MOTHERS' EXPERIENCE WITH DOWN SYNDROME'S CHILD : SOCIAL SUFFERING, CONTEXT, MEANING AND MANAGEMENT

MONDHA KENGGANPANICH

A THESIS SUBMITTED IN PARTIAL FULFILLMENT
OF THE REQUIREMENTS FOR
THE DEGREE OF DOCTOR OF PHILOSOPHY
(MEDICAL AND HEALTH SOCIAL SCIENCES)
FACULTY OF GRADUATE STUDIES
MAHIDOL UNIVERSITY
2004

ISBN 974-04-5459-3

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Mondha Kengganpanich
Mrs. Mondha Kengganpanich
Candidate

Pimpawun Boonmongkon
Assoc. Prof. Pimpawun Boonmongkon, Ph.D.
Major-Advisor

Mullika Muttiko
Assoc. Prof. Mullika Muttiko, Ph.D.
Co-advisor

Supot Dendoung
Assist. Prof. Supot Dendoung, Ph.D.
Co-advisor

Rassmidara Hoonsawat
Assoc. Prof. Rassmidara Hoonsawat, Ph.D.
Dean
Faculty of Graduate Studies

Arayan Trangarn
Lect. Arayan Trangarn, Sc.D.
Chair
Doctor of Philosophy Programme in Medical and Health Social Science
Faculty of Social Sciences and Humanities

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was submitted to the Faculty of Graduate Studies, Mahidol University
for the degree of Doctor of Philosophy (Medical and Health Social Sciences)
on
December 9, 2004

Mondha Kengganpanich
Mrs. Mondha Kengganpanich
Candidate

Pimpawun Boonmongkon
Assoc. Prof. Pimpawun Boonmongkon, Ph.D.
Chair

Mullika Muttiko
Assoc. Prof. Mullika Muttiko, Ph.D.
Member

Supot Dendoung
Assist. Prof. Supot Dendoung, Ph.D.
Member

Panee Vong-ek
Assist. Prof. Panee Vong-Ek , Ph.D.
Member

Suchada Ratchakul
Asst. Prof. Suchada Ratchakul, Ph.D.
Member

Rassmidara Hoonsawat
Assoc. Prof. Rassmidara Hoonsawat, Ph.D.
Dean
Faculty of Graduate Studies
Mahidol University

Suree Kanjanawong
Assoc. Prof. Suree Kanjanawong, Ph.D.
Dean
Faculty of Social Sciences and Humanities
Mahidol University

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ACKNOWLEDGEMENT

It is a great honour for me to express my deep feeling to number of people for their myriad contributions to this study. First of all, I would like to articulate my hearted indebtedness to all of key informants who shared their intimate and private life experience in providing complete information, and specially the innocent down syndrome children who make me know the valuable life, love, and motherhood 's spirituality.

I would like to express my foremost gratitude and heartfelt appreciation to Assoc. Prof. Pimpawun Boonmongkon, my major-advisor, for her invaluable advice and professional help as an academic advisor. I am equally grateful also to my co-advisors, Assoc. Prof. Mullika Muttiko, Assist. Prof. Supot Dendoung, and my committee, Assist. Prof.Panee Vong-Ek and Assist. Prof. Suchada Ratchukul, for their constructive advice, comments and keen suggestions in developing and organizing my dissertation.

I would like to articulate Dr.Arayan Trangarn, (Chair of Doctor of Philosophy Programme in Medical and Health Social Science); to Assoc.Prof. Suree Kanjanawong, Ph.D. (Dean of Faculty of Social Sciences and Humanities) and to all the respected teaching staff for their excellent teaching, their kindness and warm relationship. Acknowledgement is also given to all of the staff of the program.

I also would like to extend my profound gratitude and admiration to Dean of Public Health Faculty, Mahidol University; to Chief of Rural Training and Research Center, and to Chief of Health Education and Behavioral Science Department, Public Health Faculty, for their permission, supporting and motivations throughout of my study.

My sincerest acknowledgement and appreciation are owed to my beloved family, especially to my beloved husband, Assoc. Prof. Tharadol Kengganpanich, for his persisting encouragement which has been countless power for 5 years and my older sister, Sr.Kanchana Singsa, for her prayer and devoting her time for hard editing. I am deeply in debt to my lovely sons, Phai and Pruk. I beg them to forgive me for not taking care of him during my five-year study. I also would like to express many thanks to my classroom's friends, Saguan, Ju, Jang, Hlan, Hnui, Lek, Tom, and Nid, for their supporting and helps.

At last, I would like to express my deep appreciation again to everyone who I has mentioned or don't mention in this acknowledgement. I keep all of you in mind and in my prayer, and ask God for blessing all of you too.

Mondha Kengganpanich

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MOTHERS' EXPERIENCE WITH DOWN SYNDROME'S CHILD : SOCIAL SUFFERING, CONTEXT, MEANING AND MANAGEMENT

MONDHA KENGGANPANICH 4237558 SHMS/D

Ph.D. (MEDICAL AND HEALTH SOCIAL SCIENCE)

THESIS ADVISORS: PIMPAWUN BOONMONGKON, Ph.D., SUPOT DENDOUNG, Ph.D., MULLIKA MUTTIKO, Ph.D.,

ABSTRACT

Mothers' Experience with down syndrome's child was studied to understand social suffering, context, and meaning and management of the suffering with the concept of Critical Medical Anthropology (CMA). The qualitative research design was operated with in-depth interview technique and observation of 18 poor mothers and 4 comparative mothers from 11 slums in Bangkok and 4 peripheral provinces. The result reveals the political ecology of poor down syndrome child mothers who lived in a vicious life cycle and social disparity according to the following compositions: agricultural occupation, poor economic status, rural-urban migration, separated family, domestic violence, sexual abuse, limitation in work opportunity, and unstable and insecure shanty. The family sphere of political ecology widens for the women whose background of husbands are the same. The grounded social disparity has effects on social suffering experience which is produced by the medical power such as communication problem between medical personnel and poor down syndrome child mother which is medically oriented, the difficulty of medical information and inaccessibility of the poor and medical moral problem of time and space of informing bad news including worthless judgment of down syndrome as abnormality. Moreover, the discriminating service such as the complexity of medical process with double standard to abnormality and poverty, the medical enormity, and operational ordering to the poor as the last were double stardards that effecting to have more suffering . Both social and cultural structure have an effect on social suffering. Firstly, the structural violence is composed of sexual violence both to womanhood and abnormality such as religious and social rules controlling and dominating the social life of women, social rule of birth control on women body within patriarchy, and operation of normative standard to abnormality; Secondly, the poverty is comprised with classification and the lack of assurance which are inaccessibility to social service and social welfare both of health and education. The result shows the different suffering management according to different meaning of having down syndrome child in each period of life experience. The different meanings are mental retardation, physical and intellectual disability, disease, slow development, incarnated disease, and genetic disease. Such meanings have influences on the following different managements: seeking information, dependence on medicine, religious and belief dependence, diluting the others, shifting from negative to positive meaning and from suffering to happiness. Finally, the results of the study come up with the recommendations to the prenatal system especially for the poor risk mothers such as the potential development of health care delivery, information development system, communication system and community participation, coverage health insurance, the medical personnel production's system, social welfare, environment support, and empowerment of the down syndrome mothers' group.

KEY WORDS : SOCIAL SUFFERING/DOWN SYNDROME/MOTHER EXPERIENCE/ CONTEXT/MEANING/ MANAGEMENT

295 pp. ISBN 974-04-5459-3

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ประสบการณ์ของมารดากับการมีบุตรอาการดาวน์ : ความทุกข์เชิงสังคม บริบท ความหมาย และการจัดการ (MOTHERS' EXPERIENCE WITH DOWN SYNDROME'S CHILD : SOCIAL SUFFERING, CONTEXT, MEANING AND MANAGEMENT)

มณฑา เก่งการพานิช 4237558 SHMS/D

ปร.ด. (สังคมศาสตร์การแพทย์และสาธารณสุข)

คณะกรรมการควบคุมวิทยานิพนธ์ : พิมพ์วัลย์ บุญมงคล, ปร.ด., สุพจน์ เด่นดวง, ปร.ด., มัลลิกา มัตติโก, ปร.ด.,

บทคัดย่อ

การศึกษาประสบการณ์ของมารดากับการมีบุตรอาการดาวน์ถึงความทุกข์เชิงสังคม บริบท ความหมายและการจัดการความทุกข์ โดยใช้แนวคิดมานุษยวิทยาการแพทย์วิพากษ์ ดำเนินการศึกษาด้วยวิธีวิจัยเชิงคุณภาพด้วยการสัมภาษณ์เจาะลึกและการสังเกตมารดาที่ยากจนจำนวน 18 คนและกลุ่มเปรียบ 4 คน พื้นที่ศึกษาได้แก่ 11 สลัมในเขตกรุงเทพมหานครและจังหวัดปริมณฑลรวม 5 จังหวัด ผลการศึกษาพบว่านิเวศน์วิทยาการเมืองของมารดาที่ยากจนที่มีบุตรอาการดาวน์ซึ่งเป็นวัฏจักรชีวิตของคนจนและความด้อยโอกาสทางสังคมมีด้วยกัน 9 ลักษณะได้แก่ ประกอบอาชีพเกษตรกรรม ฐานะยากจน การศึกษาต่ำ การย้ายถิ่นจากชนบทสู่เมือง ครอบครัวแตกแยก ความรุนแรงในครอบครัว การข่มเหงทางเพศ ทางเลือกที่จำกัดในการประกอบอาชีพและการอยู่ในสภาพสุขาภิบาลสิ่งแวดล้อมไม่ถูกสุขลักษณะ ขณะเดียวกันลักษณะนิเวศน์วิทยาการเมืองของบิดาทั้งหมดมีลักษณะที่ไม่แตกต่างกัน พื้นฐานของด้อยโอกาสทางสังคมส่งผลต่อประสบการณ์ความทุกข์เชิงสังคมที่เกิดจากการกระทำของอำนาจทางการแพทย์ ได้แก่ ปัญหาในการสื่อสารระหว่างบุคลากรทางการแพทย์กับมารดาที่มีบุตรอาการดาวน์ที่มีศูนย์กลางที่บุคลากรทางการแพทย์ประกอบด้วย การให้ข้อมูลและความรู้ที่ยากเกินกว่าที่คนจนที่ด้อยโอกาสจะเข้าใจได้ ปัญหาเชิงศีลธรรม กาละเทศะในการแจ้งข่าวร้าย และการตีค่าชีวิตของเด็กอาการดาวน์อย่างต่ำค่า นอกจากนี้ยังมีปัญหาในการให้บริการที่กีดกันการเข้าถึงบริการ ได้แก่ กระบวนการทางการแพทย์มีความยุ่งยากซับซ้อนที่เป็นภาระสำหรับคนจน การกระทำที่เป็นมาตรฐานเชิงซ้อนต่อความผิดปกติและความจน ความอหังการ์ของวิชาชีพแพทย์ และการจัดลำดับในการปฏิบัติต่อคนจนเป็นลำดับหลัง สำหรับบริบทของโครงสร้างทางสังคมและวัฒนธรรมที่มีผลต่อความทุกข์เชิงสังคม ประการแรกคือความรุนแรงเชิงโครงสร้าง อาทิ ความรุนแรงทางเพศในสังคมต่อทั้งความเป็นผู้หญิงและความผิดปกติ กฎศาสนาและกฎสังคมกับการควบคุมและครอบงำชีวิตทางสังคมของผู้หญิง กฎสังคมเรื่องการคุมกำเนิดที่กระทำในผู้หญิงภายใต้อำนาจของชายเป็นใหญ่ และการใช้มาตรฐานของความเป็นปกติต่อความผิดปกติ ประการที่สองคือความยากจนและชนชั้นกับปัญหาการเข้าถึงบริการสังคม อาทิ ความจนกับการไม่มีหลักประกันสุขภาพ การไม่สามารถเข้าถึงบริการและสวัสดิการต่าง ๆ ของสังคม ไม่ว่าจะเป็นบริการด้านสุขภาพ การศึกษาและระบบประกันชีวิต มากกว่านี้การศึกษายังพบการจัดการความทุกข์ที่เป็นไปตามการให้ความหมายของมารดาต่อการมีบุตรอาการดาวน์ในแต่ละช่วงเวลาของประสบการณ์ชีวิต อาการดาวน์มีความหมายที่หลากหลาย ได้แก่ โรคปัญญาอ่อน พิการทางกาย สมองและจิต โรคทางการแพทย์ พัฒนาการช้า โรคเวรโรคกรรม และโรคทางพันธุกรรม เป็นต้น ซึ่งการจัดการความทุกข์ปรากฏมีมากมายหลายวิธีการ อาทิ การแสวงหาข้อมูล การพึ่งพาแพทย์ การหาที่พึ่งจากศาสนาและความเชื่อ การระบายให้คนอื่นฟัง การให้ความหมายใหม่จากสิ่งที่ไม่ดีเป็นสิ่งที่ดีของชีวิต และจากความทุกข์เป็นความสุขดังเช่น ความตายคือการหมดเวรหมดกรรม ผลการศึกษานำไปสู่การเสนอแนะต่อการจัดระบบบริการสุขภาพต่อหญิงตั้งครรภ์ โดยเฉพาะอย่างยิ่งต่อมารดาที่มีอายุมากซึ่งถือเป็นกลุ่มเสี่ยง การพัฒนาศักยภาพของสถานบริการสุขภาพ ระบบการให้ข้อมูลข่าวสาร ระบบการสื่อสารและการมีส่วนร่วมของชุมชน ระบบประกันสุขภาพถ้วนหน้า ระบบการผลิตบุคลากรทางการแพทย์ การจัดสวัสดิการสังคม การสร้างสิ่งแวดล้อมและการรวมกลุ่ม เป็นต้น

295 หน้า ISBN 974-04-5459-3

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CHAPTER 1
INTRODUCTION

1.1 Rationale and Significance

> "When my third month pregnancy had hard problem of blood breeding, the doctor told me that that sign was very risk and possible for giving abnormal birth. He advised me to terminate the pregnancy with the reason of protection the sequent problems and burdens. I agreed with his reasons but it made me fear and worry for confronting to this unexpected event. I fell in sadness, confusion and frustration because I didn't wish to have abnormal baby and I didn't want to terminate the pregnancy too… However I decided to continue pregnancy with the reason of "what ever will be, will be" and the pregnant termination was horrible and sinful. It was the period of suffering and fear which it still be in my memory until now."
>
> My life experience, 8 years ago

From my experience, I didn't know why I was afraid of abnormal or disabled child though I hadn't had any experience with him and also about Down syndrome. Surprisingly, I've just known well about Down syndrome when I interested to study this issue. Before that time, I felt detestable and horrible as if the Down syndrome's child was a young monster and I understood that this symptom was mental retardation. I hardly knew Down syndrome and this was not different from the most people in society. Neither Down syndrome or mental retard, nobody want to happen with their families. So, the mothers who had experience of having Down syndrome's children which were undesirable, how they suffered with confronting these experiences in their social and in biomedical context.

Long time ago, Down syndrome was understood and named "mental retard". Namely before Down syndrome was founded and understood by biomedical knowledge, most of society and culture had experience with Down

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syndrome (Harwood, et. al., 1999) and gave the different meanings and practices according to the social and cultural beliefs. (Reynolds and Ingested, 1998). The medical study discovered evidence in the sixteenth century and the first academic lecture about Down syndrome appeared in 1846. So, more than 160 years that Down syndrome appeared, was known and developed the body of knowledge for explanation the cause for the abnormal chromosome, trisomy 21.

In global, the epidemiological prevalence of down syndrom was in range of 0.5–2.35 : 1,000 (appendix A) and the trend increased continuously. In USA, Egan et. al (2000) reported that the prevalence of Down syndrome increased from 1.186 : 1,000 in 1960 to higher than 1.5 : 1,000 during 1990–1994. (Staples, et. al., 1991) In North Netherlands, the prevalence increased from 1.26 : 1,000 in 1987 to 1.62 : 1,000 in 1996. The phenomena of increasing the Down syndrome's prevalence partly was because of the new technology of prenatal testing or testing fetus. Moreover the lived births trended to decrease, it's because of the natural abortion and pregnant termination.

The medical knowledge of chromosome abnormality was an important cause for decreasing the lived birth of Down syndrome's infant. The knowledge intervention of obstetrics had influenced on the pregnant mothers, especially for the mothers who were risk group, aged more than 35 years. (Noppawan Sriwongsepanich, 2000). More age and more risk for pregnant mother to have Down syndrome baby, this knowledge based on the medical causal of protection the abnormality and burden of treatment and care in long run with controlling and elimination the fetus. (Jaroff, 1992) Nevertheless, there were high different rate of prenatal examination between the developed countries of Europe and America and developing countries of Africa. The prevalent rate of developed countries were so high in range of 90-100% but in the developing countries, it were very low. (Wagner, et. al., 2002). In Thailand, there was not formal record and disclosure about the pregnant termination of the abnormal testing.

The high prevalent rate of prenatal testing in the developing countries reflected the meaning of Down syndrome in those societies that Down syndrome was abnormality, impairment and burden. (Turnbull & Turnbull, 1990). The pregnant termination or the elimination's of abnormal fetus rightly was in medical

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system and was accepted among the people especially in the developed countries. The rightness of abnormal elimination was registered by World Health Organization (WHO) who specified the disability as the indicator of health problem and under development. (Estava, 1992 : 7) So this thought had influenced on providing the standard indicator of development of each county. Namely the goal attainments of population policy and medicine were normalcy and healthy and healthy of population and these attainments dominated the way of thinking of people to wish the healthy (Kaufert, 1996) and normal baby (Wertz and Fletcher, 1991). The developed countries and being capitalist system therefore terminated the pregnancy when found abnormality of chromosome have absolutely done by the medical institutes which had authoritative role (Davis-Floyd, 1996) and were supported by the development policy. These abnormal abortions were not mistaken (Breck, 2002) because the reasons were consequently protection the problems (Callahan, 1973), the burden of nurturing and suffering of parents. (Chadwick, 1987)

Contrarily, in the developing countries, the prevalent rate of prenatal rate of prenatal testing and pregnant terminations was so low. The important reasons were the health services accessibility and the illiteracy of the people especially for the poor who were in limited condition and had more obstacles to access health services. In Thailand, there was not formal report of Down syndrome so the referable data of Down syndrome always indicated by the survey of mental retardation since in 1957, the ratio 1:1000. Moreover, the expert of abnormal institute had reported that the risk pregnant mothers about 75% could be more chance to natural abortion and many mothers who accessed the prenatal testing, always decided to abort when the testing found. (cited in Noppawan Sriwongpanich, 2543)

The pregnant termination of the abnormal fetus was under the dominance of normalcy that effected to the discrimination the abnormal baby. So Down syndrome which was abnormality and became horrible thing and shamefulness. (Das and Addakha, 2001) The study of Laakso and Paunonen-Illmonen (2002) found that mothers who gave births of Down syndrome's children, felt disappointing, lost hope of healthy baby and future dream. Rosemarie (2002) also

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found that mothers who gave birth of Down syndrome's children in the mainstream society would be suffer and stigma in the status of the reproducer of abnormality. In addition to the studies of Sjogren and Uddenberg (1989) and Rapp (2002) found that the pregnant women were afraid of abnormal pregnancy, testing and finding abnormality and the crucial decision of abortion (Kennett, 1994). Nevertheless, Rayna Rapp (2002) criticized the authoritative knowledge of medicine that it had influence on suffering and root of fear of women and mothers. In general society, the mothers' fear of abnormal delivery has been normal feeling of the most pregnant mother. However, many critical studies indicated that the fear would be produced and felt more because of the medical knowledge especially the risk age group who was explained the more risk opportunity of having Down syndrome's child. As the instance of my friend, she had directed experience of pregnancy at aged 37 years and she examined the amniotic fluid for chromosome's diagnosis. After the testing found abnormal chromosome, she decided to abort as the doctor's advice. She told me that she could not forget it and it has still provoked her attention whenever she saw a kid. In many risk pregnant mothers they always had terminated the pregnancy when they found the abnormal fetus. Nevertheless, the pregnant termination was perceived as the abortion which Thai society still be refused and was not accepted so that the exact data of this event was not disclosed.

Howover, not many risk mothers could access to prenatal diagnosis, because this procedure only can be operated by the expert and specific tools which have only in a large hospital and high expense. So this condition limited the accessibility of prenatal diagnosis, especially for the poor. The Annual Report of Ramathibhodi Hospital reported that the prenatal diagnosis began in 1987 but it was not popular. Namely, the most access were the mothers who had high educated and high economic status. Whereas, the political-economic conditions of the poor mothers were limited their accessibility. This evidence indicated to the difference and inequality of economic status which lead to the unequal accessibility. So Down syndrome's child unavoidably appeared in Thai society. However, Down syndrome was undesirable thus mothers who had gave birth the Down syndrome's child were not only effect to the mothers' emotional burden but

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also suffered to live with uncertainty of symptom (Roach, et. al, 1997), frustration , disappointment, isolation and hopeless. (Florian and Krulik, 1991) De Ridder et.al (1997: 553) called these feelings that' emotional inequilibrium, while Kleinman et.al (1995) called "emotional burden" or in another name "hidden patient" (cited in Yupapin Siripohgham, 2540: 6).

There were many studies about the complicated care and the stress of mothers who had Down syndrome's child. But the most studies were in psychological concept and nursing. Not many study which interested studying suffering with the factors of social structure, structural relationship within health care system, relation of structural factors between macro-level and micro level. Moreover, at the micro level, life's experience of Down syndrome child's mothers especially for the poor mothers who were courtesy stigma, hardly had studied so that the suffering of the poor mothers were not voiced or reflected. I agreed with Kleinman (1997) that background of real suffering of human being especially the poor people, were social suffering, because the poor people would have more suffering than the rich. Kleinman attempted to analyze and related the political-economy factors to the human suffering which those factors were origination of inequity and opportunities' gap to access the social service between the poor and the rich. This concept was on the Critical Medical Anthropological (CMA) perspective which forced me interesting and questioning to the poverty and lack of social-economic opportunity and how Down syndrome's mothers had life experience, suffering in poverty, having Down syndrome's child, and inequitable relationship within health care system and social system. These circumstances were dominated by capitalist ideology and modern medicine in constitution the knowledge and socio-cultural representation and belief. So I focused to study the impact or suffering which was social suffusing from reflection and perspective of mothers by CMA and the reality of individual reflecting the social reality of macro level. (Singer, 1986: 1196-1200) I has expected that this study will be the route for amplifying the voice of the poor sufferer and open the worldview of understanding Down syndrome problems, which have not only the biomedical frame's. I attempt to understand the causal and root of suffering that are from sufferers' perspective i.e. the doctor and patient relationship and political-economic factors in Thai context that the most people are poor and lack of opportunity.

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1.2 Research Questions

1.2.1 In experience of having Down syndrome's child, which period did the mother suffered ; pregnant period delivery or giving birth period ,checking and confirming Down syndrome and living with Down syndrome's child? How did it make the mothers sufferable?

1.2.2 What were the situations, conditions and factors of economic, social, and political structure and including the medical service system, which had effected on suffering of Down syndrome's mothers. (social suffering) ? How did these condition effect to the mothers' suffering?

1.2.3 How did Down syndrome child's mothers give the meaning to Down syndrome in each period of an experience of having Down syndrome's child?

1.2.4 How did Down syndrome child's mothers manage the social suffering?

1.3 Objectives

1.3.1 General objectives

To understand social suffering of mothers who had experience of having Down syndrome's child by understanding the social factors and context such as socio-economic structure and medical care system that made them sufferable, and giving the different meaning of Down syndrome and suffering's different management.

1.3.2 Specific Objectives

1) To understand social suffering, meaning, and social suffering's management of mothers who had Down syndrome's child within social and cultural context of Thai society by dividing the experience into 4 period; pregnant period, delivery or giving birth period, checking and confirming Down syndrome and period of living with Down syndrome's child.

2) To analyze the cause of social suffering of Down syndrome's mothers especially political-economic factors, cultural factor and medical care system, etc.

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1.4 Operational Definitions

Down syndrome's child: Children's which physical features and several symptoms that physician can diagnosis that was Down syndrome either by visibility or by clinical diagnosis generally they had similarly physical features and some have only a for but some have all these features; flattening of the back of the head, slanting of the eyelids, small skin folds at the inner corner of the eyes, depressed nasal bridge, slightly smaller ears, small month, decreased muscle tone, loose ligaments, small hands and feet, have one line across the palm, have a gap between the first and second toes and etc. The most Down syndrome's children were diagnosed and confirmed muscle tone, loose ligaments, small hands and feet, have one line across the palm, have a gap between the first and second toes and etc. In this study, the most Down syndrome's children were diagnosed and confirmed being Down syndrome by the physician and the mothers perceived Down syndrome of their children.

