doctor's decision. So, I would like to suggest the doctor not to rigidly stigmatize your own patients, but to provide them your medical opinion and allow them to decide for their own alternative treatment ways.

2 I suggest that doctor should allow the disabled people to have their own choices for treatment. Allow them to seek for more knowledge, to seek

for the “second opinion”, and to seek from the other resources in order to finalize their own treatment solution.

6.3.3 Recommendation to the Education System

1. I suggest the school to allow the disabled students to attend the normal class with their normal peers as if those students were normal, not in the separated room or other equivalent isolated classes. The normal classroom’s society can help disabled students to develop and adapt themselves by mimicking their normal peers. Moreover, the education society should be the initiate societies that allow the disabled students to live in the same society in order to create the mutual acceptance among normal peers and disabled students. This initiate acceptance model will lead to spill-over effect in the wider society.

2. I suggest people in the educational institutes to accept that disabled students could study with their normal peers. Studying together would automatically bring difficulties. Therefore, the educational institutes should prepare additional resources to cope with those difficulties systematically.

3. I suggest the system to sincerely accept that the disabled students can study in the normal classes with the conditions that; the students must not have been stigmatized and they study in a class with optimal ratio, such as 1 or 2 of them in a class, to make them adapt to normal peers and make normal peers accept their disabled classmates. Therefore, the separated classroom should have been deconstructed, which was an enormous matter, for this was done for the disabled’s sake to study with their normal peers. The outcome was; the disabled students that learnt in the same room as their normal peers would have better developed progress, for the disabled students needed their normal peers to help improving their characters. The disabled people would normally be obstacles in the classroom society, but if the society accepted them, they could help their disabled friends to adapt themselves to cope with.

6.3.4 Recommendation to the Society as a Whole

1. I suggest the family with a disabled member to oppose its community by explaining the situations and refusing to let the community pressure them with the structure. The structure, however, must be reconstructed to the

community where the disabled could join. The outcome was, people in the community could accept the disabled better than before, for the family with a disabled member had proven that the disabled person had his or her capability.

2. I suggest parents of a person with disability to oppose and lead the person to the society, deconstruct the structure of “the disabled should stay home” and lead the person to the open society without considering the outcome. No matter what, I suggest you to try once. From my narrative story, every communities I was introduced to rejected my family and me at first, but after my family’s explanation with reasoning as they introduced to the communities, I was finally accepted as a capable person who did not give up to her misfortune.

6.3.5 Recommendation to the Government and Agency

1. I suggest the government to give the monetary support to give rights to disabled education and give the institutes chance to improve the class’ and educational buildings’ environment to support the disabled’ study with their normal peers. Moreover, the government also has to give the monetary support to remodel the educational building to that having slopes for disabled wheelchair users.

2. I suggest the government to apply the act to accept the disabled who pass the entrance exam to the academic institutes and to order the workplaces or governmental agency to accept the disabled to work at their capability.

6.3.6 Recommendation for Further Study

To the person who wants to study in this subject, I suggest to add the detail of deconstruction and reconstruction the social structure to give the suggestion to other disabled families about how to oppose in order to rightfully change and deconstruct the social structure. You can bring the narrative story up as your example to other disabled families, to stimulate them to oppose and deconstruct the social structure for themselves.

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