Mother of Down syndrome's child : Mothers who have Down syndrome's child and child age was not more than 12 years. The maternal age was not limited but tried to distribute to cover both maternal during pregnancy, lower than 35 years and upper than 35 years. (35 years is the cut point of medical knowledge that risk to delivery Down syndrome's child).

Experience of having Down syndrome's child: Life experience of mothers who had Down syndrome's child, which can be divided the life experience into 4 periods; pregnant or prenatal period, delivery or giving birth period, checking and confirming Down syndrome's period and living with Down syndrome child 's period.

Pregnant period or prenatal period : period of boring the fetus in womb until delivery Down syndrome's child, was about 40 weeks and may be less than or more than 40 weeks. In this period, mothers had prenatal care in health service station and for the old mothers, aged more than 35 years, some began exposing to the information about risky age of having abnormal baby.

Delivery or Giving birth Period : Period of giving birth which mothers were told from the medical personnel that baby had something wrong or being Down syndrome, or perceiving by themselves from seeing the abnormal physical which provoked mothers attention that had something wrong to their children.

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Checking and confirming Down syndrome's period :After giving birth and physician had seen the signs and symptoms of Down syndrome but for surely confirmation, these children were processed to the clinical diagnosis's procedure. Some children didn't pass this stage, it depended on the physicians and health care system of each hospital.

Living with Down syndrome's period : Physician surely informed and confirmed about being Down syndrome of infants to mothers, mothers can't avoid the reality of having and living with Down syndrome's children.

Suffering: Emotion and feeling which arose in mind. It is because of the threatening events or undesirable phenomena and threatens the emotion and feeling to be unpleasure, grief, sorrow, frustration, confusion, apprehension, melancholia and etc., and these feelings expressed in many ways: expression, gesture, symbolic features and abnormal behavior which can be either visible such as crying, or invisible which kept in mind. For the invisible feeling, the qualitative techniques, in-depth interview and observation, were used to understanding from the mother's narratives.

Social suffering : Sufferings were from the unequal social relation which had influence on and impact to individual. This study emphasized on the structural factors; political – economic, social factors and medical care system. The poverty and lack of opportunity in livings, illiteracy and lack of educational opportunity, abnormality and discrimination of accessibility to social welfare and social service were the condition of the poor to have more suffering than the others.

Meaning of Down syndrome : The message of mothers that was intended, expressed or signified to "Down syndrome" and "having Down syndrome's child" which related to their perceptions, belief and socio-cultural background in their social contexts.

Suffering management : The way of thinking and way of life of Down syndrome child's mothers, which were the means to confront, adapt, and live with social suffering in each period of lived experience of having Down syndrome's child.

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1.5 Scope of this study

This study purposed to understand social suffering of mothers who had experience of having Down syndrome's children. The children aged not more than 12 years. And by the conceptual theory, Critical Medical Anthropology, the target mothers were the poor, and lack of socio-economic opportunity which leaded the researcher to select ‘slum’ as research setting. The research settings were only in Bangkok and peripheral provinces and the number of research informants depended on saturation of data.

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CHAPTER 2
THEORETICAL CONCEPTS

This study reviewed related concepts and theory and related researches for directing and providing the conceptual framework. These were presented into 4 parts as these follows;

2.1 Critical Medical Anthropology (CMA) and Social Suffering

2.2 Social Stigma and Courtesy stigma

2.3 Knowledge and Understanding Down Syndrome

2.4 Conceptual framework

2.1 Critical Medical Anthropology (CMA) and Social Suffering

2.1.1 Critical Medical Anthropology (CMA)

CMA was called in other name, Political Economy Medical Anthropology (PEMA) (Morsy, 1990 : 32-33) because it interested in the political and economic factors which has influence on the dairy life and health. CMA emerged among the society which was dominated by the disease model in biomedicine and has engaged in debate with various other perspectives within medical anthropology, particularly clinical at medical ecology and postmodern. However, the critical perspective is limited to analyze the life experience of patient or individual level and ignored the political economy. After 1950, the critical perspective always critiques the western power of the world system which extended to westernize the whole society. (Jameson, 1983 cited in Baer et. al. 1997). The critical perspective conflicts with the fundamental medical anthropology, which interests the illness from the popular

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perspective and the different context. The concepts of illness and causes shifted from supernatural belief and natural cause to the cosmopolitan medical system. The other names of cosmopolitan medical system are scientific medicine, modern medicine or western medicine. Explanation the medical system of medical anthropology based on the Structural – Functionalism for social equilibrium. Until CMA emerged, it reflected the power differences which shaped social processes like the research of Navarro (1976) and Waitzkin (1978, 1992). These works used critical perspective which based on Marx and Engels Theory. CMA reflected the dominant ideological and social patterns in medical care which related to hegemonic ideologies and biomedical hegemony. The biomedicine put their status over the other system by using the power of science, modernity and regulation. For the medical service, it made the difference, based on class, caste, race, ethnic, region, religion and sex.

Baer and Singer were the critical medical anthropologists who labeled 'CMA' in their paper, presented at the 1982 American Anthropological Association meeting. CMA's focus on understanding the specific structure of social relationships that give rise to and empower particular cultural construction. CMA asks, whose social realities and interests (eg., which social class, gender or ethnic group) and under what conditions do they arise?

CMA efforted to incorporate a critical or political-economic approach into medical anthropology. These were because of perspective on capitalism which had influence on inequitable health so that capitalism was an important starting point for CMA. CMA attempts to understand health issues within the context of encompassing political and economic forces, including the forces of institutional, national and global scale, that pattern human relationships, shape social behaviors, condition collective experiences, reorder local ecologies and situate cultural meaning. The emergence of CMA reflects both the turning of political – economic perspective in anthropology in general and an effort to engage and extend the political economy of health approach. (Baer et.al. 1986, cited in Baer et.al, 1997 : 26-27)

Biomedicine as a starting point for CMA, because biomedicine treated health, based on mechanic approach, physical body and disease approach, and based on capitalism which made profit and seek interest from patient. Criticizing the capitalism with Marx and Engels perspective revealed the

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inequitable power. CMA seeks to understand who ultimately control medicines and what the implications are of such control. An analysis of the power relations affecting biomedicine address these questions (1) who has power over the agencies of biomedicine? (2) How and in what forms is this power delegated? (3) How is this power expressed in the social relations of the various groups and actors that comprise the health care system? and (4) What are the principal contradictions of biomedicine and associated arenas of struggle and resistance that affect the character and functioning of the medical system and people experience of it? The discussion of the impact of power relations in the delivery of health services needs to recognize the existence of several levels in the health care systems of developed capitalist, underdeveloped capitalist, and socialist-oriented societies. The relationship of multi-level of health care system, individual level to macro level can present as Figure 1.

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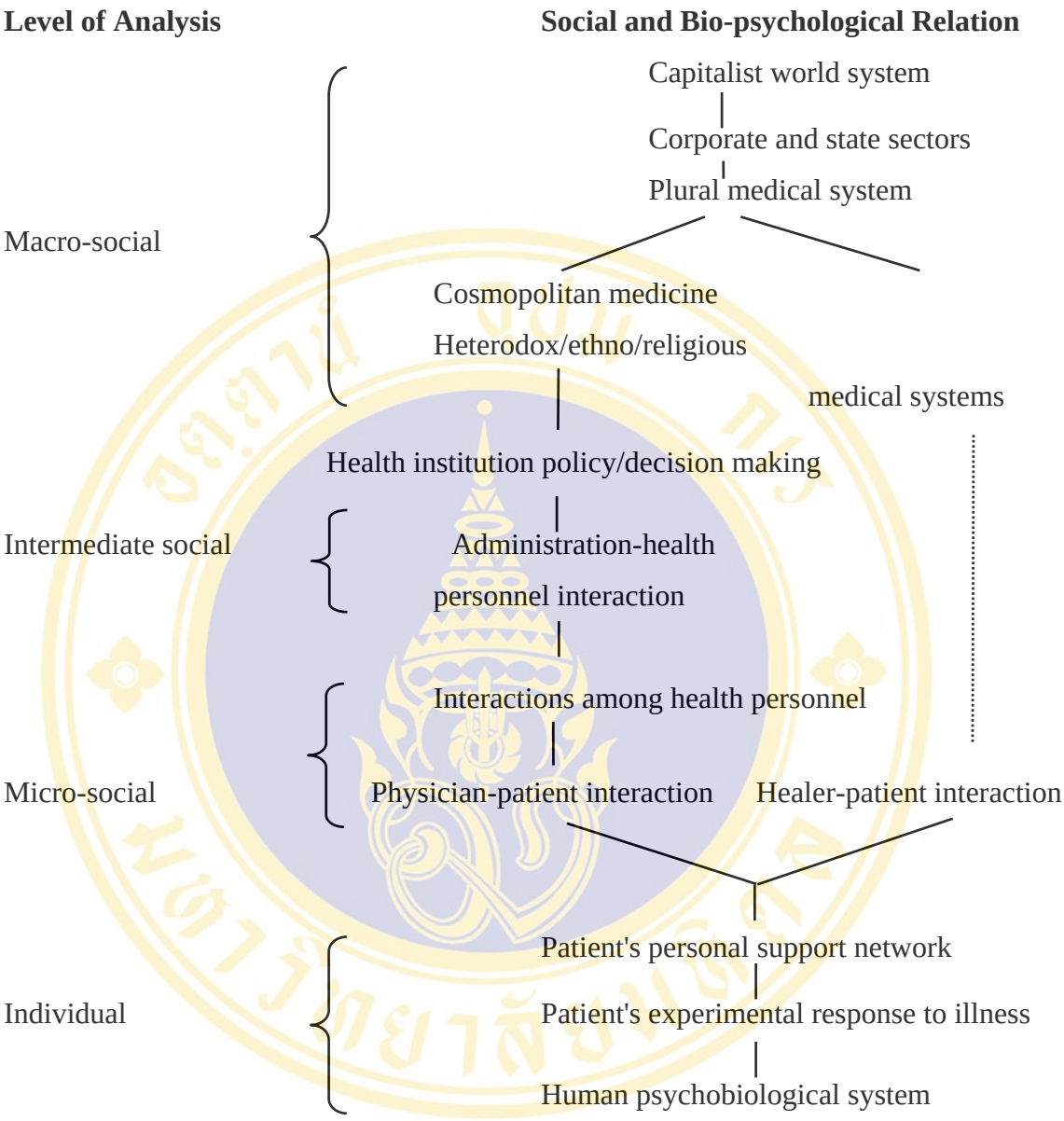

Figure 1 : Levels of Health Care System

Source : Baer, et.al. (1997 : 28)

CMA analyzes macro-social level that biomedicine is in the context of capitalist world system which shapes social life and the structure of class relation. (Elling, 1981a, cited in Baer, et. al., 1997 : 27) At all levels, the health care systems of capitalist nations reproduce the structure of class relations and the profit-making orientation, which caused biomedicine heavily used high

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technology and medical complexes. At the international level, the World Bank becomes a key player in establishing health policies and making financial loans to health care system and has WHO and UNICEF are the routes of aids. (Walt, 1994 : 128 cited in Baer et. al, 1997 : 29) Medicine is the pilot mechanism of imperialism or neocolonial form which drives and control the Third World countries collaborate with international agencies foundations, and bilateral and program to determine health policies. This biomedicine gives importance to curative approach more than protective and promotive approach.

Though the complex societies exhibit a pattern of medical pluralism but the global hegemony of biomedicine has a dominant status over the heterogeneous and ethnomedical system by legitimacy laws that give it a monopoly over the other types of healing. However, in many arenas, the popular and folk medicine are repracticed and learned outsite of bureaucratic settings which reflects the struggle and resistance to domination or as a marker of groups' solidarity and identity. And this also has effect on the growth of non-government organizations (NGOs) has come more to serve as a counter hegemonic force challenging the state health policy, private corporation and the formal institutions.

At the intermediate level of health care systems, CMA interests the hospitals which have various size from central hospital to community hospital which has become the primary arena of social relations, human resource and technological distribution. Navarro (1976 cited in Baer, et. al, 1997 : 30) attempted to demonstrate the power of health institutions, which hospital administrators and physicians delegated their powers. Because of their monopoly of medical skills and congruence between the version of disease theory and capitalist ideology, they find themselves subject in hospitals.

At the micro level, CMA refers to the physician – patient relationship or the therapy management group. In the medical treatment, the major task of the physician is not determined by the needs of the patients but it serves the special needs of physicians and other powerful sectors. The physician role performs the functions for the encompassing social system and its existing distribution of power; controlling the access to the special perogatives of the sick

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role and medicalizing the social distress. CMA criticizes these functions that the physicians have role to transform the social structural factors affecting to disease with reductionist model of disease in which physicians assign the source of disease to pathogenic or related factors. Zola (1978, cited in Bear, et. al., 1997 : 32) argues that these physicians functions are for social control so that the understanding the micro level must locate the physician – patient relationship in the broader political and economic framework.

At the individual level, the individual level considers the patient's response to sickness, or sufferer experience. CMA interests "mindful body" as term by Scheper – Hughes and Clock (1987 cited in Bear, et. al., 1997 : 32)) which suffering can express pass through the individual's body. The critical approach to the individual level begins with the recognition that sufferer experience is constructed and reconstructed in the action area between socially constituted categories of meaning and the political – economic force that shape the context of daily life (Baer, et. al., 1997 : 32). Recognizing the powerful influence of that force does not mean that individuals are passive or impersonal objects but they respond to the material conditions or confront with constitution the outer image of social relation. CMA needs to generate awareness of the ways in which sufferer experience produces challenges to medical hegemony at both the individual and collective level.

Scheper – Hughes and Lock (1987 : 7) studied sufferer experience of patient individual with rejecting medical perspectives to health which separates body and mind as mechanism like Decartism. Mindful body is individual body which is one of 3 bodies; individual body, social body and body politic. Body is as the perceptional map of natural, supernatural, social – cultural and space relation. Moreover, individual body and social body reflects the power relation either in specific society or world system which builds controllable rules and control action of individual body.

The current of political economy of health had effected to concept of CMA. At the beginning, Singer (1989 : 1193-1203) concluded the interest of CMA as these follows: 1) examination of the social origins of disease and ill health in light of the world economic system 2) analysis of health policy, health resource allocation,

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and the role of the State in Third World nations 3) re-thinking of the contemporary understanding of medical pluralism 4) development of a critique of biomedical ideology, practice, and structure 5) attending to the role of struggle in health and health care 6) re-examination of the microlevel of the individual, including illness behavior and illness experience, within the context of macrolevel structures, processes, and relations and 7) investigation of health and health program in socialist-oriented countries. And later American Anthropological meeting concluded the studied direction of CMA (Singer and Baer, 1997) that 1) To examine the linkage between micro and micro level which was constructed in integrated paradigm and was social determinant to produce the outcomes 2) To use medical anthropology to reflect medical structure and organization to be the approach of reproductive avoidance of medicine's authoritative pattern in ways of development, expression and body of knowledge and 3) To reflect the oppressed voice such as countries in the third world, marginal people and the poor people, which is intended to construct a space for demystifying hegemony as ruling class ideology. This is for challenging hierarchy and class domination more than reinforcing.

The emergence of CMA as both theoretical framework and a form of health praxis, bases on conflict or critical theory of Gramsci and Marxism, CMA utilizes the term 'biomedical hegemony' and how the power of the biomedical profession is deligated. Gaines (1991:221) identifies 5 CMAs: 1) the Marxist political economies in medical anthropology as exemplified in the work of Singer (1986 : 2) the 'cultural critique of medicine' school as exemplified in the work of Justice (1986); 3) the 'dependency theorists' as exemplified in the work of Baer, Singer, and Johnsen (Baer et,al. 1986) : 4) the Gramscian school which employs the notion of hegemony as exemplified in the work of Morsy (1988); and 5) the critical theorists as exemplified in the work of Schepes-Hughes and Lock (1987). CMA recognizes the presence of both hegemonic and counter-hegemonic elements in the medical beliefs and behavior of patients (Singer,1987) as well as in alternative medical systems. If also recognizes that these are other influences besides macro-level or political-economic ones such as human agency.

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2.1.2 Social Suffering

1) Suffering : Definition

It is belief that every human life has ever confronted to suffering because human being is in many conditions which effect to suffering such as living in unpleasured condition, uncertainty, impermanence, disappointment, and etc. (Fischer, 1997) In Webster's Dictionary (1976: 2284), suffering has 2 meaning which are 1) the condition that happens to person and makes him troublesome and painful and 2) tolerance to pain and trouble. In Encyclopedia of Religion Knowledge (Jackson, 1969: 130), suffering means pain of body and mind which conforms with Buddhism (Pheathampidok, 1995).

In American heritage Dictionary of English Language (2000) Webster's Dictionary (1998) and World net (1997), suffering is 1) pain both body and mind, grief from loss, injury and punishment 2) tolerance to uncomfortableness, injury, pain, sorrow and death 3) unhappiness, distress, pain and suffer with pain, disturbance and grief and 4) surrender to grief and distress. In Morse and Johnson (1991), suffering is global experience of impaired quality of life and sorrow for threatened events to the personal certainty, integrity, ability to play role and feeling to self-identity and it includes the experience of severe mental pain which comes form medical causal. This suffering is individual subjective of each society.

Furthermore, suffering's meaning bases on culture and religions belief. In western society, suffering is private and individual experience and human will differently act subjectively in form of pain, sorrow disappointment, depression, and hopelessness but these depend on the severity and in-depth suffering. Suffering generally, is used in other words, such as adversity, affection, anguish, calamity distress, grief, misery, sorrow, pain, tribulation, trouble, etc. For Christian they believe that the more suffering, the more holy and human suffering is incarnated by the purpose of god and the cause of this suffering is sin. (Graham, 1974 : 88).

In Eastern society, the Tukka suffering is on the basis of Buddhism and coexist of 2 Pali words (Pra Ratchaworarnunee, 1986 : 99)

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- Tu + Khama : ‘Tu “means” hard or difficult’ and ‘Khama’ means ‘to bear or be patient’ and ‘Tukkha’ means ‘hard to be bearable for’
- Tu + Kha : ‘Tu’ means ‘ugly’ and ‘kla’ means ‘empty’ and ‘Tukkha’ mean ‘the undesired / non-substantial conditions’

Dhukka or suffering in Buddhism is essence of the Four Noble Truths (Pra Thampidok, 1995) which is and ordinary thing of human life, Anatman (had not self) and Anicca (uncertainty). Every thing in the world is delusion, even the rule of real life, birth aging, sickness and death. Dhukka is mysterious and mere definitive and is the mental condition, including the spiritual condition.

In psychology, suffering means narrower than the stress because its scope specifies only mental condition, undesirable and frustrated. Suffering is only a stage of stress so that it always use in the same meaning of stress and apprehension. Psychologist and psychiatrist interest suffering in frame of ‘stress’ which can indicates and diagnoses the signs by medical testing (Richard, et. al, 1981 : 30).

Mosby (1993) concluded the meaning of suffering that it was different by the way of giving meaning and context of the person who defined it. His definition covered to social suffering that social suffering occurred among the human relationship and human was origin of suffering. This meaning showed that the different meaning and suffering expression were social and cultural construction. Each one had different threshold and trigger so suffering was organized in different form though in the same context, the suffering could be different. Suffering is existential, fluid, and uncertain and varies by context of person, space and time. The suffering expression also be different form, visibility, personality, manner and language which passes through conversation and narrative. Chumlong Dissayawanich (2541) classified the suffering expression into 3 types, 1) suffering within mind and keep in mind 2) suffering within mind and expresses through physique statement and mind and 3) suffering expresses through physique and disease which caused from mental suffering.

From the above mentioned meaning of suffering, they have wide meaning and social suffering which I interest, is a dimension of suffering.

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2) Social Suffering : definition and concept

Before the time that Kleinman seriously studied social suffering, Mosby (1993) mentioned it in his definition of suffering. The turning of interesting the social – structural factors was the origin of studying suffering of critical professionals. Kleinman was a medical anthropologist who extended his interesting from suffering phenomena of individual and illness of from popular culture, folk medicine and popular perspective to social suffering. Social suffering is problematic phenomena which is from the push of social factor to make human have suffering experience. The social factors affecting to social suffering are power of politic, economic and institution. These undesired situations or suffering are political and cultural matters. Social suffering is health problem and indication of social process which occurs in all societies of low and high income and in different settings. Nevertheless, in the hopeless place, poverty and powerless society the people have mental problems and social suffering more than the high income society or powerful society.

The cultural representation to social suffering varies from local to global and expresses the suffering experiences in many forms such as painful procedure, sorrow, illness experience and technological influence on illness management. The suffering experience can be both local and global and occurs within modernization which effects to ethical impact and as if it is normally and naturally social experience. However, in suffering experience, it hides the powerful practice to social life so the social suffering is the convergence three overlapping themes: cultural representations, social experiences, political and professional processes.

Social suffering is the cultural representations of sufferings, images, prototypical tales, metaphors, and models which are appropriated in the popular culture or by particular social institutions or social use which are in historical memories of suffering eg. war, imperialistic and post-imperialistic oppression. The representations express in form of authorize nationalism or class and ethnic resistance. Collective suffering is also a core component of the global political economy and norms are become into normality. The learned and shared

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experience become natural condition which has not power of changing the political – economic system. Political and professional processes powerfully shape the responses to types of suffering eg. medicalization, state its institutions and groups that contest state control press medicalization for its advantages in regulating persons, their bodies and networks. But political processes and public policies, they construct social suffering through intended and unintended effects and intensified human misery.

Emerging concept of social suffering is for questioning how the suffering is reproduced or constructed and why the painful endurance or suffering acceptance are as the cultural processes. The cultural processes distorted the expression of suffering experience and expresses in different and various forms. Kleinman et. al. (1997) collected the research about social suffering of several culture to reveal the political – economic structures affecting to human suffering. The study of Vera Schwarcz (cited in Kleinman, et. al., 1997) described the variation of silent endurance and indirect expression of the trauma of political oppression in modem China. In India, Veena Das described the magnification of the images of nation in the anti-colonial movements where men came to appropriate the bodies of women as cultural medial through which new political programs would be expressed.

Lawrence Langer (cited in Kleinman, et. al, 1997), writing in Holocaust, he found models in religions or professional discourse to make sense of the suffering of the Jews 'normalizes' that which can never be normalized, never, rationalized. He found attempts to explain extreme atrocity naïve to his way of thinking, misguided efforts to cure survivors of their trauma. Massive social suffering is from disappointment between traditional and modern medicine. Harrington's discussion of the relationship between holism and Nazi medicine that a humanistic critique of scientific objectification in biomedicine which was appropriated by National Socialism. This is to unmask the fierceness of Nazi and to critique the biomedical objectification which are the source of human suffering.

Margaret Lock (cited in Kleinman, et. al., 1997) reminds to concern to different cultural relationship that can generate the different responses to suffering. These debates over the experience of dying and the definition of death in Japan and North America may be driven by certain of the same global processes of

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technological rationalization, political economy and biomedicine. Lock pointed out the cultural appropriation through technology which was taken as ‘natural’ and changed one expectations about life events such as birth, illness and death. These events; production of perfect babies, an extended life span, and the elimination of disease is in daily life and is intervened by the politic.

Lock and Allan Young traces the normalization of biomedicine within powerful bureaucratic institutes that has effects to social life both normal and abnormal. Biomedical concept of normality leads to use technology to build the normality and reduce suffering that medicine is transformer of bureaucratic power and remake sufferers as consumer and to transform death and fear into commercial stakes and financial opportunities. The study of Paul Farmer shows how the cultural politics, ethnicity, poverty and international relations relate to transmission of AIDS in Haiti. Poverty is a major risk factor of social suffering but it is obscured. This study confirms that the political – economic influence has effect to suffering and suffering experience, especially for the extreme poverty. The inequitable distribution and allocation of resources produces the different suffering among the unequal access to the scarce resource. And the decision of physician to prioritize who should deserve the scarce resources, this brings to the question of social justice and undesirably ethical – problem.

2.1.3 Conceptual Conclusion

Social suffering arises according to Critical Medical Anthropology (CMA) which gives importance to sufferer experience of individual level that it is social reproduction in interaction space between the classification of social meaning and political – economic influence on providing daily life. The passive expression reflects to take advantage of economy and political oppression as in work of Scheper-Hughes (1992), Death without Weeping: The Violence of Everyday life in Brazil. She studied the shifting of suffering expression of people in poorest area in North Brazil. Fighting for basic minimum need of the poor mother, which is not different from the suffering appearance in the most weakness of children. Agricultural development by sugar cane planting as the development policy of state doesn’t make the people have higher quality of life, but the almost people are without enough income for survival.

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For the agricultural business development and industrial development, they invested by multi – national cooperation so that the local people had not any benefit. Understanding suffering experience with critical concept will lead to understand structure of social relationship which had influenced on social and cultural construction, including medical hegemony both individual and group level. Therefore, studying to understand the individual level will finally relate to the power in macro level.

Explanation with social suffering and CMA is complex such as the studying illness will stress at sufferer's experience more than disease. Because its basic assumption that biomedicine brackets disease by the outsider professionals and dominates way of thinking about disease management without the question to the different accessibility and management of each society. Engels and Virchow are pioneer to explain health problem and relates to the political powerlessness, and reflects the inequitable social relationship which is the important causal. (McNeil, 1976, cited in Baer, et.al, 1997: 6). The inequitable power produces suffer and illness more that the ought and it is in historical condition or constructive process and structure which has class, or political–economic structure which has influence on social life, (Singer, 1996: 497) social behavior, life experience and giving the cultural meaning. (Morsy, 1990).

In biomedical structure, this concept questions to bias of science (Herrnstein and Murray, 1994; Harraway, 1991: 186) and ordering the reality and experience with inappropriate digital. This method discriminates someone to out of frame like as down syndrome children, they are classified to be mental retard with IQ criteria. The decision the abnormality with the opposite of normality and biomedicine which separates physique and mind like as mechanism, and treat the client as the object. Medical anthropology is not much interesting to powerful relationship and social inequity so that the shifting to social suffering and CMA concept will be appropriate to analyze sufferer's experience and structural relation especially for medical powers that effect to the different suffer, especially the more in the poor.

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2.2 Social Stigma and Courtesy Stigma

2.2.1 Social Stigma : Definition and Concepts

The term “stigma” was introduced by the Greek which describes signs that indicate something out of the ordinary or bad about the person (Goffman, 1963); to refer to a mark that was cut or burned into the body of a person with blemished character, a criminal or slave. Goffman’s definition and concept of stigma are the most widely accepted by the researchers today. (Crocker, Major, & Steele, 1998) Goffman (1963) first defines the social stigma as a spoiled social identity, a definition based on the premise that a stigma represents a deviation from the attributes considered normal and acceptable by society. Stigmatizing is a process in which a social meaning is attached to behaviors and individuals and believe that the stigmatized are not fully human because of holding the negative stereotypes. Goffman described three types of stigma. The first is *physical deformities*. The second is because of *character blemishes*, which may include traits such as weak will, dishonesty, or mental illness. The third is *tribal stigma*, because of race or religion. Tribal stigmas can be passed on through familial lines with all members of a family or group being equally stigmatized. Attributes deviant from societal norms are likely to be seen as failings, or handicaps.

Schneider and Anderson (1980) defined the stigma, refer to any physical and/or behavioral characteristics that result in an individual being the victim of negative expectation. Coleman's thought (1986: 24) supported that not only does stigma result in "downward mobility" for individual but it also reflect a societal agreement that their differences are unacceptable. Social stigma makes the people who is stigmatizes tend to suffer from excluding or discriminatory acts and has been linked to many social, behavioral and psychological outcomes (Steele, 1997). The stigmatized are defined or categorized their membership which include the person with physical and mental disabilities (Harvey, 2001: 174). Persons who have deviant attributes are discredited and excluded from society. Persons with stigma may be discredited, undesired and shameful and always react in negative affective reactions (Jones et.al., 1984).

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Jones et, al. (1984) identifies six dimensions of stigma, and the interpersonal roles of those stigmatized. The first dimension is *concealability*, the degree to which the condition is hidden or visible. Visibility plays an important role to producing negative social reactions. The second dimension is the *course* of the condition, the extent to which the condition changes over time. The third is *strain* that the stigma places on interpersonal relationships. The more visible and aesthetically displeasing the condition, the more relationships are strained. The fourth dimension is *aesthetic qualities*, the extent to which a condition affects the appearance of a person. The fifth dimension is *cause* of the stigma; is the condition congenital or acquired. The sixth dimension, *peril*, focuses on the dangers associated with stigmatized persons.

A discredited individual is one who show visible signs of being different (Goffman, 1963). When signs are visible, those individuals are stigmatized and discredited by others. Those without stigma generalize from a particular disability to a variety of disabilities of imperfections. (Strauss et.al. 1984) A person's physical appearance is important in the most societies. Appearance affects how individuals feel about themselves and how the others perceive and value them (McCall, 1990). Societies seem to be obsessed with the physical perfection and dysfunction of body. Persons with disability may be discredited and learn about the individual's qualities and be described by the word, "damaged goods" which portrays people with disabilities (Phillips, 1990). Hence, such people have spoiled social identities.

Goffman emphasized that a stigma was a construction of society more than an attribute of individuals. Deviancy is relative to a particular societal context and is not a primary property of stigmatized individuals so that an attribute may be stigmatizing in one context and empowering in another. Goffman asserted that social stigma was not a property of individuals but, of contexts. An attribute stigmatized in one context may be considered normal, or even cherished in another. Therefore, distinguishing the trait of stigmatization can be difficult at times. The people who has face prejudice and negative stereotypes may display a more stable trait of stigmatization across situations and contexts. Variability between contexts is important to the degree and the level of disruption between

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stigmatized and non-stigmatized. An attribute may be stigmatized in one context because it is disruptive and not stigmatized in another because it is not disruptive.

Stigmatization constructs a belief system and rationalize that the stigmatized are dangerous and always use words such as moron, loony or cripple to stigmatize the inferior attributes. Belief about stigma are often related to public perceptions at certain time, for example, epilepsy which has historically been associated with evil and the demonic possession. (Lennox & Lennox, 1960) Conversely, some without stigma appear to believe that disabled person are more vitrous than the person who are not (Thorne, 1993). Nevertheless, the stigmatization has multidimensional social and metaphoric meaning (Sontag, 1988), all of them negative. Crocker et al. (1998) analyzed how stigmatized individuals negatively understood and interpreted their stigmatization and suggested four aspects of stigmatization: a) frequent experiences with prejudice and discrimination, b) awareness of the devaluated quality of one's social identity, c) stereotype threat, and d) attributable ambiguity. For the two appeared relevant to the present development of an individual-based assessment of stigmatization. Within stigmatized category, individual group members are likely to vary in the degree to which their attributes as disruptive to their ability to function and participate in society and also to one's social relationship (Crandell and Coleman, 1992). The degree of stigmatization leads to develop the stigmatization scale from the conceptual definition of stigmatization. Two core components of the definition are the perceived experience of prejudice and discrimination and a heightened awareness of the devaluated quality of one's social identity which are consistent with Goffman's conception of social stigma as an attribute that is deeply discrediting within a particular social interaction. (Goffman, 1963 : 3)

Becker and Arnold (1986) criticized the writing of Sociology Psychology about Stigma of Goffman that it stressed at individual level more than to concern to cultural, social, political and historical context which individual had experience of stigmatizing. Concept of Stigma is universal which each society will have their belief in giving cultural meaning and providing the specific appearance to be stigma. Stigmatization is social and cultural construction of each society and not being personal specialty. To understand and to explain stigma must do within that social and cultural context.

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2.2.2 Courtesy stigma

1) Courtesy stigma : Definition and Concepts

Courtesy stigma hardly had studied in the past research. (MacRae, 1999) The most studies of stigma have focused on the experiences of persons who possess a discredited attributes or conditions of stigmatized individual but Goffman has term *"courtesy stigma"* which has received less research attention (MacRae, 1999). He argues that there is a tendency for stigma to spread from the stigmatized individual to his close connections (Goffman, 1963 : 30). When an individual is related through the social structure to a stigmatized individual, the wider society may then treat both individuals in some respects as one. Goffman (1963 : 30) argues that the individuals are obliged to share some of the discredit of the stigmatized person to whom they are related. According to children with down syndrome, their family members may experience stigmatization because of their affiliation with the stigmatized individual rather than through any characteristics of their own (Gray, 1993 : 104).

There are many researches, for example Alzheimer's disease, which indicates that when one family has a stigmatized illness, other members have experience courtesy stigma too and use strategies to control or avoid it. (Conrad, 1991; Gray, 1993). The research evidence showing that families experience a great deal of stress as they struggle to cope with the unique challenges that caring for persons with disease present (Semple 1992). Alzheimer's disease would be stigmatized because of the out of the ordinary (Dingwall 1976) or problematic behaviors of those who are afflicted with it. Clearly, their often bizarre behaviors challenge dominant social norms regarding appropriate conduct, and encounters with others can be awkward. Evidence of shame and fear of stigma is also found within narratives written about families' experiences with Alzheimer's disease (Anifantakis 1991, Roach 1986), description the impact of her mother's illness on her family. Some studies have noted that relatives and caregivers reported that they often felt embarrassed by the behaviors of their ill family member (Greene et al. 1982, Argyle et al. 1985, Fontana and Smith 1989). The caregiver and the person with Alzheimer's disease also engage

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in what Goffman has termed ‘covering’. Covering practices are employed where the stigma becomes visible or is known about but effort is made to keep it from ‘looming large’ (Goffman 1963: 102).

As Blum (1991:270) explains, ‘as the stigma becomes visible in interaction, the caregiver makes efforts to minimize its salience. Thus covering involves situation management, such that the visibility of the trouble and the embarrassment it may cause are kept to a minimum’. The caregiver now realizes and sides against the family member in order to maintain social order as well as preserve his or her own face’ (Blum, 1991: 281–2). Most previous studies of courtesy stigma have focused on management strategies. However, as Sigelman et al. (1991: 45) note that little research has been conducted to establish whether courtesy stigmatization does in fact occur or to identify the circumstances under which it is most likely to occur. In their study of stigma among the associates of gay persons, they found that courtesy stigma occurred but only under circumscribed conditions. Similarly, Freeman and Simmons (1975), investigating stigma among relatives of former mental patients, discovered that feelings of stigma appeared to be characteristic of only a minority of their respondents. Gray (1993) reports that while the majority of parents in his study of perceptions of stigma among parents of autistic children did perceive themselves as being stigmatized by their child’s condition, a substantial minority did not. As the findings of these studies indicate, courtesy stigma and its occurrence is a complex issue that needs to be further investigated.

In sum, mothers of children with illness or disabilities are considered to be a group at risk for problem with emotion and adaptation (Wallander, & Noojin, 1995). They were in the midst of the oppression of being women in male-dominated societies and the oppression of being produced disability in societies by the able-bodied (Wendell, 1989: 105), sameness vs. difference, and independence vs. dependency.

2) Illness as Metaphor

Social norm gives importance to ideal body and has influence on body image about beauty and normality. Disability is presented as ugliness and joker

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(Murphy, 1995: 143) Talipors and MaCabe (2002) studied body image and physical disability and found that physical disability had effected to mental and emotional experience and negative attitude about body. Hence It is very difficult for a person who is physical disability to confront to social world of positive body image, such as physical fitness and body beautiful image (Lawrence, 1991: 140) The presentation the disability as ugliness or worthless thing is stigmatization to disease and illness by language and speech in dairy life to be tool for eliminating the disability. Taylor (1990: 56) said that this was attempt for relieving from the worse that threatened living life. According to Clatts and Mutcher (1989: 107) they show that language is as metaphor for deviating the demoralized illness to become the disease of others and the most attempts to eradicate the suffering, fearfulness and insecurity.

Metaphorical language in daily life refers to negative image of disease, is essence of thought, belief expectation, emotion, feeling and way of life which human uses to manage the health problem that leads to suffering, loss, fear and death entirely (Scheper – Hughes and lock, 1986: 137-138). Metaphorical language also means to relate between illness and existential social symbol. It reflects picture of disease and illness which passes the interpretative process form the major member of society and is shadow graph which has meaning and has influence on the way of thinking and the way of life. And it also builds the severe suffering to related person more than the biological reality of disease and illness (Clatts and Mutechler, 1989: 107). The writing of Susan Sontag (1988) in ‘Illness as Metaphor’ pointed out the power of linguistic metaphor and relation of illness meaning and socio-cultural context in patient’s perspective or emic view. Susan Sontag believed that using metaphoric language to disease and illness was distortion the reality of illness to become the new thing which was absolutely different from the old and stigmatized the patients to become the worthless person. This process repeated the suffering and made them lose their human dignity.

3) Courtesy stigma and Impacts to Mothers

Suffering in social relationships and contextual condition occur as people deal with stigmatized persons. The contextual condition which has effected on the psychosocial adaptation to the chronic illness and disability (Livneh, 2001 : 152) as these followings ;

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1. Biological and biographical status : such as current health status, type and source of onset (e.g., gradual vs. sudden, internal vs. external), level of physical maturity, chronological age, gender, religion, and ethnicity.

2. Psychosocial status : include personal and social identities ; cognitive, emotional, and moral developmental phases; family and marital developmental phase; and degree of resultant life threat.

3. Environmental conditions : refer to existing external conditions, including physical, economic, social, and attitudinal conditions. (Whitman, 1999)

Almost family with Down syndrome's child, which is chronic illness, always have impact to mothers' life. The first is daily life of mother. (Hoyert & Seltzer, 1992, Barrette and Boyce, 1995). Mother is main caregiver who sacrificially nurtures and cares. The second is economic impact, because Down syndrome must life long care so many mothers leave their works to look after their children and some children need specific treatment which is high expenditure. The third is social impact. Many mothers feel guilty to have abnormal child and always isolates or don't communicate to others. The fourth is families' relation. Mothers must do home work, take care the family member and specially look after the illness child. This always effect to relation of spouse. The fifth is emotional and mental impact. The symptoms' severity which threatened the children life, has effected to mental health of mother. The sixth is impact to sibling. Special care of mother to sick child makes the siblings react in many feelings such as stress, fear, guilt, shame, and loss.

Having chronic illness child doesn't have effect to only the way of mothers life but also to mental affect such as guilt. The most mother accept the stigma experience to their children to be their own experience or courtesy stigma. Childs (1985 : 13-15) concluded the feelings and reactions of mothers to children illness into 13 types; 1) guilt 2) Denial 3) inferiority 4) Question religions belief 5) shame 6) Confusion 7) Death wish 8) Anger 9) Need to blame others 10) Loneliness 11) Unloved 12) Infanticide and 13) Helplessness.

Furthermore, many researchers confirmed that (mother) accepted the fate and suffering of confronting to have illness children, more than men (father) (Damrosch and Perry, 1989; Hedov, et. al, 1999, Bernett and Boyce, 1995, Mallow and Bechtel, 1991). The expression of suffering is either struggle or management with using

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suffering or medium by remembering and retelling and resisting and redeeming. (Copeland, 1996:136-137). As the study of Whaley and Wong (1979: 900), they studied the emotional affect of mothers who have had chronic illness children, when the doctor informed that they gave birth the abnormal babies. Mothers always be stress, anxiety and depression which divides the reaction and management into 4 periods; 1) Shock and denial 2) Adjustment 3) Reintegration and Acceptance and 4) Freezing–out phrase.

The above review shows that when mother has suffering experience, they are not living without doing nothing. Many researches revealed the reality of contorting to suffering and managing of sufferer or mothers, as courtesy stigma. In my study, I deeply interest to study the living reality of mothers who suffer from having down syndrome children, meaning of down syndrome which affects to managing the suffering in the patients perspectives.

4) Mothers' Adaptation and Suffering Management

The level of adaptation is an upward spiral in which coping mechanism, learned from one at a time to other times. Reaction of people to illness depends on at least 3 conditions (LeMaistri, 1999). The first is the severity of the illness. The very sick must pull all their energy into healing may not have the luxury of energy left over for emotional growth. The second is the social support available and the third is the pre-illness personality of the person.

The emotional trauma of illness is caused by loss of a valued level of functioning, such as ability to walk, study or work. The disability person not only suffers the loss of competency but is deprived of an expectable future. In the face of such unexpected events, to experience with fear, anger, depression, and anxiety, is normal. It would be abnormal to deny that health and life had changed for the worse. Serious emotional difficulties are more often the lot of people who don’t acknowledge the emotional stress they feel and thereby bottle up depression or anxiety until these feelings are so powerful they break through their defenses. By the time on emotion becomes their powerful, it’s much more difficult to survive its impact without severe scaring.

The people always overcome the displacement and depression caused by physical loss and the loss of goals and dreams which is in the stages of the

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The people always overcome the displacement and depression caused by physical loss and the loss of goals and dreams which is in the stages of the ongoing emotional process as these 6 stages; crisis, isolation, anger, reconstruction, intermittent depression, and renewal. LeMaistre (1999) proposed the positive coping skills that are required by unavoidable health change as these ways, 1) make the expectation realistic 2) approach problems actively 3) seek appropriate help 4) handle the auger 5) participate 6) live in the present and 7) cherish the good times.

Living with uncertainty and undesirability makes mothers stress (Mishel, 1984) and feels riskful (Chrisman, et.al. 1988). Some mothers can mange it but some can't. However, the most mothers attempt to seek the ways to reduce uncertainty or manage it in many and several ways. Schneider and Conrad (1983) classified the ways of uncertain management into 2 ways; 1) Caution and 2) Vigilance; and reduced uncertainty many ways such as seeking knowledge, seeking explanation or diagnosis, avoidance to see the doctor, want to know only the good news and information's. (Camaroff and Maguire, 1981), develop supernatural belief and religious ritual. (Felson and gmelch, 1979). They accumulate the experiences and various knowledge which are feasible to manage and response to the risk of uncertainty. Nevertheless, the ways of response to the risk of uncertainty and the ways of management will be different by their experiences. (Donglas and Wildavsky, 1982).

Aquilera et.al (1970 : 54) provided the factors affecting to balancing condition and eliminating suffering, as these follows; 1) Acceptance to evidence 2) Circumstance supporting and 3) Mechanism for confronting to suffering. Thoits (1982 : 142) showed that social support from social network in emotion, social material and information helped mothers to confront to their sufferings. Lazarus and Folkman (1984) agreed with mechanism of social support to lead to reduce suffering and pass through this period. The social supports are in many ways; emotional support, instrumental support, information support and appraisal support. These relate to Jacobson (1986: 246) that there were 3 social supports; emotional support, cognitive support and materials support

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West (1985) described three ways of managing stigma: `concealing', a strategy adopted by most parents; `avoidance', which also involves avoiding situations with a high risk of misadventure and stigmatization; and, occasionally, `avowal of normality', which involves disclosure to reduce the risk of misadventure and maximum participation in activities to accomplish normal identity when other strategies fail. Disabled persons manage the suffering in order to normalize their attributes by looking for the secondary benefit, resisting and challenging the status quo (Dudley, 1983) and covering (Goffman, 1963). Covering is an attempt to minimize the effect of the stigmatizing condition. When the condition is open for others to see, covering minimizes its effects and decrease suffering. This is an attempt to make "normal" feel comfortable. If the signs of the stigma are invisible to others, the individual is discreditable but not yet discredited. The person will decide to tell or not to tell others about the condition. Nevertheless, down syndrome is visible disability, which is automatic disclosure so that it can't avoid the stigmatized and discredited condition (Joachim and Acorn, 2000) . These undesirable conditions make the related persons suffering.

2.3. Down Syndrome : Knowledge and Understanding

2.3.1 Concepts of Disease and Illness

Mainstream concept of biomedical perspective explains sickness with separating physique and mind and stress at disease which is the etic view or outsider’s perspective (Chrisman, 1991). This explanation bases on standard of biological indicator and visible symptom which ignores social context and environment (Parry, 1984). Biomedicine gives importance to visible signs and measurable symptom which measures by the objective measurement and treats by doctor centered. (Leininger, 1981). With scientific knowledge and modern technology and causality which considers with objective method (Bloom, 1965), body is compared with mechanic engine which can repair and change the disorder part. (Kelman, 1977) Physique and mind absolutely are separated and medical personnel has the right authority to decide

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the patient's health and life which visibly appear in medical service system and medical professional.

Illness in popular perspective is different in individual level both the illness perception and illness management. Illness meaning of people depends on socialization, life experience and belief which have effect to various method of illness management (Ackerknecht, 1942). The person who has the different cultural background, has the different illness perspective as the perception and experience to that illness. (Lea, 1994). Belief about cause of disease lead to have curative method and health behavior as that belief. (River, 1924) Illness explanation by the popular is emic view or insider's perspective which the person directly is socialized in status of member and can reflect to belief experience as their own culture. (Kleinman, 1978) The experience of illness perception is used to decide about the illness by patient, family or social network of patient (Mullika Muttiko, 2530). Illness problem is the co-experience between individual and social network, in illness perception and decision making about the effective method. Understanding with the insider's perspective is important to understand behavior which reflects the personal reaction, and culture of health. (Holloway & Wheeler, 1996)

2.3.2 Medical Knowledge of Down Syndrome

1) Background and types of Down Syndrome

In 1866, Dr John Langdon Down published his first work on a group of children in his care at the Earlswook Asylum in Surrey, England. It was an intuitive paper for his discovery that there was a subset of people with mental retardation that had a common appearance and characteristics which had the shortsight so they were named the down characters that "Mongolism" and later changed the name to be Down Syndrome according to the founder, John Langdon Down. In 1959 a French biologist, Jerome Lejeune, established that production of a germ cell with an extra chromosome, Trisomy 21. In 1961, a letter was written to the prestigious British scientific journal *Lancet* by 19 scientists requesting that the term "mongolism" be abandoned in favor of one of the following terms: "Landon-Down's anomaly," "Down's syndrome or anomaly,The term "Down's Syndrome" was first

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used, scientific publications in the 1960s. The structure of each human cell is made up of 46 chromosomes, 23 pairs. On each chromosome the genetic makeup of a person is imprinted. In Down syndrome there is an extra chromosome making 47 in all and this extra chromosome is the number 21. This gives 3 number 21 chromosomes and hence the medical terminology Trisomy 21. The extra genetic material gained from this gives the characteristics of Down syndrome. Most cases arise when the chromosomes donated by the mother or father has failed to divide correctly. There is as yet no definitely known reason for this. From this two types of cells are produced, one with an extra copy of the chromosome 21 and one with only one. The latter type will end in a miscarriage of the pregnancy. This type is called standard or regular Trisomy 21 and accounts for 95% of people with this condition. This type is not hereditary but it is known from statistical analysis that if a woman has a child with this type of condition then the risk will be higher of it occurring in the next pregnancy. As known that the fault of division occurs more frequently in babies of older women although there is no conclusive evidence as to why this occurs.

There are three main types of chromosome abnormalities in Down syndrome:

1. The vast majority of children with Down syndrome (approximately 95 percent) have an extra 21 chromosome. Instead of the normal number of 46 chromosomes in each cell, the individual with Down syndrome has 47 chromosomes. This condition is called trisomy 21.

2. The second type is called translocation since the extra 21 chromosome is attached or translocated on to another chromosome, usually on chromosome 14, 21 or 22. If translocation is found in a child with Down syndrome, it is important to examine the parents' chromosomes, since in at least one-third of the cases, a parent may be a carrier of the translocation. This form of chromosome error is found in 3 - 4 percent of the individuals with Down syndrome.

3. Another chromosome problem, called mosaicism, is noted in about 1 percent of individuals with Down syndrome. In this case, some cells have 47 chromosomes and others have 46 chromosomes. Mosaicism is thought to be the result of an error in cell division soon after conception.

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2) Incidence

The incidence of Down syndrome rises sharply with the mother's age more than 35 years. Mothers aged 35 to 39 years have risk about 6.5 folds when compares with mother 20-24 years old and increases to 20.5 folds when compares with mother aged 40-44 years. Age 35 years is the risk point which medical service uses to advice the pregnant mother to do prenatal diagnosis. About 40 % of the pregnancies who attribute to prenatal diagnosis and elective abortion of affected fetuses. All populations and is an overall population risk Down syndrome occurs in approximately 1: 800 births. (Wald and Thompson, 1987 : 387-402) The incidence rises sharply with the mother's age. It affects both boys and girls equally.

Age of mother	Risk	Risk in percentage
20 years	1:1500	0.066
30 years	1:800	0.125
35 years	1: 270	0.37
40 years	1:100	1.0
45 and over	1:50 and greater	2.0

The risk is also given as a percentage. A woman with a risk of 1: 270 has a 0.37% chance of having a child with Down syndrome or another way is to say that she has a 99.63% chance of not having a child with Down syndrome.

3) Characteristics

People who have the same chromosomal disorder have the same characteristics. These are recognizable for that particular condition and this is the same with Down syndrome. In Down syndrome the most recognizable facial features are that the eyes appear to be upslanting. The head also appears to be slightly smaller with a distinguishable flatness at the back and more roundness of the overall shape. The nape of the neck can appear to be thicker and have a distinctive fold of skin. The ears may appear to be smaller and are usually set at a lower level. This may not always be noticeable without close examination. Small white flecks, called brushfield

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spots, can be seen in the iris. This does not interfere with the function of the eye and is only a diagnostic feature. Cataracts, squints and nystagmus can also be present but is not a feature of all children with this condition. The limbs and fingers can be slightly shorter than average. The small finger on both hands is usually in turned into the palm after birth and return to this position when the hand has been opened. Quite commonly the fist can appear to be clenched and this is a feature which may be seen on an ultrasound scan during a pregnancy. The hands also have a single crease on the palm although this feature can also be seen on babies who do not have this condition. The toes have a gap between the first and second toe known as a sandal gap, again this can be seen in babies with no problems. Muscle tone is usually poor at birth and may continue to be for some time. This leads to a delay in the motor development and consequently children with this condition reach their physical milestones at a later date than other children.

4) Other physical problems

Although many medications and various therapies have been treatment for people with Down syndrome but there is no effective medical treatment available at the present time. People with Down syndrome have problems about the developmental sequences because they always have the interfere syndrome or diseases as these follows ;

1. Sixty to 80 percent of children with Down syndrome have hearing deficits. Therefore, audiologic assessments at an early age and follow-up hearing tests are indicated. If there is a significant hearing loss, the child should be seen by an ear, nose and throat specialist.

2. Around 40 to 45 percent of children with Down syndrome suffer with a congenital heart abnormality, which may require surgery. Many of these children will have to undergo cardiac surgery and often will need long term care by a pediatric cardiologist depending upon the condition. This may be detected on an ultrasound scan later in the pregnancy but it is not always possible to see. Detection quite commonly is after birth and for this reason all Down babies should have cardiac investigations performed after delivery.

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3. Intestinal abnormalities also occur at a higher frequency in children with Down syndrome. For example, a blockage of the food pipe (esophagus), small bowel (duodenum), and at the anus are not uncommon in infants with Down syndrome. Approximately 6% of children will suffer with digestive problems. Problems with the intestinal tract are also more common and can lead to surgery after birth at once in order to have a normal functioning intestinal tract.

4. Children with Down syndrome often have more eye problems than other children who do not have this chromosome disorder. For example, 3 percent of infants with Down syndrome have cataracts. They need to be removed surgically. Other eye problems such as cross-eye (strabismus), near-sightedness, far-sightedness and other eye conditions are frequently observed in children with Down syndrome.

5. Another concern relates to nutritional aspects. Some children with Down syndrome, in particular those with severe heart disease often fail to thrive in infancy. On the other hand, obesity is often noted during adolescence and early adulthood. These conditions can be prevented by providing appropriate nutritional counseling and anticipatory dietary guidance.

6. Thyroid dysfunctions are more common in children with Down syndrome than in normal children. Between 15 and 20 per cent of children with Down syndrome have hypothyroidism. It is important to identify individuals with Down syndrome who have thyroid disorders since hypothyroidism may compromise normal central nervous system functioning. Diabetes is also more common particularly in adulthood.

7. Skeletal problems have also been noted at a higher frequency in children with Down syndrome, including kneecap subluxation (incomplete or partial dislocation), hip dislocation, and atlantoaxial instability. The latter condition occurs when the first two neck bones are not well aligned because of the presence of loose ligaments. Approximately 15 percent of people with Down syndrome have atlantoaxial instability. Most of these individuals, however, do not have any symptoms, and only 1 -2 percent of individuals with Down syndrome have a serious neck problem that requires surgical intervention.

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8. Other important medical aspects in Down syndrome, including immunologic concerns, leukemia, Alzheimer disease, seizure disorders, sleep apnea and skin disorders, may require the attention of specialists in their respective fields.

9. All children with Down syndrome suffer with more pronounced respiratory tract problems. This is due to the small nasal bridge and the shorter lung capacity. Bronchitis and cold conditions will become more problematical.

10. 1% will develop leukaemia. The reason for this is unclear.

Children with these conditions are now beginning to live a longer life with the advent of improved medical treatment. About 44% will survive until the age of 60 years. It is now recognized that with this there is an increased probability of developing Alzheimer's disease. Again in studies it has been shown that 50% of adults with Down syndrome will develop Alzheimer's disease. The most serious consequence of this condition is learning disability. This is very variable and no test prior to the birth will be able to ascertain this. 10% of children have profound learning difficulties. 70% have severe learning difficulties and 20% have mild learning difficulties. Behavioral problems are much more common.

5) Prenatal Screening for Down syndrome

Over the last 10 years, new technology has improved the methods of detection of fetal abnormalities, including Down syndrome. While there are ways to diagnose Down syndrome by obtaining fetal tissue samples by amniocentesis or chorionic villus sampling, it would not be appropriate to examine every pregnancy this way. Besides greatly increasing the cost of medical care, these methods do carry a slight amount of risk to the fetus. So screening tests have been developed to try to identify those pregnancies at "high risk." These pregnancies are then candidates for further diagnostic testing.

The difference between a screening test and a diagnostic test; in diagnostic tests, a positive result very likely means the patient has the disease or condition of concern and in screening tests, the goal is to estimate the risk of the patient having the disease or condition. Diagnostic tests tend to be more expensive and require an elaborate procedure; screening tests are quick and easy to do. However, screening tests have more chances of being wrong: there are "false-

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positives" (test states the patient has the condition when the patient really doesn't) and "false-negatives" (patient has the condition but the test states he/she doesn't).

5.1) Maternal Serum Screening

The mother's blood is checked for three items: alpha-fetoprotein (AFP), unconjugated estriol (uE3) and human chorionic gonadotropin (hCG). These three are independent measurements, and when taken along with the maternal age (discussed below), can calculate the risk of having a baby with Down syndrome.

- **Alpha-fetoprotein** is made in the part of the womb called the yolk sac and in the fetal liver, and some amount of AFP gets into the mother's blood. In neural tube defects, the skin of the fetus is not intact and so larger amounts of AFP is measured in the mother's blood. In Down syndrome, the AFP is decreased in the mother's blood, presumably because the yolk sac and fetus are smaller than usual.
- **Estriol** is a hormone produced by the placenta, using ingredients made by the fetal liver and adrenal gland. Estriol is decreased in the Down syndrome pregnancy. This test may not be included in all screens, depending on the laboratory.
- **Human chorionic gonadotropin** hormone is produced by the placenta, and is used to test for the presence of pregnancy. A specific smaller part of the hormone, called the beta subunit, is increased in Down syndrome pregnancies.
- A very important consideration in the screening test is the age of the fetus (gestational age). The correct analysis of the different components depends on knowing the gestational age precisely. The best way to determine that is by ultrasound.

5.2) Ultrasound Screening

The main usefulness of ultrasound (also called sonography) is to confirm the gestational age of the fetus (it's more accurate than dating from the mother's last menstrual cycle). Another benefit of the ultrasound can also pick up problems of a serious medical nature, such as blockage of the small intestine or heart defects. Knowing these defects exist as early as possible will benefit the treatment of the child after birth.

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There are several items that can be found during an ultrasound exam that some researchers have felt that may have a significant association with Down syndrome. These findings may be seen in normal fetuses, but some obstetricians believe that their presence increases the risk of the fetus having Down syndrome or other chromosomal abnormality. These "markers" include choroid plexus cyst, echogenic bowel, echogenic intracardiac focus, and dilitation of the kidneys (pyelctasis). However, these markers as a sign of Down syndrome are still controversial, and parents-to-be should keep in mind that each marker can also be found in a small percentage of normal fetuses. In early 2001, a study of Smith-Bindman (2001) was published that looked at all of the previous studies on this topic. The authors concluded that *"[these markers] could not discriminate well between unaffected fetuses and those with Down syndrome."* So the use of ultrasonographic screening for Down syndrome in high-risk women to avoid invasive testing should be limited to specialized centers." (ACOG Practice Bulletin, May 2001)

Many researchers have attempted to find if any combination of ultrasound findings and maternal blood or urine tests may be more likely to determine if a fetus has Down syndrome. The most common ultrasound marker used for identifying Down syndrome is the nuchal translucency marker at 11 to 13 weeks. However, one recent review of the topic (Stewart & Malone, 1999) concluded: *"Results of nuchal translucency sonography are not yet sufficiently uniform to allow counseling of patients on the risk of aneuploidy [chromosomal abnormalities] based on a particular nuchal translucency thickness."* It is important to keep in mind that even the best combination of ultrasound findings and other variables is only predictive and not diagnostic. For true diagnosis, the chromosomes of the fetus must be examined.

5.3) Amniocentesis

This procedure is used to collect amniotic fluid, the liquid that is in the womb. It's performed in the doctor's office or in the hospital on an "out-patient" basis. A needle is inserted through the mother's abdominal wall into the uterus, using ultrasound to guide the needle. Approximately one ounce of fluid is taken for testing. This fluid contains fetal cells that can be examined for chromosome tests. It takes about 2 weeks to determine if the fetus has Down syndrome or not.

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Amniocentesis is usually carried out between the 14th and 18th week of pregnancy; some doctors may do them as early as the 13th week. Side effects to the mother include cramping, bleeding, infection and leaking of amniotic fluid afterwards. There is a slight increase in the risk of miscarriage: the normal rate of miscarriage at this time of pregnancy is 2 to 3%, and amniocentesis increases that risk by an additional 1/2 to 1%. Amniocentesis is not recommended before the 14th week of pregnancy due to a higher risk of complications and loss of pregnancy. The current recommendations by professional obstetric groups is that women with a risk of having a child with Down syndrome of 1 in 250 or greater should be offered amniocentesis. There is controversy over whether to use the risk at the time of screening or the predicted risk at the time of birth.

5.4) Chorionic Villus Sampling (CVS)

Instead of amniotic fluid being taken, a small amount of tissue is taken from the young placenta (also called the chorionic layer). These cells contain the fetal chromosomes that can be tested for Down syndrome. The cells can be collected the same way as the amniocentesis, but another method is to insert a tube into the uterus through the vagina. The method depends on the mother's anatomy.

CVS is usually carried out between the 10th and 12th weeks of pregnancy. Side effects to the mother are the same as with amniocentesis (above). The risk of miscarriage after CVS is slightly higher than with amniocentesis, increasing the normal risk of miscarriage to 3 to 5%. Studies have shown that the more experienced the doctor performing the CVS, the less the miscarriage rate. Early on in the use of CVS, a number of babies were identified with missing or shortened fingers or toes. However, that has been connected to the use of CVS before the 10th week of pregnancy. The same recommendations for amniocentesis apply to CVS. The decision as to use amniocentesis versus CVS is an individual one, and should be discussed thoroughly between the mother and her physician.

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2.3.3 Down Syndrome as Disability

1) Definition of Disability

In society, people with disabilities are mostly on the margins. They are perceived as individuals with a problem, a "victim" who has "suffered" a "tragedy." Individuals with disabilities are considered objects of pity and charity, persons (barely) who cannot work or be expected to take a full role in society. They are a burden (often resented) to be carried by their families or on public welfare assistance.

The official state definition of the Government is found in the Ordinance on Disabled Persons, Article One:

> "Disabled persons by definition of this Ordinance, irrespective of the causes of the disability, are defective of one or many parts of the body or functions which are shown in different forms of disability, and which reduce the capability of activity and cause many difficulties to work, life and studies.

The ministries that work most closely with disability include the Ministry of Social Development and Social Affairs, Ministry of Public Health and Ministry of Education. These ministries have officially adopted the International Classification of Impairments, Disabilities and Handicaps (ICIDH) issued by the World Health Organization (WHO) in 1980. These classifications distinguish between the organ or body-part level disability (impairment) the personal level (disability) and the societal level (handicap). The definitions of disability under ICIDH fall under seven categories:

1.1) Mobility impairment such as amputees, paralysis, cerebral palsy, polio, *down syndrome* etc.

1.2) Hearing/Speech (communication) impairment

1.3) Visual/Seeing impairment including blindness, color-blindness, astigmatism, etc.

1.4) Learning (cognitive or intellectual impairment) impairment including *Down syndrome*

1.5) Strange behavior (usually as a result of schizophrenia or psychotic or other mental illness)

1.6) Epilepsy/ Fits

1.7) Other disabilities not mentioned above

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From these categories, down syndrome are group of several symptoms which are the problems of all level of the organ or body-part level disability (impairment) the personal level (disability) and the societal level (handicap).

In America, the Americans with Disabilities Act (ADA) is the movement which caused some changes of definition , as well as the result of the corresponding shift in public policy. Questions of status and identity are at the heart of disability policy. One of the disability rights' movement, which can claim primary political responsibility for the ADA, is to move American society to a new and more positive understanding of what it means to have a disability

Exception ADA, the United Nations uses a the different definition of disability that is different from the ADA:

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

Disability: Any restriction or lack (resulting from an impairment) of ability 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 limits or prevents the fulfillment of a role that is normal, depending on age, sex, social and cultural factors, for that individual.

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 are available to other citizens. Thus, handicap is the loss or limitation of opportunities to take part in the life of the community on an equal level with others. (U.N., 1983) This definition reflects the idea that to a large extent, disability is a social construct. Most people believe they know what is and is not a disability. If you imagine "the disabled" at one end of a spectrum and people who are extremely physically and mentally capable at the other, the distinction appears to be clear. However, there is a tremendous amount of middle ground in this construct, and it's in the middle that the scheme falls apart. What distinguishes a socially "invisible" impairment - such as the

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need for corrective eyeglasses - from a less acceptable one - such as the need for a corrective hearing aid, or the need for a walker? Functionally, there may be little difference. Socially, some impairments create great disadvantage or social stigma for the individual, while others do not. Some are considered disabilities and some are not.

The example of the social construction of disability is when society discriminates against an individual who may have an "impairment" (in the sense of the U.N. definition) without a corresponding functional limitation. "The power of culture alone to construct a disability is revealed when we consider bodily differences - deviations from a society's conception of a "normal" or acceptable body - that, although they cause little or no functional or physical difficulty for the person who has them, constitute major social disabilities. An important example is facial scarring, which is a disability of appearance only, a disability constructed totally by stigma and cultural meanings. Stigma, stereotypes, and cultural meanings are also the primary components of other disabilities, such as mild epilepsy and not having a 'normal' or acceptable body size." (Wendell, 1996 : 44)

The definition of disability in the ADA reflects a recognition of the social construction of disability, especially by including coverage for persons who are perceived by others as having a disability. The U.S. Equal Employment Opportunity Commission's ADA Title I Technical Assistance Manual provides the following explanations of how this prong of the definition is to be interpreted:

- The individual may have an impairment which is not substantially limiting, but is treated by the employer as having such an impairment.
- The individual has am impairment that is substantially limiting because of attitudes of others toward the condition.
- The individual may have no impairment at all, but is regarded by an employer as having a substantially limiting impairment.

The definition protects people who are "perceived" as having disabilities from employment decisions based on stereotypes, ears, or misconceptions about disability. It applies to decisions based on unsubstantiated concerns about productivity, safety, insurance, liability, attendance, costs of accommodation, accessibility, workers' compensation costs or acceptance by co-workers and customers.

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Accordingly, if an employer makes an adverse employment decision based on unsubstantiated beliefs or fears that a person's perceived disability will cause problems in areas such as those listed above, and cannot show a legitimate, nondiscriminatory reason for the action, that action would be discriminatory under this part of the definition. (Equal Employment Opportunity Commission, 1992 : 28)

The definitions within a statute are related to the purpose of the statute. This is especially relevant in the field of disability policy, as one can find many different statutes, all with different definitions of this term. The purpose of the ADA is to prevent discrimination and to provide a remedy for people who have experienced it. This is consistent with the disability model of understanding disability, which places great importance on discrimination as a major cause of disadvantage. In order to provide an appropriate remedy to the full range of individuals who experience discrimination based on disability, it is necessary to explicitly recognize that there are people who would not consider themselves "disabled", nor would they be considered so by most others, but who receive the same disparate treatment as "the disabled".

The courts have had a difficult time interpreting this complex definition. There are numerous cases in which judges have treated the ADA definition as though the purpose of the law is to provide a social benefit, rather than protect an individual from discrimination. (Gilday, 1997 : 1571) The notion that the ADA should only be used to protect persons who are somehow "truly" disabled reflects an unsophisticated or naive understanding of the nature of disability. Given the significance of social and cultural influences on determining who is regarded as disabled, it makes little sense to refuse to take these same influences into account.

There are many reasons for not identifying yourself as disabled, even when other people consider you disabled. First, disability carries a stigma that many people want to avoid, if at all possible. For newly disabled people, and for children with disabilities who have been shielded from knowledge of how most non-disabled people regard people with disabilities, it takes time to absorb the idea that they are members of a stigmatized group. Newly disabled adults may still have the stereotypes of disability that are common among non-disabled people. They may be in the habit of thinking of disability as total, believing that people who are disabled are disabled in all respects. ...They may fear, with good reason, that if they identify themselves as

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disabled others will see them as wholly disabled and fail to recognize their remaining abilities, or perhaps worse, see their every ability and achievement as 'extraordinary' or 'courageous'." (Wendell, 1996 : 26)

The reason that so many people reject the label "disabled" is that they seek to avoid the harsh social reality that is still so strong today. Having a disability, even though the ADA has been in place for almost a decade, still carries with it a great deal of stigmatization and stereotyping. It is ironic that those who could benefit from the law choose not to do so because they wish to avoid the very social forces that this law seeks to redress and eradicate.

People who may fall under the coverage of the ADA because of the presence of a genetic marker are certainly not likely to think of themselves as disabled. While there may be discomfort at the thought of coming under this label, it is worthwhile to recognize that no one with a disability, visible or otherwise, wants to experience the stigma and discrimination that is still all too common for those who society considers disabled. There are many others who do not consider themselves to be disabled but who do experience discrimination. The ADA provides a legal remedy when this occurs. Since the ADA definition recognizes the social construction of disability, whether it can apply to a person is a function of the social treatment that the individual receives. In other words, the question of whether a person with a genetic marker is covered by the definition does not arise in the abstract. If the individual has experienced discrimination based on the individual's physical or mental characteristics, then that individual may take advantage of the ADA to redress that discrimination.

The nature of disability discrimination is that it often has very little to do with the individual's capabilities and true characteristics. The stigma and stereotypes are the cause of the discrimination, much more than the disability itself. It could be argued that the disability per se is not the cause at all, that the social reaction to disability is the cause. In seeking to avoid the stigma associated with disability, there is a choice of strategies. Social and legal activism that challenge the assumptions behind the disability discrimination address the issues head on. The goal is to eradicate the stigma. The decision to disassociate from those who have historically been stigmatized tends to perpetuate the stereotypes and discrimination.

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The disability rights movement is working towards a society in which physical and mental differences among people are accepted as normal and expected, not abnormal or unusual. There are plenty of methods and tools at our disposal to accommodate human differences. Ironically, the growth of technology in our lives provides us with both the ability to detect more human differences than ever before, as well as the ability to make those differences less meaningful in practical terms. How reaction to human differences is a social and a policy choice to advocate for a social structure that focuses on including all people in the social fabric, rather than drawing an artificial line that separates "disabled people" from others.

2) Models of disability

Disability Policy Scholarships describes four different historical and social models of disability as these followings

2.1) A ***moral model*** of disability which regards disability as the result of sin. This model is historically the oldest and is less prevalent today. However, there are many cultures that associate disability with sin and shame, and disability is often associated with feelings of guilt, even if such feelings are not overtly based in religious doctrine. For the individual with a disability, this model is particularly burdensome. This model has been associated with shame on the entire family with a member with a disability. Families have hidden away the disabled family member, keeping them out of school and excluded from any chance at having a meaningful role in society. Even in less extreme circumstances, this model has resulted in general social ostracism and self-hatred.

2.2) A ***medical model*** of disability which regards disability as a defect or sickness which must be cured through medical intervention. This model came about as "modern" medicine began to develop in the 19th Century, along with the enhanced role of the physician in society. Since many disabilities have medical origins, people with disabilities were expected to benefit from coming under the direction of the medical profession. Under this model, the problems that are associated with disability are deemed to reside within the individual. In other words, if the individual is "cured" then these problems will not exist. Society has no

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underlying responsibility to make a "place" for persons with disabilities, since they live in an outsider role waiting to be cured.

The individual with a disability is in the sick role under the medical model. When people are sick, they are excused from the normal obligations of society: going to school, getting a job, taking on family responsibilities, etc. They are also expected to come under the authority of the medical profession in order to get better. Thus, until recently, most disability policy issues have been regarded as health issues, and physicians have been regarded as the primary authorities in this policy area.

One can see the influence of the medical model in disability public policy today, most notably in the Social Security system, in which disability is defined as the inability to work. This is consistent with the role of the person with a disability as sick. It is also the source of enormous problems for persons with disabilities who want to work but who would risk losing all related public benefits, such as health care coverage or access to Personal Assistance Services (for in-home chores and personal functioning), since a person loses one's disability status by going to work. (Los Angeles Times, 1998 : M4)

2.3) A ***rehabilitation model***, an offshoot of the medical model, which regards the disability as a deficiency that must be fixed by a rehabilitation professional or other helping professional. This model is similar to the medical model; it regards the person with a disability as in need of services from a rehabilitation professional who can provide training, therapy, counseling or other services to make up for the deficiency caused by the disability. Historically, it gained acceptance after World War II when many disabled veterans needed to be re-introduced into society. The current Vocational Rehabilitation system is designed according to this model.

Persons with disabilities have been very critical of both the medical model and the rehabilitation model. While medical intervention can be required by the individual at times, it is naive and simplistic to regard the medical system as the appropriate locus for disability related policy matters. Many disabilities and chronic medical conditions will never be cured. Persons with disabilities are quite capable of participating in society, and the practices of confinement and institutionalization that accompany the sick role are simply not acceptable. and

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2.4) The ***disability model***, under which "the problem is defined as a dominating attitude by professionals and others, inadequate support services when compared with society generally, as well as attitudinal, architectural, sensory, cognitive, and economic barriers, and the strong tendency for people to generalize about all persons with disabilities overlooking the large variations within the disability community." (Pfeiffer, 1998)

This model has taken hold as the disability rights and independent living movements have gained strength. This model regards disability as a normal aspect of life, not as a deviance and rejects the notion that persons with disabilities are in some inherent way "defective". As Professor David Pfeiffer has put it, "...paralyzed limbs may not particularly limit a person's mobility as much as attitudinal and physical barriers. The question centers on 'normality'. What, it is asked, is the normal way to be mobile over a distance of a mile? Is it to walk, drive one's own car, take a taxicab, ride a bicycle, use a wheelchair, roller skate, or use a skate board, or some other means? What is the normal way to earn a living?" (Pfeiffer, 1998) Most people will experience some form of disability, either permanent or temporary, over the course of their lives. Given this reality, if disability were more commonly recognized and expected in the way that we design our environments or our systems, it would not seem so abnormal.

At the present, Down syndrome is categorized in the disability model which recognizes social discrimination as the most significant problem experienced by persons with disabilities and as the cause of many of the problems that are regarded as intrinsic to the disability under the other models. The cultural habit of regarding the condition of the person, not the built environment or the social organization of activities, as the source of the problem, runs deep.

2.4 Conceptual framework

Using concept of Critical Medical Anthropology (CMA) and Social Suffering is for explanation the suffering of down syndrome child 's mother which occurs within unequal relations' system both in micro level and macro level as in the figure 1.

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At the individual level, the basic assumption is that life experience and daily life among the poverty and disparity is the ground of suffering and the more suffering will be in the poorer family.

At the family level, family is the first institute that has influence on life experience both the way of life and way of thinking. Poverty and disparity cover social life and limit the social world, lack of social and political opportunity, unequal accessibility the social service; health and education, and unequal chance to have quality of life or health behavior. Limitation is suffering, though mother may not concern but this has much effect to the future life.

At the community and social level, the political and economical structure limits and discriminates the poor to access the social services and welfare, especially for the poor family which has down syndrome child. Social rules is norm of the majority by the concept of normality and healthy so that down syndrome which is abnormality, hardly had social arena in the normalized world. Medicalization , medical structure , normalization, gender, and patriarchy , are the structure which CMA interests that these have effects to the social suffering of the poor mother who gives birth and lives with down syndrome child. This links to the state/nation level, who has authority to provide the development policy, direction of national development and operates the strategic plan, and health plan.

This study focused and aims to analyze the suffering of poor mothers who have down syndrome children within context of the poverty and disparity and linkage between micro level and macro level with many aspects such as the political and economical structure, and health system as show in figure 2 and 3. The assumption bases on the top-down approach or the influence of the macro or state/nation level to micro or individual level. The suffering in daily life in form of poverty and scarcity is basic assumption of suffering, and will be more suffering of the more poor mother. Moreover the more sufferings are from the political, economical , and health system structure which limits and discriminates the service accessibility of down syndrome. The conceptual framework are as the figure 2 and 3.

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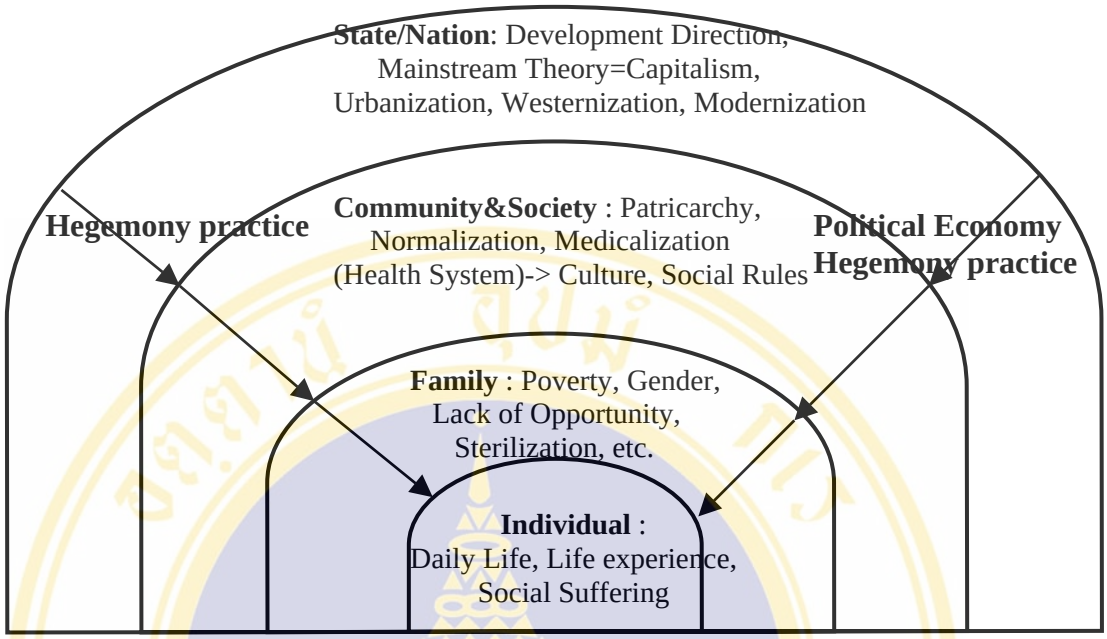

Figure 2 Political Economical Structure and Suffering Influence from macro level to micro level

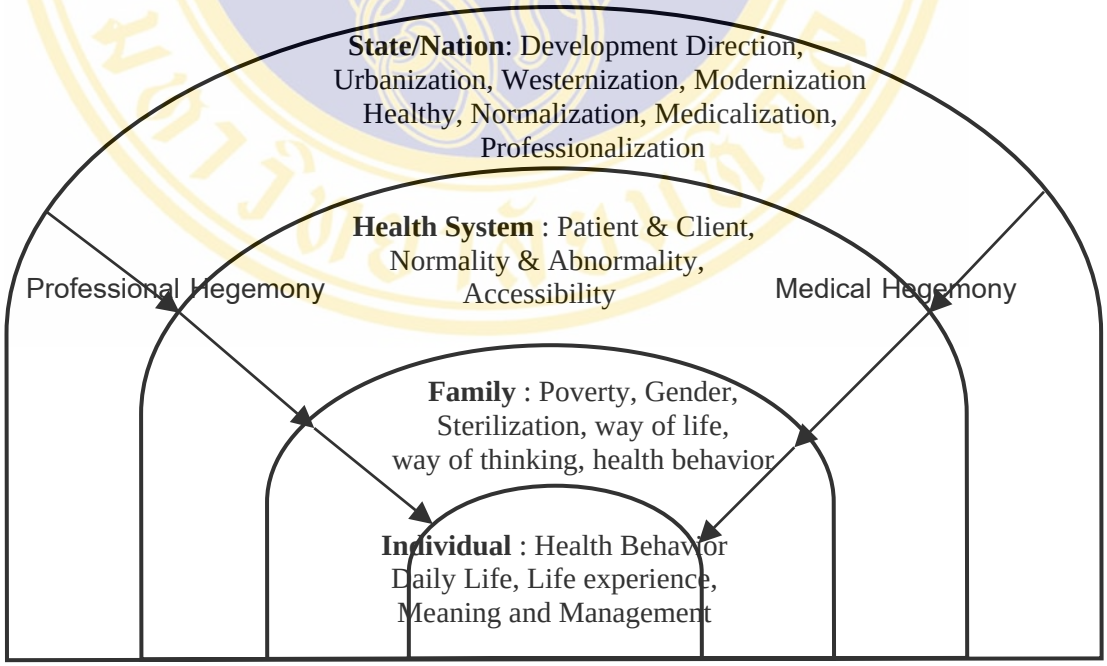

Figure 3 Political Economical Structure and Health System Influence from macro level to micro level

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CHAPTER 3
RESEARCH METHODOLOGY

3.1 Research Design

To study social suffering used qualitative research design which was retrospective study to understand life experience from key informants' narrative. The key informants were selected by the theoretical frame of CMA and Social suffering. This research design is suitable for studying the phenomena which relates to structural factor of individual and relation between provider and patient in health care system.

3.2 Key informants : Down Syndrome's Mother

3.2.1 Why do I focus at Down Syndrome's Mother?

Firstly, my unforgettable memory to the life story of two down syndrome girls and their familes which I knew them during I looked after my son at a hospital. Both of them had suffering which caused from unequal relationship between them and health personnel.

Secondly, it's my concern to the dominance of structural functional theory which makes mothers accept mothers' role to nurture and care their children. I, myself, had ever looked after my son at hospital for a month when my son had an accident and I met the other mothers do like me. Moreover, the hospital's rule permits only women to stay at might with the young patient. I questioned to this rule "why be only women?" and why women accepted it without any question? So the critical concept like Critical Medical Anthropology (CMA) was reviewed to shape my idea and this conceptual framework.

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3.2.2 Why do I focus at the poor mother?

Because of poverty, it made the communication gap between the poor patient and provider. When I cared my son at hospital, I had seen the poor mothers keep silence when they faced to the health personnel. They sometimes be blamed and scolded when they didn't do as the personnel order. One event which still be in my memory, was the phenomena and conversation between a poor grand mother and a nurse as this follows;

Nurse: How many times did your daughter urinate?

Grandmother: (shake her head and answer) don't know

Nurse: Why did you not wear pampers (pads for absorbing urine), often change and weight it at the frontage and remember how many weight? (the reason of nurse to know in and out of urine)

Grandmother: …….(keep in silence)…..

I saw unpleasant face of nurse but grandmother was still be in silence with her calm face. When nurse went out, I asked grandmother why she didn't do as the nurse's order. She told me that she didn't know why she must wear pampers to her daughter and she didn't see the importance of wearing it. The most important reason was "stinting money". These reasons were not in the interesting of nurses but these made me think about illiteracy, poverty and inequity which were the political-economy factors that related to suffering of the poor. These lead me to interest to study the social suffering with Critical Medical Anthropology (CMA).

3.2.3 Key informants and Recruiting

Poor families which have down syndrome child are my key informants which I knew the first one from the advice of the health office and non-government organization which worked with the poor in slum and selected the continued key informants with snowball technique. Providing and recruiting target informants were as these followings;

1) CMA provided theoretical sampling which was purposive selection or to select the extremed key informants who had the theoretical

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characters such as low income, low education and lack of social opportunity which were basis of inequity and suffering. The poor is the target key informant and slum is the target setting for finding them.

2) One character of the key informant was having down syndrome child aged less than 12 years. This indicator was come form the least 2 reasons; firstly, because of health problem of young down syndrome child need treatment, development program and suggestion of health personnel so I can meet them when mothers came to see doctor and get development service at health office. And secondly, this age group accorded to the education so the schooling period can be divided as, pre-school kindergarten and primary level. This division related to one factor which had effected to interaction between down syndrome family and social system; kinship, health care education and economic.

3) The first key informant of snowball technique came from selection and suggestion of non-government worker who has worked in Social Work's foundation and from public official who undertook development work of the sluggish children.

4) Theoretical sampling shaped the selection of key informants which attempted to specify with extreme characteristics and distributed with maternal age, by using 35 year the cut point of distribution. The maternal age, more than 35 year, was the risky period for giving birth down syndrome child.

5) Key informants were 18 down syndrome mothers who had extreme characteristics as theoretical sampling. I stopped at 18 down when I had considered that my collective data was saturated. And I interviewed 4 mothers of rich families for comparing with the extreme mothers.

The obstacles of recruiting key informants were these follows;

- Selection key informants with snowball technique, in the big city which had not primary relationships of community member could not be in one linkage because the key informant couldn't advise the next key informant. And sometimes the next key informant who was advised, not permitted to interview her. So the first key informant always be reset.

- The particular relationship between down syndrome mothers was arose within the health problem condition so it was not in-depth relationship

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which leaded to communicate or interact outside the health service place. It was very difficult for mothers to tell the address and telephone number of others. I took much time to wait for mothers to ask the other poor mothers' addresses.

- Not every body permitted me to go to see and interview. Someone refused and was angry why I knew that she had down syndrome child.

- The address which was registered at public service office not the residence of down syndrome mothers but always be the address of house rent owners. And as we know, these mothers always moved and changed both residence and work, so it's very hard to follow and appoint to interview them.

3.3 Research Setting

1) Bangkok and Periphery. I set this area by these assumptions;

- Bangkok is the center of economic growth and is the target place of rural people to migrate to look for jobs. Slum is the consequence of the rural poor migration and this is the target place to find out the poor family of down syndrome.

- Bangkok in the center of modernity and modern medicine which includes the expert institute of Down Syndrome. This condition makes me study about down syndrome and find out the key informants easily.

- Bangkok and peripheral provinces have the comfort both transportation by the public vehicles and communication by the same area code (02).

2) Key informants came from 5 provinces; Bangkok, Nonthaburei, Pathumthani, Samutprakarn and Nakornprathom. After attempt to looking extremed key informants by snowball technique and decision the collective data saturatedly, I found that the key informants came from these 5 provinces.

3) Slum is target setting. As the above mention, slum is a residence of the poor people so it is the place which I can find the theoretical informants. After I decided that my collective data was saturated, I found that the key informants came from 11 slums or communities (community is the word for calling 'slum') in urban area eg. Thareau Klongtoey community, Bon Kai community, Mahadthai

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community, Bangkoknoi community (beside railway of Bangkoknoi), Arjnarong community (under the expressed way), Hintaak community (Udomsuk), Talaad Phrakanong and etc.

3.4 Researcher as the Most Important Tool

3.4.1 Preparation the researcher's readiness

I realized to the importance of preparation my readiness to study deeply and validly. I prepared my readiness in many ways;

1) Methodology : I studied the concept of qualitative research, interview guideline construction, technique of in-depth interview and observation, recording, analysis and interpretation and applied to my study.

2) Medical knowledge of Down Syndrome : I studied and reviewed the medical literature of Down Syndrome to understand pathology, symtom treatment and development.

3) Theoretical review : I reviewed the theoretical concepts of CMA and social suffering for shaping and conceptualizing my framework.

4) Doing a address's record of poor down syndrome : I copied the records of poor down syndrome from public health service and some parts were from non-government organization and telephone to check the address, setting and how to travel to visit them.

3.4.2 Positionality of Researcher and Validity

I realized that the researcher was the most important tool to access the natures of problem and data, especially the fluid data and different context. For accessing to sensitive feeling, social suffering and fruitful answer, I attempted to fade down my status which may have effect to the key informants' expectation and had been useful for building trust and acquaintance.

I realized to my 2 statuses as the follows;

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1) Academic professional or public health professional.

This status had effect on the expectation of the key informants to my status becomes the general society accepted and put this status as the expert and the prestigious and powerful occupation. Hence, some key informants called me for some help when they had the problem about the sickness and access to health service. Moreover, they called me Ajarn (teacher), Khun Mho (doctor) or 'Khun' (polite pronoun) which showed the perception of the different class between themselves and me.

2) High economic status and more social opportunity.

The key informants welcomed and perceived my status was higher than them, indicated by economic status, income, more right and more welfare. Though, I tried to fade down my different status in many ways; clothing, transporting and outlook but they welcomed and privilege me.

3.4.3 Self-reflexivity

I realized to my status and relation to the key informants, which would be effected to the validity and reliability of data. I realized to the status of outsider, more privilege and the different characteristics which had more power than key informants such as the different economic status of my ancestor and my family which wasn't poor as these key informants. I didn't live with the miserable, uncertain and unsafe circumstance. I had opportunity to have high education, look for good job, have permanent income, be the privilege occupation and have health insurance. I didn't have experience of having down syndrome child, being sexual disadvantage and inequitable relationship between spouse. These were the different symbolic power that I was over them but I tried to adjust and reduce the difference and own self/identity for access the data or reality as the insider' view for reflection the key informants' reality.

3.4.4 Trust and Rapport

Social suffering is sensitive issue which depends on the good relationship between researcher and key informants. Trust and rapport are

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necessary for access the data and data exchange. I built the good rapport by many ways; informal conversation, in-depth interview, interesting the life history and background of family, giving respect by polite greeting and calling pronoun to represent myself and themselves, giving gift for down syndrome child and food and fruit for family, revealing my real status, expression politely, not detesting the inferior circumstance, and not being burden for welcome me.

My success of building good rapport can remark and confirm by several events such as giving in-depth data of life history and down syndrome child during interviewing or conversation, calling from down syndrome mother to invite me to join her birthday's daughter, calling for advice when they had family life problem and inviting me to her son's funeral and, etc. And after finish the research process, I sometimes visited them or called for greeting and asking about these livings.

3.4.5 Research Partnership

The key informants were as partnerships in form of dialectical relationship which emphasized on conversation's participation and interactive. The key informants didn't only answer the questions but they could express their opinions and reflected to my opinion, my understanding and interpretation too. And they sometimes asked some questions, exchanged their opinion and suggested service and practical system and health policy and social for down syndrome situation.

3.4.6 Intersubjectivity

In the procedure of interaction between I and key informants, I placed my heart into down syndrome mothers' heart too. I understood and could absorb their feelings and emotional burden because, I had passed the experience of abnormal pregnancy, breeding from 3 months until giving birth. I was afraid of abortion and I felt abnormality apprehensive and suffered with the doctor's advice to terminate the pregnancy. I distressed and confused to think about the future of living with the disability, but finally I and my husband decided to keep the fetus.

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My experience of suffering made me perceive and could go inside the key informants' emotion so that I sometimes felt sad, and cried with key informants when they narrated their life stories which were so suffering.

3.5 Tools for Data Collection

Interview and non-participation observation were main methods for data collection which consisted of many tools as these follows;

3.5.1 In-depth interview guideline

This was the main tool for collecting the life history, family life and life experience of down syndrome mother from pregnant or prenatal period to period of living with reality of having down syndrome child. The opened question built from research question and conceptual framework and tried out with 4 down syndrome mothers. Guideline was adapted and added the questions to cover the research objectives.

3.5.2 Observation and field note

Interview in the key informants' residence and context of their life's was advantage method for observation and understanding the physical environment, interaction of family member, interaction of mother to down syndrome child and etc. After interview the key informants, the audio and visual picture during interview were wrote in field note such as the seen event of nurturing and domestic violence of mother to her down syndrome child. Including the physical environment of community which reflected the living life of Slum people, was recorded in field note too. Field note help to more understanding the contexts which are political and economic condition of life and is useful for interpretation and discussion the research results.

3.5.3 Record by digital recorder

Record the in-depth interview was necessary method for recording in details and directly coding the word and sentence of the key informants. I used

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small digital recorder which was more comfortable for recording because its small size didn't disturb the interview procedure. However, record must be permitted by key informants. From interviewing experience, I found that the key informants was not serious to the recorder, they narrated their lifer endlessly.

3.5.4 Recording form

Short form for record the data base of disease and health care service of down syndrome child was simply designed for copying from personal book. I copied symptom development, treatment and useful data for understanding the severity of disease and confirmation of health service access. Moreover, I took a short note if there was any remark.

3.6 Timing and Duration of Data Collection

I spent for 8 months for collecting data. It' was a long time because stranding the poor life must be flexible according to the key informants' condition. Appointment date, time and place of interview was very difficult because the almost poor key informants had worked outside community. Their lifes depended on the daily income and this for providing exactly made them work everyday. They hardly had holiday or leisure time and this was the obstacle interviewing plan. Data collection had high flexibility, depended on the key informants' convenience so it had not exactly time and place. Some key informants were interviewed at their offices or worksites, and some were at home and health service offices.

Interview each key informant took 2-3 times and about 2 hours per a time. Not only face to face interview, I also interviewed by telephone in possible case.

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3.7 Data Validity

Realizing the researcher's self, positionality and outsider who many different characteristics which would effect to understand the life experience of down syndrome mothers, was in my concern and I tried to fade down it. However, attempting to fade down my positionality to be partnership with the key informants was the important method to validate the data. The other 3 methods were used to examine the data validity 1) Repeated question or new question which expected the same result or asked the old question but in different time to check the reliability and relevance of data 2) Data triangulation or checking different key informants such as husband (down syndrome father) siblings and kin's to validate the data and 3) Methodological triangulation or checking with different research methods, interview and observation.

3.8 Ethical Consideration

I strictly concerned to ethic essentials for protection the key informants' right especially down syndrome mothers who were in the both status of mother and women which related to gender issues and unequal power. I respected to their human right and dignity by these ways;

3.8.1 Informed consent

The key informants were reelected by the consent condition. For the first connection to each key informant, I introduced myself and my research objectives to them and gave them freely division to be key informants. Only consent mothers were appointed to explain the research procedure in detail, right's protection and confidentiality. And when they certainly confirmed to be the research key informants, I would ask for them to sign in informed consent from.

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3.8.2 Key informants' Privacy

I respected to the key informants' privacy and the key informants' convenience must come first so time and space of interview depended on the key informants' center.

3.8.3 Confidentiality

Though, interview and record had been permitted by the key informants but I confirmed to keep the data confidentiality. Data will be kept in the safe place and presented by the anonymity.

3.9 Data Processing and Data Analysis

I applied the data analysis technique of Jaylor & Bogdan (1998: 134-163) and Colaizzi (1987) as these following methods;

3.9.1 Classify the general data of key informants, from record and personal book in form of frequency by had.

3.9.2 Transform the data form recorder to document, by myself, I listened to recorder and typed the conversation by personal – computer and printed it in form of document

3.9.3 Content analysis was used to analyze the data from in-depth interviews which were as these stages;

1) Recording tape transcriptions: I transcribed the conversation recorded in the tape word by word by word into written documents and typed into text file. The documents were printed for reading and assigning codes.

2) Read the key informants narratives to acquire a feeling and their ideas in order to understand them and assigned codes as the research questions and conceptual framework.

3) Giving codes to documents: I used the computer application program for coding the documents of each key informant. This was aimed to group and classify the data as the theoretical factors and research objectives.

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4) Print the documents of each code: After I gave codes to the documents the data of each code was grouped by the computer application program and printed for easily reading and writing the report.

5) Write the report: Data classification was written according to the research question and research objectives and these provided the sequence of writing results into 4 chapters; The Political Ecology : Life Cycle of Poor and Social Disparity ; Medicines, Its Power and Suffering Experience; Suffering Under Social and Cultural Structure; and Meaning and Managing Suffering of Having Down Syndrome Child.

The process of data analysis is as the figure 4.

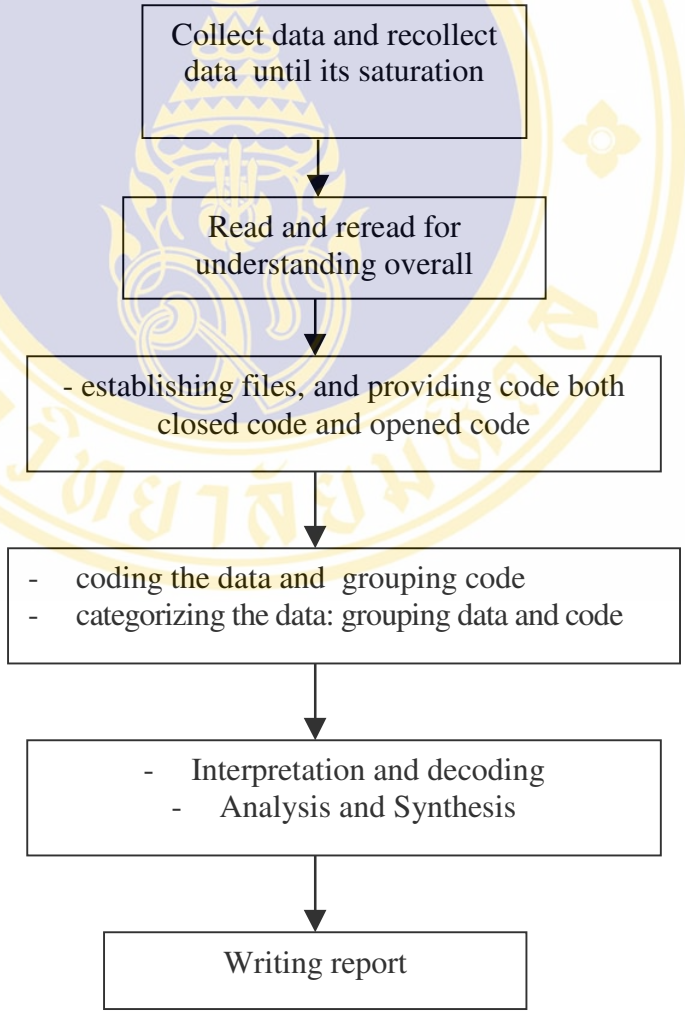

Figure 4 : Process of data analysis

Source : adapted from Colaizzi (1987) , the grounded theory approach (Glaser and Strauss, 1967) and analytical induction (Supang Chanthawanitch, 2540)

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CHAPTER 4
POLITICAL ECOLOGY : LIFE CYCLE OF POOR AND SOCIAL DISPARITY

4.1 Poverty Realization of Down syndrome Child's Mother

Social Suffering of mothers who have experiences on taking care of Down syndrome's Child is studied with the concept of Critical Medical Anthropology (CMA). It is assumed that the cause of “Social Suffering” is emerged more in the people who are living with hopelessness, poverty and powerlessness than the people who are rich or powerful. Similarly, poverty is the major risk factor for illness and suffering. This framework is directed to the selection of specific target group in order to access to the extreme mothers who are poor and lack of opportunity such as illiteracy, threatening human rights and inaccessibility to services. These characteristics has been regarded as “vicious cycle” which is the root of poverty and social disparity. In this regard, it is generally acknowledged that vicious cycle reflects to the difficulty of people to access to the public services and social welfare as the common Thai citizens are deserved to access according to their human rights. The experiences of 22 Down syndrome child’s mothers are recorded and reported. Eighteen mothers are poor and inaccessible to public services which regard as extreme case while another four mothers are recorded for comparing with the target group. The information of comparision these two groups is to understand the different context of social suffering, meaning of Down syndrome and suffering management. The experiences of the respondents are classified by demographic, economic and social characteristics which are categorized into two period of life, that are (1) Lived period I : Childhood in parents’ family and (2) Lived period II : AdultHood in family life.

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To select the mothers, it was started in the slum where is recognized as the place for living of the poor. The poor are realized as the people who live in the troubled economic status. The mothers evaluated and called themselves as “the poor” or “the troubler”. This study indicates the demographic and economic characteristics of the Down syndrome Child’s mother which ensure their poverty life. They are, mostly, the rural poor who has failed from agricultural sector and push them to migrate to seek for a job in Bangkok. There are thirteen mothers who came from the North-Eastern region (Isan). Their occupational backgrounds were agriculture which ten of them were doing paddy field. Most of them completed only the primary school (eight mothers completed grade 1-4 and six of them completed grade 6). It is the different for the rich that they completed high school and higher. For the present occupation, the majority of the mothers are a general worker which are comprised of nine mothers (cook and saleswoman), seven of them are a housekeeper (do not get any payment) and three are a shopkeeper. Their wages are very low. From the economic and social characteristics of the Down syndrome children’s mothers, they can be ensured that the selection of the mothers is compatible with the theoretical selection.

The cut point of age, 35 years is referred to the clinical principle which specified the women who is over 35 years, will be the risk group of having Down’s Syndrome Child. So, the selection tried to cover all those who are risk and non-risk group. The result of the selection is comprised of fourteen mothers who are less than 35 years old and eight mothers are 35 years and over (the youngest is 21 and the oldest is 44 years old). The selection by the critical age point is used to realized the clinical influence on the pregnant and lived experience of the Down syndrome Child’s mothers. Key informants’ selection has been done according to the conceptual framework to explore the poor family.

Moreover, the information of the political-economical ecology of the Down syndrome Child’s fathers also have the similar characteristics of poverty to the poor mothers. They are also a low paid worker. Eight of them are workers such as cook, monthly paid worker, daily paid worker, taxi driver and painter/construction worker. Three are vender and one is scavenger. Conversely, in the rich group, they

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are engaged in the more stable job such as one government official, two businessmen, and one manager of the private company. For the educational status of the poor fathers, they are not different from the mothers which ten of them completed primary school and six completed high school.

There are 14 families of the mothers live in the rental houses/rooms, and four of them live in their own houses (the rich mothers). Three families live in the government apartment and one family lives in the unoccupied building. Most of the mothers live in a unstable and insecure shanty in slum which the wall and roof of small piece of wood, zinc, card box and advertisement poster. Their shanties are in an unsanitary environment that reflect to their health risk and quality of life. For instance, their house are located over the smelly filthy refuse water swamp, which is the breeding place of mosquitoes, and dense living.

Beliefs and religions of the Down's Syndrome Child parents are strongly influenced on their way of thinking and taking care of their children. They are comprised of Buddhist, Christianity and Muslim; eighteen couples of Buddhist, one couple of Christian-Buddhist, three couples of Buddhist-Muslim and one couple of Muslim-Muslim. Understanding the different beliefs of mothers is useful to illustrate the influence of them to the way of life meaning of Down syndrome, and suffering management.

According to the social disparity of the disabled children in the social context which overwhelm with a healthy person and gender inequity that reflect to social suffering which is because of the accessibility to the public services, especially education. The mothers selection is, therefore, considered by the gender and age factor of the Down syndrome's Children. The study is explored on nine mothers who have Down syndrome's son and 13 of them who have daughter. Age group of the children is divided into 4 age groups that are; (i) seven children are lower than 3 years old; (ii) nine children are 3 – less than 6 years old; (iii) three children are 6 – less than 9 years old; and (iv) three children are 9-12 years old. This division is also based on the educational norm which the results are 13

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children who are in school age but only seven of them are studying like general children while 6 of the children are not studying according to their age.

Additionally, the mothers' selection is also considered the number of children and the order of Down syndrome's Child which are influenced by social policy with its background of political-economic conceptual theory. These factors have influence on the suffering of the mothers. This study found that the first child of the six mothers is the Down syndrome and then they never have more child. Similarly, there are seven mothers who stop having more baby after having the second baby as a Down syndrome's child. While another two mothers have more child after having the second child as a Down syndrome. The third child is the Down's Syndrome of six mothers, and four of them do not have more child while two of them still have one more child. The rest one mother has the fourth child as a Down syndrome.

According to the illness perception of the mothers, there are seven mothers who perceive that the symptom of their children are serious. The rest feel that they have already passed the tough time during the early stage after delivery and infant period of their children. Mostly, the sicknesses of their children are congenital heart abnormality, respiratory and gastrointestinal tract syndrome. However, the common symptoms that all mothers face are skeleton problems and slow development.. There are nine mothers who are the main caretaker of the child, while the other five mothers let their child to be taken care by grandparents and three are by relatives. Although mothers are not the main caretaker in some families but they always know about their children because they stay together and also sometimes take care of their children while they are free from work. Thus, those mothers are the main caretaker in compare with other people.

4.2 The Poor Experiences of the Poor

The compilation of the history of the Down's Child mothers from the past are categorized into two period of life time which are; (i) Lived Period I: childhood in parents' family which is the life after born and grown up with their

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poor parents before having their own families; and (ii) Lived Period II: Adulthood in own family life which is the life in poverty with their husband until having the Down syndrome's child.

4.2.1 Lived Period I : Childhood in parent's family, Born and Grown Up in Poverty

I studies the history of the Down syndrome children's mothers from their childhoods after born, grown up and live with their parent. The author believes that this is the origin of poverty which influence these mothers on still stay in the vicious cycle of poverty, illiteracy and sickness. The study indicates that there are nine common characteristics of political-economic ecology of the poor which are composed of ; (1) Agricultural occupation, (2) Low economic status, (3) Less education, (4) Rural-urban migration, (5) Separated family; (6) Domestic violence; (7) Sexual abuse, (8) Limitation of working opportunity and (9) Unstable and insecure residence. The illustration of the mentioned characteristics are described as follows.

1) Agricultural occupation

The backgrounds of the Down syndrome children's mothers are from agricultural families which relied on agriculture such as a paddy filed, orchard farmer and a worker in agricultural sector. Actually, farmer in Thai society is known as the back bone of the nation. It is such a honorable name to admire the Thai farmers. Instead of being proud in that honor, the mothers feel unsatisfied for the troubled life and hopeless in their agricultural way of life. They lived from hand to mouth and were used to starving. Their childhood were spent with helping their parent to work and they were expected to grow up to be a labor force of the family. For them, therefore, agriculture was not the main earning of the family as in the past but it was painful and become a repulsive occupation of someone. Their agricultural occupation can be categorized into 4 types as follows.

1.1 Land owners' farmer : Kaew's and Bass's mother had an agricultural ancestor who had their own land. However, it was a small piece of land and the main labor force was the family members. Most of them were not satisfied

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with agriculture since it was not profitable as they worked hard but gained less income as well as an unpredictable climate and uncontrollable price which insecure for agricultural production.

Farmer's Spirit

Though, the poor farmers had experience with the failure of their cultivation but they can't stop. Most of them felt that it was the farmer's spirit which reinforced them to do when the season come like as Kaew"s and Bass's mother.

> **Kaew's mother :** "My parents are only know how to work in agricultural work. But it was not productive because of droughty climate. Even the rice to eat, it was almost not enough for our family. We lost in investment almost every year. It's better if we use those capital to buy rice to eat instead of planting ourselves. I told them to stop planting but they have never listened to me and said that if the farmer never do the cultivation so what should the farmer do…they didn't know how to do other works, so they only wanted to be a farmer. I wonder why they are still doing. I have never seen them earn any money except in debt…"

> **Bass's mother : a 33 year-old lady** "My father said that we could not stay in rural since the rice price was fallen and effected to the farmer to be very poor. He told that it's necessary to move to Bangkok because he thought that it should be easier for earning. For my mom, her parent were a farmer, so she needed to help her parents. But after my grandpa died and grandma had a new husband and new children, and then they had a dispute on land, so that my mom decided to move to Bangkok to be a street vendor…"

1.2 Land lost Farmers: Some mothers were in the family which had their own agricultural land. However, finally it has been gone to the land lord through selling or pawning. Therefore, their families had to change to work in the different way of life such as agricultural labor, a construction worker and street sweeper as in life experience of Sor's and Afifa's mother.

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The Lost of the Poor Property

> **Sor's mother : a 33 year-old lady**: "My home was somewhere around Meanburi. My parents were a farmer but they have already quit. I wonder why they have done, because the more they work, the more they are poor. We had owned a lot of land but my grandma sold it out. So that her children did not have anything left. That is why my mom don't have any property at all. She must depend on the income of son and daughter "

> **Afifa's mother : a 33 year-old lady** "Formerly, this area was a paddy field and we were the owner. My dad possessed a lot of land. He was a farmer and also rented out his land for other farmers. But he did not save money. Moreover, he has many wives.He paid the money for nothing like gambling in cock fighting . Finally, all his own land was pawned with a Chinese pawnbroker. My mom had to buy the land back but could afford only as big as we constructed the house…and my mom had to become a street sweeper worker of the municipality for earning money for looking after her children."

1.3 The leaseholder farmer : Some mother of Down syndrome's Child are from the families which have not own agricultural land, so they have to rent the land for cultivation as they are strongly attached to agricultural occupation. Unfortunately, the failure in agriculture causes them to change from a leaseholder farmer to be a daily paid worker for their family's earning. This was the reason why they decided to shift from an uncertain job in agricultural sector to a certain earning job industrial sector like as Boss's mother.

> **Boss's mother :** "My parents possessed no land at all, so they needed to rent the land for plantation. Later, my dad was paralyzed so that he could not work any more. My mom was only person who had worked but it was too difficult for her to lead and manage family alone. But to hire someone for helping her was expensive, it was not acceptable, she therefore, became a daily paid labor in the agricultural sector and also did for whatever who hire her to do. It was just only to earn and she has never complained even it was very hard.

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1.4 Being both a farmer and labor : Some mothers were in a family that earned their living by both on farmer and labor. Earning from agricultural cultivation was not enough for a big family, so that their parents had to do a sideline as a labor to earn more for supporting the family as Namwan's mother.

> **Namwan's mother :** "My parents were a farmer but what they earn were not enough for supporting a family because they have many children. They had only expected to have rice to eat so. To work for wages were just only to buy necessary things and to afford for schooling of their children. Because they were poor so they hadn't enough money for buying food so they just took vegetable from the paddy field, and raised chicken and fish to eat…"

2) Low economic status

These mothers lived in poverty in their childhood. It was a life which lived from hand to mouth and struggled for existence. As they stayed in poor living without capital and production which was not lead them to socio-economic development of the families. So the parents always needed child labors to earn more income. This was the factor leading to rural-urban migration in the childhood. This can be illustrated in the conversations of Kaew's and Boss's Mother as follows.

> **Kaew's mother :** "At present, my parent are still living in Rasrisalai District, Srisaket Province (in the north-east) and they are very poor. The rice that they plants almost not enough to eat, so don't speak about profit. They lose in investment every year and this is wonder why they still plant. As hard as they work it means as much as they are in debt and are poorer and poorer. When they have only a drought paddy field which is hopeless, maybe they might not have anything to eat…"

> **Boss's mother** "Our family was so poor. My parent did not possess any land and unfortunately my dad became sick, he could not work at all as he got paralyze. So, only my mom worked for supporting our family. She stopped renting an agricultural land and became a labor because it was too hard for her to work alone. My mom is very patient, she fight without afraid of death. She never complained how hard of her job but just only to gain money, she could … She was alone who took care of four children. Her life is very difficult, as starving at times and have something to eat at times…"

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3) Less education

These mothers were in the family which the children are low educated. They are also the same that they only completed primary school. And then they had to leave the school to became a labor force of their families. The children had not only worked for housekeeping and plantation but they also worked as a labor in farm. They worked for supporting their families and finally became a labor in the city. However, because of less education dued to the poverty, these conditions and effected to the limited environment. Moreover they were grown up in the community which the schools were available only a compulsory education. The more obstacle was their attitude to education that schooling was recognized as compulsory which they just took that time to wait for enough physical growth in order to be a paid labor. To study in high school was complicated and required more money,so higher education was not in the families thoughts and mothers's of thinking.

3.1 Because of poverty : Many mothers hadn't studied in the higher level because of families' poverty. They were accepted to be a paid labor as their duty from childhood. Additionally, the limitation of schooling system in the community which only provided the compulsory level so it leads to the difficulty for the poor in schooling outside the community because that was related to more expenses. Therefore, the poor had less chance to study in higher level as the narratives of Kaew's and June's mother.

> **Kaew's mother :** "My parent have 4 children, I am the youngest one. Every children completed not more than grade 6 and after that we had to move to Bangkok to find job. My brother was lazy to study and he thought that it was not useful to study more, so he finished only grade 4. For me, I completed grade 6 and then followed my friend to look for job in Bangkok. By that time, I was still young and hadn't known about Bangkok. I came to Bangkok without aim. I faced limitation in searching job because of less education…"

> **June's mother :** "When I graduated in grade 6, my parents wanted me to work at home. Firstly, I helped them to work in agricultural area, cassava's field, but after sometime I could not resist on that because it was so hard a work. I could not resist on that so I had shifted to Bangkok until now."

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3.2 Because of broken family : Because of the broken family, the mothers were completed even less than the compulsory educational level. They had to leave the school before graduating the base line educational level as Rung's and Pond's mother.

> **Rung's mother :** "I studied in the community's school in Thamoung District, Kanchanaburi Province. I completed only grade 4 though I wished to study more. I was shut off the educational chance because my mom died and my dad got a new wife and children. It was just like a tale story, My stepmother prohibited me to continue study and my dad agreed with her. From that time, I was at home to take care of my new sister (the step mom children) and to do a house work as well as to work in a sugar cane farm until 12 years old. If my mom had died faster, I might not have chance to go to school at all. I am very ignorant and illiterate…"

> **Pond's mother :** "While I was studying in grade 2 in Nakornayok, my parent were separated. My dad went back to his home in Mahasarakam and took me with him. My mom moved from Nakornayok to Samutprakarn and had a new husband. I did not completed grade 2, though my daddy house was near by the village's school. I had no chance to study so I can not read, write and know nothing…"

3.3 **Because of womanhood :** Less education in some mothers is because of gender disparity as male is more favorable than female in the society. Because of womenhood is the limitation of the educational accessibility and other chances of life. Bengi's mother is the case of the Chinese family which a son is more preferable than a daughter. And Afifa's mother is the case of the Muslim family which does not encourage a daughter to go to school.

> **Bengi's mother :** "My parents were Chinese so they do not like daughter. The daughters were in troubled both the living and education. They did not let us (me and my older sister) go to school… Actually, they expected me to be a son but unfortunately I am a daughter and then they have never concentrated to me. It made me painful. I had to struggle for having an additional study myself. We were not allowed to study in formal education so I studied in non-formal education. My parents said that no need for woman to study

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but she had to do a housework. When I was young, my mom took us to the casino. I had to take care of my younger sister and brother stay in the casino for all days and nights. Really, I grown up in the casino without any concentration of my mom."

Afifa's mother : "The Muslim people did not admire to provide schooling for daughter. Normally, after finishing compulsory educational level, a girl had to leave school and get married. Muslim women have many children because they get married very early… My siblings are 6 which are composed of 4 brothers and one sister. My brothers all are higher educated in the vocational certificate and Bachelor degree. But not for me and my sister, only completed grade 6. After that, I finished compulsory level, I had to leave the school for helping my family through selling food and dessert… My mom is a hard working lady. We had to work hard to support schooling of my brothers…"

3.4) **Because of many children :** Besides having less education, it found that some mothers are "ignorant" or their believe is not compatible with scientific knowledge that effects to health care behavior, for instance, the belief of the birth control with the sterilization. So some families had problems about the numbers of children which effected to the burden of nurturing and schooling which illustrated by the conversation of Namwan's mother.

Namwan's mother : "My parents have many children. My mom is not old but she has lot of children. Actually, there were 11 children but 2 died so finally she has 9 left. She did not accept for contraception and she was also allergic to contraceptive pill. She said that she used to take the pill and then became skinny and weak as well as got blemish on her face. That was why she was scare of contraception."

4) Rural-urban Migration

The study indicated that the hometown of Down syndrome children's mothers in this study are mostly in rural area, especially in the North-Eastern region. To escape from poverty and hardness of rural agricultural

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production, they migrated to the city (Bangkok or its vicinity) in order to find job. Someone migrated in childhood with their family, while someone only came alone in teenager to find job. And some came with their siblings, relatives and friends. The information of 18 mothers who are poor shows that 16 of them are from rural villages of that mostly from the North-Eastern region or known as "Isan" such as Srisaket, Kalasin, Surin, Khonkhan, Ubonratchathani and Udornthani. The migration models are consisted of the whole family migration and group or individual migration.

4.1) **The Whole Family Migration :** The whole family migration means migration all together of father, mother and children as the case of Bass's and Mameaw's mother. Their families moved both their parents'generation and their children the reason of poverty in countryside. The city is the hopeful place for mobilizing their economic status as known in Thai word *"kud thong"* (gold digging). They mostly have settled in slum with their relatives or people who came from the same village as the story of Bass's and Mameaw's mother.

> **Bass's mother :** "The hometown of my parent are in Isan. My dad came from Srisaket and mom from Burirum. They met each other in Bangkok, so that I was born here in Bangkok. At the beginning, my dad lived in Bangkok with working as a construction worker and my mom worked as a street vendor selling dessert. They said that they can not survive in the rural village because earning from agricultural production was not enough. Moreover, their relatives were not friendly so they decided to take the risk in Bangkok where they had heard that it is the place that easier for earning money so everyone expects to *"kud thong"* (be rich) in Bangkok…"

> **Mameaw's mother :** "My parents are from Yasothorn (Isan region). They have moved to Bangkok when they were a teenager for over 30 years. They failed in love in slum… When my mom gave birth (me), she sent me to be and study with my grandparents in the countryside. The reason was because they had to work hard, and no time to take care of me. From time to time, when my grandparents had died, they let me move to stay with them… Stay here until now which, I seem like Bangkokian."

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4.2) **Individual Migration** : It was migration of the key informant generation, but their parents still stayed in the rural and relied on the income of their sons and daughters who had worked in cities. Kaew's and June's mother are the illustration of this model.

> **Kaew's mother :** "My parent still be in Rasisalai District, Srisaket (Isan region). They have 4 children and I am the youngest one. I and my siblings are graduated not more than grade 6 and then had to move to Bangkok for job. It was useless to stay at home because it was only poor and poor and so difficult living… I came to Bangkok with many friends. Most of the rural children had to leave the school for job after completed grade 6…"

> **June's mother :** "I came from Nonthai District, Nakornratchasrima (Isan region). Previously, when I'm a girl my parent wanted me to stay at home and helped them to work in the cassava field. I could not resistto the hard work and sunny so I worked in a farm not more than a year, and then I moved to Bangkok for a better job. I told my mom that I will go for earning and will hire the others to work in the farm as I could not resist to do it myself. At the early stage in Bangkok, I just followed my fellows who told from mouth to mouth for the places which are good to work.."

5) Separated family

Some of the key informants are from the family which father and mother separated or divorced so that the situation of the family members were in troubled. Moreover, their parent had a new spouse that strongly reflected to the children, so that some of them were oppressed. This especially was a reason of childhood migration outside hometown to find job. In addition, the death of parents also reflected to a trouble life of children. The separated family can be divided into 3 forms as follows.

5.1 Mother's death : Some of the key informants had pressure to escape from home to look for job because her mother died and then her father got a new wife. She encountered with the problem on a relationship among father, step mother and step daughter. The situation of Naey's, Rung's and Mod's mother can clarify this particular case.

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Naey's mother : "After my mom died, my dad got a new wife and many new children. Unfortunately, we were not compatible… We had never got any property, so that my sister and I decided to find job in Bangkok…"

Rung's mother : "My dad had many wives, around 3-4 wives and that was why he has a lot of children. Nevertheless his property (land) was not enough to distribute to all children. We just got only 1-2 Rai each. So it's better to move to the other different places… After some times, my dad again had a new wife and child. My step mom was a very envious lady, so she didn't let me go to school. It was just like a fairy tale. And my dad also agreed with her. From that time, I was at home to take care of my sister (the step mom children) and to do a housework as well as to work in a sugar cane farm until 12 years old, my aunt (mom's sister) heard that I was so suffering since my step mom bullied me (let me only do work), so that she brought me with her to Bangkok…"

Mod's mother : "Now I only have dad, my mom died for years. And dad has a new mom. They are now staying there at home. It was just like common, step mom and step daughter are always incompatible. Therefore, we better stay far away…"

5.2 Parents' death

Linda's mother : "Mom and dad both died, so that we, children, scattered to different places. My parent had not much possession, so we let the sisters to stay there at parent's home. By that time, we were young, I was around 11-12 and just finished grade 4 when my dad died. I could not rely on anybody as everybody have their own family. Therefore, I needed to come to work in Bangkok…"

5.3 Separated Parent

Pond's mother "My parent were separated. My dad went back to his home in Mahasarakam and took me with him so that I did not completed grade 2. When I was with my dad, I had no chance to study. So, I can not read, write and know nothing…After my father had a new wife and children, he let me take care of his new

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children…My mom also got a new husband and after that she moved to work in Paknam, Samutprakarn with my aunt. When my mom knew that dad got new mom and child, then she brought my sister and me to live with her and her new husband. From that time, I have lost connection with my dad…"

6) Domestic Violence

Violence in family through physical, mental and verbal action are the results of family failure and social problem. For instance, children of an ex-wife or ex-husband are discriminated from the normal system such as schooling terminated, child labor, neglected child, verbal abuse to child and taking the property by force. Moreover, in the family which father can legally have many wives as proclaimed by their religion, father abandoned mother and let her struggle to live and bring up children alone. This situation is not only hurt the mother's psychological health but also reflects to a negative perception of children to the father and unhappy circumstance.

6.1 Physical Violence : An unsteady relationship of parent results to divorce and follows with a new spouse and end up with physical abuse to a stepchild as a worse relationship of the stepchild and stepmother or step father. This situation happened in childhood of many key informant. They had a hard life as a child labor and physical abuse.

Child Labor

Naey's mother : "After my mom died, my dad got a new wife and many new children. Unfortunately, we were not compatible… We never got any property and if we stay there we had to have quarrel. So my sister and I decided to find job in Bangkok…I have started with a construction worker but it was such a hard work so I could resist on it only for few days. My hands were burnt and I got sick. Moreover, they let us work as a man, but less payment than man…"

Bengi's mother : "My mom only love a son and she hate daughter. So she just brought up daughters without paying any attention. Her

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daughters were in troubled because she did not permit me to go to school, just assigned me to work at home. But for her sons, she sent them to school and supported for higher education. My mom was crazy in gamble. When I was young, she took me and my younger brother to the casino. I had to take care of my younger brother and stayed in the casino for all days and nights… When I was about 8 years, I had to start working in a bread factory. They took advantage on us because they made me work so hard but pay very less. Still I had a sideline job to sell garland. I finished the job around 5 a.m., so that I did not have enough sleep. My life was so terrible, even I am a woman. I had to earn for myself and sometimes gave money to my mom…"

Physical Abuse

Pond's mother : "My stepfather is a drunk man. While he was drunk, he always hit my younger who was a dumb and me. We could not resist for him so that my brother left us while he was 10 and I have no longer seen him after that time. By that time I was 12, after my brother left, so I left home looking for job also …"

6.2 Verbal Violence : Pond's mother is the case of the woman who came from a divorced parent. She moved to stay with her mother and stepfather. Unfortunately, she was not happy to live with a drunk man who always bullied her. She tried to protect herself, but the result was being scold rudely by her own mother and stepfather as Pond's mother.

Pond's mother : "My stepfather was so drunk and wicked… He tried to rape me while my mom was not there, so I cursed at him inconsiderably … I told my mom for his behavior, but instead of believe me, she listened to him and blamed me that I sexually lured him intentionally. She was crazy in a new husband. "

6.3 Psychological Violence : Many key informants were suffered from her separated family. And a legal new family of their father as it is acceptable in their religion. That was also the situation which leaded them to live in a struggle life. This painful situation was the factor for them to live in a sadness, distress as well as hate in their own parent. The story of Rung's and Pond's mother are an example of this issue.

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Rung's mother : " I was sometimes angry in him and wondered when he will stop having more wife. If he was rich, it would not be problems but actually he had nothing and still he had many wives. He left me to live difficulty. It was bad because not only being scolded by dad but stepmother also bullied me. I was really hurt that dad allowed others to distress me, who is actually his own daughter… My aunt heard about his ignorance to me so my aunt was angry with my dad and brought me to live with her in Bangkok. My dad made me upset…"

Pond's mother : "After my father had a new wife and children, he forced me to take care of his new children. My mom also had a new husband … When my mom knew that dad got a new mom and child, she brought my brother and me to live with her. From that time, I have lost connection with my dad…To stay with mom was just similar situation as stay with dad since my stepfather was a drunk person. When he was drunk, he always hit me. He was so wicked so that I could not stand for his behavior. However, I must keep in silence because my mom. Instead of helping me, she was always his backup. In addition, she blamed and scolded me that I flirted with his new husband. It was so grievous for me…"

7) Sexual Abuse

According to the failure in relationship of parent and then they turned to have a new spouse, it caused a problem on sexual abuse to a stepdaughter by stepfather. This circumstance leaded to incompatible relationship between mother and daughter as Pond's mother.

Pond's mother : "My stepfather was a drunk man… He was so wicked, he tried to take advances on me… I was annoyed so I cursed at him. I hated him, I sometimes kicked him when he came close to me… I never respected him…he accused my mom of me and mom was believed him that I sexually lured him intentionally…"

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8) Limitation of working opportunity

As the poor are limited in society, the mothers were under pressure to move to urban area when they were 13-15 years old that was because of poverty and low education. Poverty was the reason to take a responsibility on themselves and their family since the childhood. As they were less education and unskillful labor, therefore, there were not many choices to get job for them. Mostly, the job that they were qualified was a low paid worker such as servant, daily paid labor and factory worker. Although, it was a low social class job as well as an insurable job under a labor law, these mothers were patient to resist in those job. Many mothers were street venders. Those were only for earning a living. For them, these were the way of the poor and to get such a work and earn money was better than starvation. However, the inconvenient of life was not an obstacle for them since they got used to poverty and hardness from their childhood.

Many works were perceived that they deserved to do by the poor or any one who had not choice for working. The occupation of these poor mothers is comprised of many works as follows.

8.1 A worker in household : A worker in household is well-known in the word *"konchai"* (servant). Servant is a plentiful required position in the city of Bangkok because most families in the city are a single family as well as higher economic status. This job is favorable for a newly girl came from rural areas. Moreover, there were many workers in food shop, which were numerously existed in the service and consumptive society of Bangkok, as well as a construction worker. Obviously, they were engaged in a non skilled labor work. Although those works were a tough and low paid work but they tried to resist since they thought that it was a starting point to move toward other jobs.

8.1.1 Worker in Noodle Shop

> **Kaew's mother :** "I came to Bangkok when I was only 13. We worked in a noodle shop somewhere around Sukhumvit. I was responsible for making noodle and delivering it to customer. I could only work following their order… They provided accommodation for

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us. We, tens people, lived together in commercial building of the business owner. I got 1,000 baht salary at the beginning, anyway I was so happy for that much salary… It was a hard and low paid work. I had to get up to work at night since our customers needed noodle to for their shop early in the morning. I felt so bored but needed to be patient. I always thought that if I get a better job I will immediately go away…"

8.1.2 Servant in the household

Linda's mother : "I was still young when I came to Bangkok, around 11-12 years old. I came as a suggestion of friends… I started working as a servant with only hundreds paid salary. Even through I didn't need to do but I had no other choices. I often moved from house to house wherever was better because I had worked but low paid in some houses. I was a servant for many years after that I shifted to be a worker in a noodle shop. This work was occasionally hard and I stayed with the owner…"

Kong's mother : "It was easier for woman to find job but it was low paid work. At the beginning, I came to Bangkok and lived in a rental house with my aunt. She helped me to find job. Firstly, I worked as a servant and changed from time to time. I sometimes worked only in day time and sometimes whole day. Finally, I moved to work in a food shop as a server at the beginning. Fortunately, one day a cook was required, the shop owner allowed me to try so that I became a cook from that time…"

8.2 Construction Worker

Naey's mother : "At the beginning of life in Bangkok, I worked as a construction worker near Bangbuathong with my sister. I could resist for only few days because it was such a hard work that made my hands burnt… My older sister had pity on me so she looked for new work as a servant which was a more comfortable work. After that I become a direct salesperson and finally, the present work is a cook at Isan food shop…"

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8.3 Industrial worker : Industrial factory is one of job opportunity for a girl labor from countryside which growing up base on economic expansion of a growing city like as Bangkok and peripheral provinces. This job is for an unskilled more than a skillful worker with a minimum daily wage rate. In some places provide health insurance as the labor law but some has not. Bengi's mother life is the case of a low paid child labor in industry without any labor insurance and Boss's and Phing's mother are the same.

> **Bengi's mother :** "I worked in a bread factory when I was around 8. I worked so hard but earn very less. If someone played during working time , the owner would be scolded and unpaid… My life was under pressure, they took advantage of me so that I shifted to work in a garment factory. At that time, there were many problems about the disadvantage of the capitalist. I joined with a labor union which sued a wicked employer that was issued on the newspaper and I also was arrested. Because of that mom shouted at me seriously…"

> **Boss's mother :** "I started my work as a worker in the same factory with my sister and friends near Bangkok, Samutsakorn province. I got daily wages… The factory owner paid the same rate no matter what level of education. There were not different in payment for grade 4, 6 or vocational education. I did not see the difference. So this made me wonder why we need to study, it was just waste time. If I had known before I would have came to work early since I completed grade 6, no need to waste my time to continue studying…"

> **Phing's mother :** " At that time, a factory worker was a grandly job that could earn money and this factory was one that required a lot of workers. I've been working here for 20 years, but I still got a minimum rate wages as the labor law. However, I don't have other choices. Fortunately, I've been working here for long time, when the employer fired the workers, they had never fired me. As I'm quite old now, if I have to leave from here, I think I cannot do any other jobs.

8.4 Street vendor : Some of the mothers lived in a vendor family which sell various types of food along the street. They were mostly help their parent for a family business like the cases of Bass's, and Meaw's mother.

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> **Bass's mother :** "My parents like selling. They change to sell various types of food. It was a good job which made they earn a lot… but afterward we had a problem on our property so we needed to move to a new place…thus job also needed to be changed. Mom became a waste picker and I became a seller in a department store. I got a daily payment and some days I work for 2 shifts for earning more. My work had to stand whole day, the employer never be allowed to take rest and sit down…"

> **Meaw's mother :** "My mom was stated with selling dessert, and then changed to sell *"somtum"(*papaya salad). It was the best seller and earned more so it made me didn't want to continue. I must help my mom so late at night everyday and that made me tired which effecting my study… Afterward, I had husband and then I left parents to sell tea juice by myself. I've began from commission earning after that I've changed to self and earn myself which is more profitable…"

9) Unstable and Insecure residence

According to rural-urban migration, temporary living place and low income, these are the limitation for the mothers affordability to live in a sanitary environment, stable and secured accommodations. Most of the mothers lived in dense accommodations, some lived with their employer and some lived in rental house which were delicate, small, dark, dirty as well as located in a filthy stagnant water, garbage and smelly. Moreover, their livings were in an insecure life with drug circumstance. Confrontation to these circumstance is because a cheap rental rate.

9.1) **Free of charge accommodation :** Many mothers lived in the accommodation which provided by the employer. They didn't pay for the rent so thst it was not much comfortable, just only a small place to live as the word that "*suk hua non*" (limited place that fit only for the head) as the saying of Kaew's, Naey's and Linda's mother.

> **Kaew's mother :** "My employer provided a free of charge accommodations in row houses, upstairs was a storehouse as well as residential place. We stayed together for tens. It was so stuffy,noisy and smelly but I had no other choices. So I had to endure because at that time of the beginning in Bangkok I didn't know where to go…"

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Naey's mother : "I was a construction worker, they built a small shanty which made of zinc plate for us wherever we moved to work. It was just a temporary shanty and it was not that good because my employer was a minor contractor… To sleep, pee and shit, it was uncomfortable at all…"

Linda's mother "I started my city life as a servant and after that I changed to work in a noodle shop which the owner provided the free of stay with the shop owner but he was actually rent a house and I stayed with him without payment. Therefore, I got low paid because of free of charge staying with him…"

9.2) **Temporary Accommodation :** Rural-Urban migration is the way for avoidance from poverty so that most of poor mothers setted in the slum and built their own houses in a public area. So these houses were built just simply to be a protection from rain and sunlight which deserved to call *"kratob"* (unsteady shanty) as Taen's, Meaw's, Linda's and Rung's mother.

Taen's mother : "My parent were here (slum beside the railway) for long time, and then they got rights to indicate ownership of the area in slum… We built a small shanty from small pieces of wood and cutout. It was just a shanty to protect us from sunlight and rain. Though we need a comfortable house, but it's no choice for the poor. We reserved our own area and live in the way of slum people… After sometime we were requested to move since that area was required for construction of a convention hall…"

Meaw's mother : "We pay a rental of land to the Port Authority. The rental rate is so cheap and this reinforced us to stay here for long times. So we built a house, should we call it house?... It is actually an unsteady shanty as you see… My parent have stayed here for 30 years. It is just a temporary shanty so no need for renovation. We don't know when we will be moved out from this area so none built the permanent house. In rainy season, it is in a mess, bad smell and tons of mosquitoes…"

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Linda's mother : " It is good that I don't need to pay for land rent, what I have to do is just tried to resist on noisy (along the railway line area)… We used small pieces of wood, zinc, poster and bought cement and some wood to build this house… We put a plank to straddle on a drainage line that is to protect the entrance of any animal… When it rains heavily, there are a lot of insects and reptiles in our place…"

Rung's mother : "Shopkeepers stay at their own shelf, we sleep on it with only a mosquito net, no need to think of house… We used a public toilet of the market. We get used to this situation and never be afraid of any thing because market is always lively whole day and night… No matter how noisy it is, I still can sleep because I get used to it…just to be alive…uncomfortably living is fine…better than to be scolded by stepmother"

9.3) **Low – price rent house :** Hard working but low paid is the reason leads them to live in the low-price rent house that is a dense, small and uncomfortable accommodation as Boss's and Namwan's mother.

Boss's mother : "It is a row house which the owner divided to be a small rental rooms. The room size is just fit for 3 person to sleep, and the toilet have to be shared. This is good enough for a poor. Don't think so much because we must save for my children so the uncomfortable room is just a place to sleep at night."

Namwan's mother : "We stay together for 4 people in a rental wooden room. It is very simple room, including toilet. We live together both brothers and sisters. Sometimes, we cook but also buy from outside…"

The political ecology of the mentioned cases can indicate the basic characteristics of the poor in various aspect. However, it is the truth of an individual life which links to many characteristics that remains these mothers to sustain in a vicious cycle with hardness, limitation and no choices. The author discovered the distribution of suffering in these mothers' life which they have perceived that pain and trouble. However, they get used to those suffering. Moreover, they were

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surrendered to the suffering as they realized that it is the truth of life. They were not questioning to the social disparity such as to be born in a rural society or a poor farmer, to stay in an underdeveloped environment which impact to low quality of life like, to graduate only a compulsory level because there were only a compulsory school in the community, to possess small piece of agricultural land or no property and to rely on agricultural earning which is out of control in investment, to face with the production factor and price and to be under pressure to work as an illegal labor in a childhood after graduated primary school. They have never thought of rights and welfare that they are deserved to be provided. On the contrary, they only accuse of their fate for a troubled life, poverty, scare, tension, anger, unsatisfaction, unhappiness, unhealthy and so on. Those are the situation in their daily life which cover and are the background of these poor mothers'suffering.

4.2.2 Lived Period II : Additional poverty with political ecology of husband

In born poverty and troubled life in childhood with in parents' families were not only limited the job opportunity but also limited the social world which effected to have husband and own family. Namely they were confined by the political ecology which fixed them in a particular socio-economic environment. As they lived among the people who were the same economic status, educational level, and occupation, therefore, they have less choices. Thus, it is difficult for key informants to get out of poverty. The result of this study reveals that the key informant still exist in vicious cycle which is comprised of illiteracy, poverty and sickness. Moreover they are limited in the poor hygienic environment and insecure environment. While poverty of woman plus poverty of a man, the result would never be far away from poverty. This study shown that the most of the mothers married with a man who has the same background which can be categorized into 4 aspects as these follows ; (1) The same background of husband , (2) Troubled life, (3) Inequitable relationship, and (4) Domestic violence.

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1) The same background of husband

This study found that most of the mothers married with a husband who is the same in sociopolitical ecology which are a poor farmer family from countryside, low education and a low paid unstable job. These husband came to the city with the same goal as them, therefore, there was less chances to improve their life. Hence, these ladies still live in a struggle way of life, troubled and disparity as Boss's, Rung's, and Pond's mother.

> **Boss's mother :** "He worked in the factory nearby mine. I met him at the birthday party of my friend. It was like general teenager, after felt in love so we became intimate sexually… His family was very poor. His parents were farmers… He finished only grade 4… I quitted job and went back home after I got pregnancy. And then his parents came to apologize to my parents and engaged me for his son… We had not our own home so we stayed in my parents' house. It was very difficult to get job so that we decided to come to Bangkok. We had only money for a bus fare. We starved and had to stay with unknown person. My husband sometimes needed to ask people for money like a beggar just for a little money for buying milk and food for my son."

> **Rung's mother :** "My husband completed grade 2 like me. We are both dull… Formerly, he was a bus driver but he could not mobilize to higher status because of low education. Then he was taken out to be a ticket speculator but still could not do… He was not healthy, as driving whole day without taking rest. After that, he became a *"Tuk Tuk*" driver who worked specially to pick up vendor…"

> **Pond's mother** "My first husband worked near Parknam as a factory worker. Before separation, we stayed together in a small rental room till we had two children. I left my two children with my mom. My second husband is Pond's father, he was a bus fee collector. He was an irresponsible, drunk, and drug abuse person. He left me with careless on how I will live…"

Most of the key informants express that it is because of their social disparity which confine them in the limitation of education, occupation, daily life and opportunity. Therefore, it is not surprised that they got a husband who are from the same background or political ecology. There are the limited condition which effected to their way of life.

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2) Troubled life

According to the same background of their husband along with their own poverty life, it is the reason that keep them to sustain in a poverty cycle and circumstances. The mothers expressed about their distressful life in slum as Naey's, Bass's and Linda's mother.

> **Naey's mother :** "Firstly, he was good but after sometime he has shown up his real habit. There is not money left from earning. We don't have our own house, just can afford to rent this one. The rental cost is 500 baht per month, it is almost collapse a house which just can protect us from rain and sunlight. I try to fix the floor, it is always spoiled as it was felt down into water. However my children acquainted to it. We can not step heavily… Below the house is filthy water because here is the low flat plain, discharge water and garbage flow through this place… There are millions of mosquito larva so my children get dengue every year… I have no other choices, this is good enough. I can not depend on my husband, so many payment like milk for children, study fee, electricity, water supply which all are relied on me. If I never work, we will not have anything to eat…"

> **Bass's mother :** "I'm still staying with my grand mom since I can not afford to pay for my own house. In this small shanty, we stay for tens. Its floor is not strong, we have to walk carefully as one day it may collapse. It is just only the place for taking rest at night. In the day time, we normally go to work or stay outside because inside is too dark and a lot of mosquitoes… We have been informed to stay here for 4 more years, but after then we don't know where to go. They will use this area for other purposes… This place is not a free of charge, we paid for high reservation cost… Nevertheless, they said that this land belongs to the Ministry of Interior, but I'm not sure for that. Anyway, I just pay otherwise we have no place to live…"

> **Linda's mother :** "This land belongs to the Train Authority. I knew someone who were here before. We came to reserve the land and most resident here are from the nearby place of my husband. We stay in a small shanty which far from railway not more 10 meters. It couldn't be a permanent house as we could afford to build it like this.

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> I used small pieces of wood, poster and old tile from waste bin but I also bought some. Therefore, this shanty is a color roof one… There are so many of mosquitoes and insects because it had to construct over a drainage ditch. There are many of reptiles which appear here when it rains… We have to be careful because we stay on soil. At the beginning, I could not sleep because of the train noise but after a while I used to it…"

3) Inequitable Relationship

Basically, family in the meaning of Thai society is relationship between man and woman along with each other role and duty to sustain the family. The author explores two issues in this aspect which are; (i) sexual inequity and (ii) disadvantage of an expected role.

3.1 Sexual inequity

3.1.1 Sexual Relationship before marriage

It is generally not acceptable for sexual relationship before marriage in Thai society. Though in some culture such as in the north-eastern region, there are the rites to lessen that wrong such as an apologized rite, but that wrong is a violation of Thai culture as well as leads to losing the reputation of the woman more than the man side. The impact was also on her family and relatives. That is because of the patriarchy ideology and biological characteristic of woman. Woman can be pregnant so that the sexual relationship without marriage consequently become the problem such as "neglectful pregnancy" and "pregnancy before marriage". These conditions cause to psychological impact to woman more than man.

a. "Neglectful pregnancy"

Some mothers had experienced on the neglectful pregnancy. Although, the sexual relationship between female and male were happened without force, but after pregnancy the man left her alone. The mothers needed to bear a child, give birth and bring up the child alone. This is not only impact to physical distress but also mental suffering for having the neglected child by an irresponsible man. Finally, this child became an orphan child without father, which made the woman feel embarrassed.

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Naey's mother "My eldest son will complete grade 9 in this year. I had him in Bangkok with my first husband when I was 15. He did not accept my pregnancy and told me to have abortion. I tried to do as he said. My friend gave me a pill to excrete the fetus and I did inserted the cloth hanger to take it out, but I was not success. So that, I surrendered to let him born… and he left me after that. I didn't know what to do, so I decided to go back home in rural… I felt embarrassed, my mom said to have an abortion again but my aunt who did not have children wanted this child. After I gave birth, this aunt help me to bring up my child…"

Pond's mother : "He never bothered of my pregnancy, he just left me alone. I stayed with him in a rental room together with other couples… He was wicked, drunk and drug abused. And also, he got arrested by police, and he was incorrigible… He left me at the fifth month of my pregnancy. He ignored for my living with the burden of bearing a child. Moreover, he showed me his new girlfriend… Let it be like that, I just live alone with my child, even though it is hard for me but I need to bring up my own child.

b. Unwanted Pregnancy

According to social change in Thai society, sexual relationships among teenagers are increased, however, it has not yet been unacceptable. Even though, there is an apologized rite for an unplanned pregnancy especially in *Isan* where they came from which is to reduce seriousness of the problem, however, this type of pregnancy is very risky for a woman on responsibility of a man. It also originates embarrass and mental suffering of woman and her family. Boss's mother is the case of unplanned pregnancy and immature to have a baby. While June's mother is the case of risk in uncertainty of a man. Both of the ladies life are uncertain while their spouses do not worried about the situation as much as them.

Boss's mother : "I was not careful so that I was pregnant. That time I was still young and afraid of abortion. So that I went back to my mom, she never blamed me for my pregnancy since she loves me so much. Fortunately, my husband asked his parent to meet my parent for and apologized rite. If he did not do that, I might be embarrassed. It was a great pity to my parent, they felt disappointed to me, their only daughter, as they cannot depend on me. Other than that they have to bring up my child also…"

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June's mother : "I had already known that he was flirtations. When he was in school, he used to leave many girls. In case which girl got pregnant, he force them to have abortion and then leave her because he was afraid of engagement… I was also afraid that he might leave me. But I didn't know why I allow him to copulate, even I was afraid that he may not be responsible for me… Firstly, he told me to have abortion but I did not agree…as I was afraid as well as unhealthy. So I still carried a child and decided that if he leave me, I will go back to my hometown… His mom known about my pregnancy so she took me to stay together. However, until now my husband have not signed for marriage registration. He said that he doesn't want to be tied with me, and it will be easy in case we break… There is only disadvantage for woman."

3.1.2 After Marriage Relationship

There are a painful life of women after getting married for both legal and illegal married. Many of them stay together until having children. But at the end, it was ended up with painful and suffering of women made by men. For instance, an abandoned woman and disloyalty.

a. Abandoned women

Women were left behind by their husband without looking back. These women and their relatives had to take responsibility on children alone. This case is happed in Pond's mother, her first husband left her alone after having 2 babies and again the second husband left her at the fifth month of pregnancy.

Pond's mother : "He left me even we had 2 babies. He got a new wife. She was shameless as she knew he had wife and children. I went to scold her at her working place but she was still shameless… Moreover, my husband was on the side of her. I wanted to slap her to make her in disgrace. Unfortunately, my husband was on the side of her so that he scolded and slapped me… Finally, we quarreled seriously, I kicked him and expelled him from home. But actually he also wanted to go… He did not care of my 2 babies… Fortunately, my mom help me to take care of them… My second husband was a drug abuse. He used to let me tried the drug but I did not tried… He got a new wife and left me after I was pregnant for 5 months…"

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b. Disloyalty

The problem on third party (woman) disturbance and flirtatiousness of husband bring the key informant not to be the last woman of her husband life. This situation created mental suffering to them as disloyalty of their husband and irresponsible to family (wife and children). It can be illustrated in the cases of Linda's and Bass's mother.

With outside women

Linda's mother : "I could not go out to help him selling because my baby was too young… I did not trust him working alone because there were many girls like him… Nowadays, girls are shameless. When we were in a rental house, she came to propose and kiss my husband in front of me… We quarreled on this topic for many times… I used to quarrel with him at the market after I knew from my son that he saw one lady with my husband. I asked my husband but he did tell so that I tried to sneak him. I was about to hit him with a knife… He also agreed with that bitch as a man innateness… The quarrel of us is often because of this topic. I have been still questioning on him and he blame me on my repeatable question. I can not ask him for his lady, sometimes we fight and he hit me till I was fainted and bled… I have never trusted him as I'm at home and when he is outside, I'm suspicious of his behavior…"

Bass's mother "It is very bad that he is flirtatious. It is wicked of man. In addition, women these days are shameless. She never bother of a family man, what they want just money… He does not care about children when he is infatuated with a woman. My children were crying follow him, he did not take a glance… It was painful. I don't feel like to do anything even eating. I have pity on my children and myself… I was worse after I gave birth and my baby was sick. He was stuck on one lady and did not see baby at the hospital. He gave all his money to that lady… I was in a bad tension, so that I had to find job. Still it's better that my mom take care of my baby… He just came back home, because he has no money so that no girl wants him anymore. It serve him right…"

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With her older sister

Bengi's mother is the case of painful life with her unfaithful husband. He is publicly love another lady and spend the time to stay with her for long time in every year. However, the most painful for her is because that lady is her own sister.

> **Bengi's mother :** "Formerly, he loved my sister, but she had high taste so she went abroad and got married with a German after that she has a restaurant there… Because of that my husband lost for many years, after sometime he came back and became intimate sexually with me… But he still keep in touch with my sister and he sometimes goes to meet her there in Germany. I know everything but my husband said that he goes for working… His sexual desire is endless… But the most painful for me is that the third party is my own sister. I can not shout at her, it is ashamed…"

Legitimacy in Polygamy through religion

The Muslim key informant have to live with suffering and taking care of her baby alone. This is because her religion allows man to have many wives. Therefore, her mother and relatives are needed to bring up her children as she has to work hard for earning and supporting her children to go to school. Her husband rarely gives her money to fulfill the father role, however all the responsibility of taking care of children is taken by her mother and herself. It is a great pity that seem like her children do not have father since her youngest child (Down's syndrome child) does not know the father at all.

> **Afifa's mother :** "My husband is also a Muslim…after he has have a second wife, I have started in trouble because I stayed in his place. Therefore, I have come back to live in Bangkok and he is staying there with his new wife… I better live with my mom, at least I have relatives to take care of my child… My husband house is located at the beginning of the lane. If I see him after my work he will drop me at my home. And if I have to go to work early, I will call him to pick me up early in the morning. However, I never let him enter to my house because my mom and aunt do not like him… They realize that he made my life in trouble. But we still keep in touch and do not

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angry with each other. And also he think that he does not do anything wrong as he never break the principle of our religion…I only have to be patient to bring up my child alone. I can not rely on him since he does not have only me…"

3.2 Exploitation

In this society, men has been regarded to have a major role in family as they have duty to earn a living for the whole family while women are responsible for taking care of children and housekeeping. Presently, social changes pressure on women to work for supporting family. The study found that women are working hard in both inside and outside home. This is because men take advantage of women as well as their own children. Naey's and Boss's mother experiences are the examples of this case.

Naey's mother "…We would have been dead, if I have only stayed home to take care of children. Our saving money was finished. We cannot rely on his salary because it is not enough. His money is only enough for his living… He never give me his money, on the other hand, he take mine. I have been taken advantage from him for everything. He wanted to buy motorcycle, mobile phone and told me that he will pay for it. But finally I have to bear for those cost. We have to rent a cheap house. This one is 500 baht per month. We cannot stay in a better one, since our salary is not enough even for eating… I work as a cook in Isan restaurant with 200 baht per day wage. If I work for 2 shifts, I will get double but I need to work from morning till midnight… I need to work late, otherwise I will get less money. I have no time to take care of my children because of hard working. I'm so tired and have not enough sleep. But still he find fault with me that I have a new husband… These days we only rely on my money… My eldest child hate her father. She said that she is in troubled because of her father. She is only 10 but she is responsible for everything. After school, she cannot go to play as general children but she has to take care of her younger brother, cook, make milk and do her homework by herself. I never have time to take care of her. She has no chance to go for tuition unlike her friends…"

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> **Boss's mother** "When he has money, he gave all to other women. But when his money is finished, who will like him. So that, he has to do a low paid work. It is not possible that a guard salary will be remained because he owes many people… We cannot stay home because the creditor come to ask for installments and shout to him everyday. I need to work as a seafood salesperson. My job is started early in the morning and finished late because I work for 2 shifts. I need to get money so I have to be patient. I have to stand whole day till I got migraine so that I always take medicine along with me. I depend on my mother for my children. The elder children take care of the younger ones after their school. I come back home very late so that the children, already slept and again I have to get up early in the morning. I go to work after preparing clothes for my children. I really have no time to meet them. I sleep deathly when I go to bed…"

4) Domestic Violence

The author indicates from the study that there are 3 type of violence in family which are psychological violence, physical violence and sexual abuse. In some families, the violence are occur only one type while in some families many of the violence are existed. These violence lead to disappointment which are burnt inside ones heart and expressed in term of temper, words and physical reaction.

4.1 Psychological violence

Besides the husband behavior to sexual relationship disadvantage of wife, the mothers reveal their mental suffering to the author. Pond's mother life is the case of a woman who realize the badness of her husband. He does not want to be bad alone but tried to influence her to become like him. Bass's mother is the case of wife who angry with her husband for the creditor who scold at her and her relatives rudely.

> **Pond's mother** "We stay together many people. He invites his friend to drink and take drug (amphetamine) every evening. It is not enough for him to be wicked alone, so that he persuades me to take with him also. Anyway, I did not…"

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> **Bass's mother** "It's very painful, when he is fascinated with other girls. He never bothers for children… We did not allow to continue renting the house. We have nothing and owe for hundred thousands… I have to move to stay with my mom. Without mom, I might be in a big trouble. She is very old but still work to make a living of us… It's hurt me so much when the creditor scold all of us rudely… My parent do not know for his debt. I have a pity on my parent. They never blame anyone, whatever anyone say, they just keep silence. However, I know that they are thoughtful because they always have headache…"

4.2 Physical violence

Generally, it is acknowledged that physical violence is only the action of hit and kick, etc. which wife is done by husband. From the author point of view, there is another type of physical violence which can be clarified in the case of Linda's mother. It is found that an unintentional physical violence is existed that is an unplanned pregnancy. Due to numerous number of children and a heavy burden that a wife cannot bear, it leads to abortion which originates pain and suffering. Therefore, it is clear that this situation is another type of physical violence according to Namwan's mother case.

> **Linda's mother** "…Such a wicked man, whenever I talk about his girls he always hit me. He used to hit me hardly till I fainted with full of blood in my mouth. I could not take spicy sauce for many days…"

> **Namwan's mother** "When I was carrying this child (Down's syndrome child), I tried to discharge the fetus because by that time my eldest child was young, still taking my milk. I was afraid that I cannot bear a new baby so that I tried every way to get rid of let the fetus. I was afraid that it may harm to myself… My mom sent me an abortive pill. I took it but I was not success. I didn't know what to do since my baby was strong. So that, I had to let this baby born because I was afraid that I may die first…"

4.3 Physical and psychological violence and sexual abuse

Unforced sexual relationship between husband and wife is a normal relationship in society. On the other hand, sexual abuse between a couple

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is an unbelievable case in the family life. In this study, the author discover at least 2 couples have the problem on sexual abuse which includes physical and mental abuse. It is the worst situation which hurt a wife deeply. The conversation of Naey's and Bengi's mother reflect to this particular case.

> **Naey's mother** "He is drunk and jealousy… I finish my work late and he think that I have sexually intimate with another man. He goes to scold me at my working place… Nowadays, he only relies on my salary. If I don't give to him, he will hit me. He always shout at me and hit me. He drink everyday. When he is drunk, he is just like a dog… Some nights I am too tired, don't feel like to have sexual intercourse. He tied me with rope and rape me. He is just like animal…last night he punched me and then forced me to have sex with him. He is a sadism… When he paunch me, my children try to stop but he kick them. That's why the children are afraid of him when he is drunk… Every one here know about my problem but no one dare to help me. I used to notify the police but they said that it is just a couple quarrel… My face often swollen, when I step into the hospital, doctor immediately know that I have been punched again… My eldest child hate her father. She said that her father made her in trouble… I sometimes want to break off him but still have to be patient because I don't want to create problem to my children…"

> **Bengi's mother** "He has done like I'm a beggar when give me money… Though I do everything. If I am not busy with taking care of children, I will work and earn myself, I sell dessert… I'm not tried. But I still wonder about him that he often goes to meet my sister abroad. I know that they are still an sexual intimate. My husband is not fulfilled for sex… After his job, he drinks 1-2 bears, and then come to me and start quarrel. If he does not satisfy with my words, he will kick me even during having dinner…When he need sex, he sometimes scratch the wall just like a dog and he has to have sexual intercourse right away… If I don't surrender, he will not satisfy me and will not give me money… He acts like I'm a prostitute. It is hurt me…"

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Summary

In this chapter, the author indicates the political-ecological aspect of the Down syndrome child's mother which is the complex interrelated fundamental aspect of poverty. For instances, the major occupation which depend on agriculture, economical status, low education, migration, violence in family, limitation in occupation and social disparity. The 2 periods of life are presented which are childhood life with parent and family life with husband. This presentation is aimed to illustrate life cycle of the poor. The duplication of poverty from family structure, community and society are revealed. The mothers were born, grown up and lived in poverty cycle, although they tried to run away from poverty but were not success. This is due mainly to the context or the place in society of them are limited. Therefore, opportunities and choices of them are also limited which are the way of living, education, occupation and social opportunity. Furthermore, they still stay among people who have the same character of poverty when they go to the stage of having their own family. The political ecology of these Down syndrome child's mothers can be showed in the figure 5. The experiences of the mothers indicate clearly about living in a cycle of social disparity. They would never have escaped from poverty and trouble even though they have their own family. In addition, it is found that structural factor such as religion, disadvantage in social relationship and social violence result in history of these women which is really painful as they have to resist in suffering and they are not deserved to question on the origin of those sufferings.

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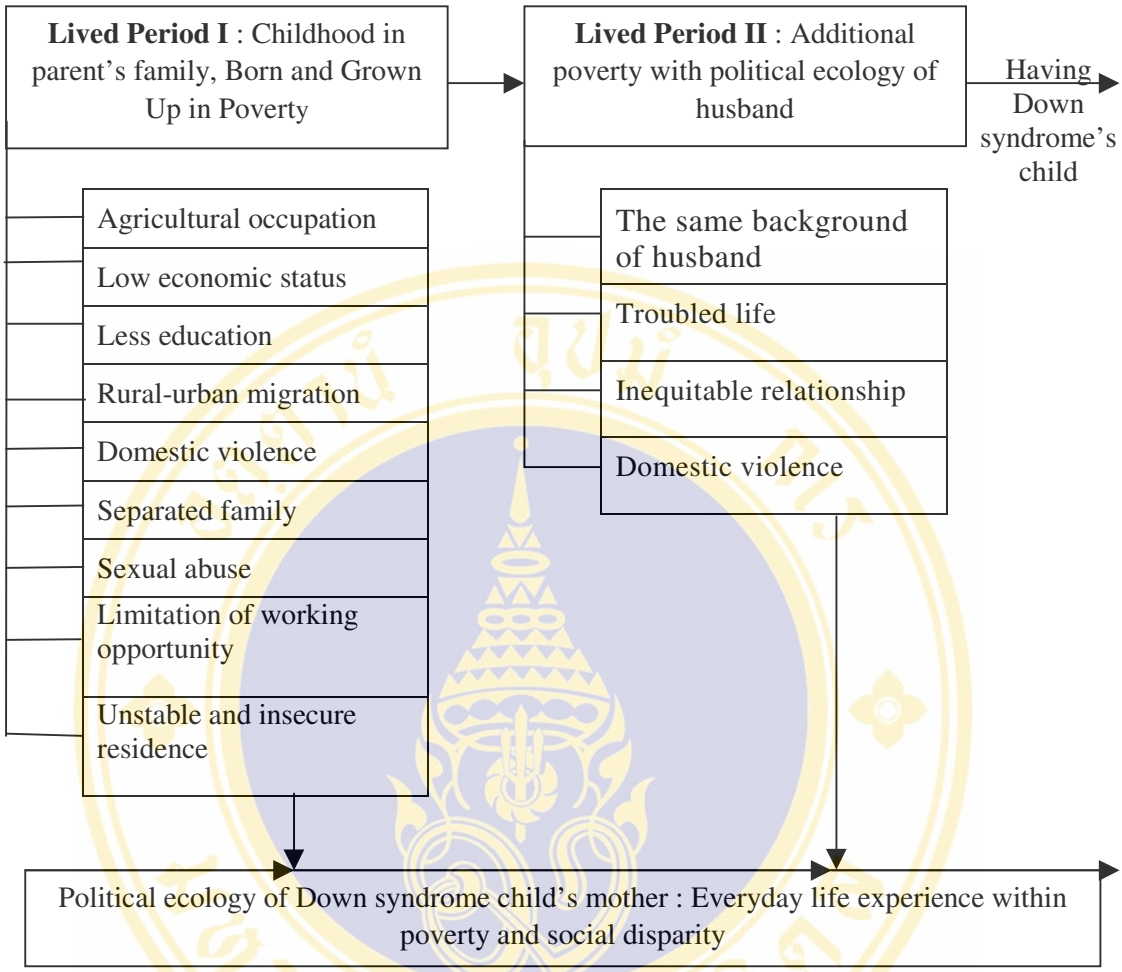

Figure 5 : Political ecology of Down syndrome child's mothers

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CHAPTER 5
MEDICINE, ITS POWER AND SUFFERING EXPERIENCE

From the study on suffering experience of mothers who have a Down syndrome's child under the medical influence, the author found the gaps of relationship between the medical services' system and service receiver or client (Down syndrome child's mother), and the relationship of medical personnel and Down syndrome child's mother . There are 2 aspects as the following presentations.

5.1. Communication gaps between medical personnel and Down syndrome child's mother which are comprised of ; 1) Medical versus popular knowledge, 2) Moral problem between medical knowledge and motherhood , 3) Bad news of unexpected baby, and 4) Down syndrome child …valuable life or worthless object.

5.2. Medicine, Power and suffering which are comprised of ; 1) Medical procedures as burden and sources of suffering, 2) Poverty plus abnormality is as Marginality, and 3) No money, no treatment.

5.1 Communication Gaps between medical personnel and Down syndrome child's mother

5.1.1 Medical and Popular Knowledge

Normally, Pregnancy is a pleasure of family and child refers to a valuable thing in family life. Nine months of pregnancy are the time of happily and hopeful waiting for a new born baby. However, this happily period was intervened by the medical knowledge and technology to the reproductive health and process management of women's pregnancy. It discloses the secret life by using medical technology and science such as prenatal care, investigation and risk assessment, fetus

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development explanation, abnormal screening, and examination genetic and chromosome which result to Down syndrome. And especially, the knowledge on over 35 year-old-mother pregnancy which is the risk age to have a Down syndrome's child. According to the medical principle, the cut point of pregnancy observation is 35 years old so that mother should be recommended to be investigated for the unusual chromosome that is the cause of Down syndrome. Moreover, the abnormal finding of the screening always leads to recommendation of abortion. The study indicates that mothers had experienced various unusual medical process and faced the covered suffering on surrendering to the order to do or not to do things. Especially for the poor mothers, they have their backgrounds and reasons which are very interesting but uninterested to the medical system. Those reasons mostly base on the poverty which impact to health behavior such as the decision on not to do chromosome investigation. Actually, the deniable decision of poor mother easily happens among the difficult and inedible medical knowledge and the supportive reason of high expenditure for abnormal investigation. So the poor mothers are not ignorant but they have the better reason on their views and they look for other choices that are suitable for their status. Exception the poverty, less education and less knowledge are the supportive factor to the decision on having medical services or not.

Phing's mother is the case of a group of the old-age-pregnant mothers, She was recommended to investigate for an abnormal chromosome in the period prenatal care. However, she neglected to those suggestion as it was unexpected, over look and uneducated on this matter. The main factor which she concern was the expense that related to her living. She worried more about her hardly earning which is an concrete object to use for making living than the recommendation which is unforeseen and doubtful. The medical suggestion and information were meaningless for her as illustrate in the following conversation.

> **Phing's mother :** "I wanted to have a baby with my present husband. I knew that I was old and had lost a child before. When I was carrying Phing, I was 39. I had a prenatal care at a private hospital… At the third month of pregnancy, the doctor said that I need to be investigated the amniotic fluid because I was old and the previous child was not normal. So that it was risky to have an abnormal baby again. The doctor made an

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> appointment with me and told me to bring 3,500 baht for investigation cost. It dismayed me, but still I thought that I could gain that much money… The doctor continued telling that he would not be responsible for any mistake of the investigation… I was wondering since I had to pay a lot of money but it was still risky. Therefore, I asked the doctor that it would be fine or not if I would not go for the investigation. And he replied "it depends on you" and just said nothing after that. Finally, I said to him that I would not do… I thought it was not an important investigation because the doctor never encouraged me to do, he just kept silence… Actually, if its cost was not much expensive I would go for it even though I have to take risk… When the doctor made appointment with me, I normally asked him for the cost and if it was too expensive, I could not afford… I met the doctor in every appointments and he said that the fetus movement is normal but not much big. So I thought that I'm small, so it is not possible that my baby is big… Moreover, the doctor checked my blood but he did not say anything. I wondered why the result did not show… I felt disappointed as the doctor knew that the Down syndrome's baby is a heavy burden, he should try his best for the poor to be provided the investigation because having the Down syndrome's baby is more expensive than the investigation cost… Actually, to make decision for investigation was also depended on responsibility of the doctor. Like this doctor said that he would not be responsible for both the cost and risk. If he have said strongly to me to be investigated or to have abortion, I would have been agreed with him… But it was hard for the poor, whatever we do, we have to think of money in the pocket 3,500 baht was not less, I had to work for months… To be born as a poor is more terrible…"

In the below-35-years-old-pregnant mothers who are not defined as a risk group, they mostly said that they were not informed about abnormal or Down syndrome's baby during their prenatal care. Majority of them had acknowledged about abnormal baby and had negative impression on that kind of baby from their lived experience. They were under the ignorant circumstance since the doctor did not inform them about Down syndrome. That ignorance reflected to fearless on the abnormal or Down syndrome which might be existed while they have nausea during their pregnancy and complications. The mothers were worried for an unforeseen future just the reason of the nature of pregnancy. So, it was a natural worry which happened to every pregnant mothers.

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5.1.2 Moral Problem between Medical Knowledge and Motherhood

1) Medical Communication with the doubtful message

Fluk's mother : "I was wondering how come I got pregnant as I was using a contraceptive ring… I went to the clinic for a prenatal care but the doctor suggested me to go to hospital with the reason of the pregnancy over 35 years . I was curious why I had to go to hospital and at the that timeI thought that he would be afraid of the danger affecting from contraceptive ring to me… When I went to see the doctor at private hospital, he asked me with a strange question that didn't I think to do anything for I was too old for pregnancy. But I was not attracted by his words, it's really nonsense for me. I'd only thought that he might be worry about contraceptive ring that would harm to the fetus. At that time, I never thought of Down syndrome's child and hardly known it…"

Bee's mother : She is an exporter's wife and has high education. She quitted a government job to stay home for just taking care of her daughter and sons. She narrated that "I was 37, when I was carrying the third baby, Bee. Actually, I realized that I'm old but I've never thought of this problem since everyone in my family, like my mother and sisters, mostly had babies at their old age… I went for prenatal care at the private hospital with a familiar doctor. The doctor also told me about the risk to have an abnormal baby at my age. Anyway, the doctor did not tell me seriously for that nor encourage me to be investigated. He just told me to observe myself for an abnormal symptom and will take action accordingly. Well, by that time I just listened unintentionally and did not think of chromosome investigation because it was not in my mind or my worry at all…Until now, I've concerned that It was a very important matter and I wonder why the doctor wasn't serious. He should intentionally made me understand, informed me seriously and tried to make me realize its important. Since, no mother think that the baby will be abnormal. I knew that it is risky to have baby at the old age, but I had no idea about its seriousness…"

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Poor mother who are pregnant in the older age results in accessing to information and investigation due to illiteracy and economic factor. The poverty and economic condition limit the poor to access to medical services. This study, however, indicates that the rich mothers do also deny to investigation according to the doctor advice. This is because of the main reason of unclear communication on Down syndrome information. Fluk's and Bee's mother are the instances of this issue. Both of them were pregnant at over 35 years old. In their opinions, the decision to deny prenatal investigation was the result of unclear information of Down syndrome given by the doctor. It effected to lacking of mother's interest, attention and making the wrong decision. From their points of view, this result is not only their own mistake but also the doctor who does not clarify the message which is a part of one reason that made the Down syndrome child's existence.

2) Inconsistent thinking between physician and client

Kwan's mother "I was almost 40, when bearing a second daughter. I actually thought that I am too old and unhealthy. But I wanted to have one more child to accompany the first one… When I went for prenatal care at the private hospital . The doctor suggested to do amniotic fluid investigation for safety reason to both of my health and child. He explained to me and gave me the document to study. He made an appointment to investigate at the fourth month of pregnancy… I somewhat less knew about abnormal child. And after the doctor said, I rethink of that and tried to look for more information. I went to Rajanukul hospital which is well-known and expert for mental retardation and down syndrome. I had found out the information as much as I can. That was because of anxiousness. During waiting time for investigation, I was nervous and tried to learn to support the decision making… Firstly, I thought it is better to investigate, in case we found any problem so it could be protected. I discussed with my husband but he did not agree. He said that let it be for what will be happened, what to do with the result of investigation. And he also gave his idea that it would annoy us because in case our baby is abnormal, there must be only one choice to have abortion in which would make us more painful and would eternally be in our memory. He questioned me about the reliable result, in case the baby is not actually abnormal

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and we get rid of the baby, that is a sin. He told that if the investigation did not provide us any other choices, so that we're better not to go for it… He decided to deny the investigation of the doctor at the appointment. The doctor was curious but he did not say any words… Finally, we did not check with the more reasons of my husband that if the investigated result was abnormal , doctor will suggest to terminate the pregnancy which it is against to our belief (Christianity)… Although the baby is a Down syndrome but his/her life is valuable so that the doctor has no rights to judge for uselessness of human being and eliminate him/her by abortion. Pregnancy termination as the doctor's suggestion is cutting off their chances for being life. It is useless if check for only to have abortion since it will result in more tension. Though, we have high income but I am also absolutely painful if having a Down syndrome's child. Nevertheless, she is better than other mothers as she gained numerous information of Down syndrome. At the same time, it is such scary information for the possible symptom and sickness in her perception. Other than that there are also the protective measurements as

3) Pregnancy value and motherhood

Ping's mother : She is a psychological nurse who is familiar and really understands the matter of abnormal children and she narrated her experience that "I have a problem with ovary, so that it is very hard for me to have a baby. I tried for long times and finally I was pregnant through medical process "Gift" which got a triple baby. For my family, it was too much for having three children. I expected to have only two because I was afraid of a heavy burden. Doctor also advised me to keep only 2 since the baby might not strong enough if there were many at the same time. Though that suggestion according to my expectation ,but how I could get one out. It's not easy to decide to destroy which baby as the doctor said I have to take a risk to choose one off… I scared for it was a artificial pregnancy, if something have been wrong I would have not got anyone. But to choose one off, it was very difficult to decide so it depended on the doctor. The doctor even did not know which one to be selected, what he needed to do was taking a risk to pick someone. That was a careless thinking and the doctor can do easily… But for mother, it is hard to do like that as all three are lives. I could not make any

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decision. Therefore, I discussed with my family, and my parents said that it is a sin… so don't do that, just let it be… Finally, I decided to keep all babies as we came this far…"

Mod's mother "I have had sexual relationship with my husband for 10 years long and I was successful for having a baby at 38 years old. It's very difficult to have one. Previously, I went everywhere to seek for a way of pregnancy especially for praying and asking for popular Buddha for having a baby, until success… I was so happy to know that I was pregnant. I have to make a thank offering in countless number of my vow… I've never listen to anyone for a burden of having child at the old age even the doctor because I think that it is better than I have none. Moreover, I did not think that I am too old to have a baby at 38 since there are many older women who can have baby… I went to the public hospital for a prenatal care. While I was carrying a baby for 3 months… The nurse said nothing, just only said me to take good care of myself as I was old and if I have any problem just come to see her. She advised me for nutritious food and did blood checking as well as physical checking. And then she gave me supplementary pills. Everything was good. Actually, I was not that elated and nothing unusual. I even was not nauseous in pregnancy. I could eat a lot and whatever I wanted to eat my husband tried to get it for me. I, therefore, gained 20 kg. I was too fat to work…Abnormal screening or investigation was not came into my mind. I did not even know what is Down syndrome so that I did not worry about anything… Nurse never told me for anything, so I did not pay attention on that. However, if she told me, I would not go for such investigation. The only thing in my mind is have a baby after waiting for a long time… I listened whatever the doctor said, there was no point for me to ask him more as I might annoy him… just so happy to have a baby…"

The both Ping's and Mod's mother are the example of women who faced difficulty in having baby. Therefore, they tried every way to make the dream comes true. Thus, when they were success, it was the meaningful time of their waiting and hopefulness. They did not think of a special investigation nor pay attention in warning or doctor's suggestion that was because their most desire was to have a baby. Investigation, hence, was not desirable measurement as they did not want to create any impact to the baby that resulted in disappointment of no chance to have baby at all.

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5.1.3 Bad News of Unexpected Baby

A healthy baby is an expectation of every mother who is giving birth, especially for poor family because children are not only the meaning of the families' loveliness but also the meaning of mode of production. Moreover, the religious belief according to the obligation structure which have been continued from the past to present day has effected to their meanings. So , Down syndrome's child is generally not desirable. Additionally, the perception on the Down syndrome's child has been realized from seeing, telling and lived experiences which the Down syndrome's child , it has been placed in the context of disordered and abnormal child as naming that "Punya-oon" (mental retardation). Hence, it seems like to have a Down syndrome's child is an additional troubled to enhance their suffering.

1) Different meaning between medical personnel and mother

Mameaw's mother : "During the delivery, I heard the nurses called my daughter that *'Nongdown"* (Down syndrome's child), it made me thought of the stars on the sky at that time. I imagined my baby should be very cute as they called "Down" because "Down"-means "star" in Thai word and we always used for comparing to the positive things. I waited for the time seeing my daughter. One nurse came to tell me that I got a Down syndrome's baby. By that time I was not shocked as I still impressed with the word "Down" which is a nice name. And also I never expected about Down syndrome. But, after they said more, it is just like *"Sayan"*- name of a slow development joker.… I was shocked after realized the reality. I felt so bad because it was absolutely contrast from "Down" (star) to "Down syndrome'. I could not stand for that and I even forgot to cry. I was confused, painful, astonished and chaotically think of the future. At the importance, she told me while I still be weak and painful from delivery so that how I suffer to her informing. After telling me, the nurse left me alone that was more sorrowful. When I had a present of mind, I really realized that my baby is abnormal so that I cried out loud. It was such a bad time and I felt lonely in the meantime nobody came to visit me. I cried like a heavy rain… By that time I thought that Down syndrome is very severe like a paralyzed and sleep

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unmindful over dirt as I have seen in the countryside… I asked my next bed to make a phone call to my mom to accompany me because I was in thoughtfulness and could not stop crying. I cried the whole day and night when I thought of my baby during I was in convalescence. You know, I did not even look at my baby face when the nurse brought my daughter to me. I could not except but it didn't mean that I hate my baby. Actually, it was because I felt totally disappointed as I expected to have this baby so much… Nurse realized my sorrow, so that she took the baby back and told me to take some rest. Anyway, I could not take rest but kept crying till I was scolded by a nurse… My next bed also said that my baby had not died why I cried that much…"

The suffering from giving different meaning between Mameaw's mother and health personnel reflected the communication problem which did not concern to the client perspectives. Naming "Down syndrome" based on medical background and history and was used to call with that word without translation into local language. Moreover, the local people also have their own words of language which refers to the concrete meaning. Therefore, the patients's perception and understanding to their sickness are ignored by the medical personnel and system which consequently effects to the problems of communication or misunderstanding.

2) Rhythm of informing bad news

Kong's mother : "I gave birth at 1 am. It was very late at night so the nurses just told me that I got a boy. I was really exciting and happy and then I could not sleep for the whole night. I only looked at the watch and been waiting for the morning come. I would like to see my son. When morning had come, nurse still tell me nothing about my son and she didn't bring me the son. She came at bed and said that the doctor did not do a sterilization after delivery as I requested because the doctor wanted me to re-think again. I wondered what I would think since the doctor had told me when I got prenatal care , he suggested by himself to have only 2 children. So I intended to do sterilization, no more baby , two is enough. Nurse said that she did not want me to be in hurry because my son is not healthy and I might want to have more. She

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> attempted to persuaded me to cancel my intention in that time. I felt and sensed something wrong in her word that my son might not survive. And then she told that my son is like “Sayan”.. It frightened me. I could recognize “Sayan” face for a glimpse and I felt my heart was sunk. It seem like drowning and going to die. I was unconscious… My wound from delivery had not yet recovered, in addition, to know about my abnormal son. It made me feel absolutely disappointed and broken heart. I've never expected of such a terrible life, it was the worst event in life… (She cried and used her back hand wipe away the tear while she was telling this story) I did not want to think about sex, girl or boy. It was very confused and pain as I really didn’t know what would happen in the future. I felt deeply lonely and put myself in tears. I did not know how to tell my husband. The nurse said that parents normally are not told immediately after delivery about the Down syndrome’s child because parents may leave their baby. Parents should bring up of their baby for a month to originate a strong relationship and then cannot leave a baby. I was angry with her why she told me when I was alone. I was so confused as I was not sure whether my baby will survive or not. However, I confirmed for sterilization because I was old. Whatever my baby is I would try my best to take care… At the beginning, I cried everyday when I visited my son at ICU (Intensive Care Unit) but I did not let my husband see. I wouldn’t like to tell him till I was confirmed about that. Then I kept the sadness alone…”

The instance of Kong’s mother shows that she is suffered by poverty as well as the additional pain from having a Down syndrome’s child. The mothers felt similarly after receiving a bad news of a Down syndrome’s child. They were shocked and frightened. In their opinions, it was the communication problem which doctors did not inform at the right time. Moreover, the unsystematic and untimely informing of bad news resulted in the more sorrowful to the mothers. Although, they had less information about Down syndrome from their experiences, but their imagination which based on the understanding with mental retardation, were fulled of scare, ugliness, and embarrassment as well as a heavy burden on taking care the child till the death. Moreover, many mothers were afraid that they might die before the Down syndrome’s child and the same time, they were afraid of an unforeseen life of the child.

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Kwan's mother : "Actually, I was prepared myself for sometime after the doctor advised me for investigation while I was pregnant… After I delivered the baby, the first question I asked my husband that 'is the baby normal?'. But my husband did not reply even he had already known from the doctor, but still I did not know… My husband told me slowly that the daughter has brought to ICU with many problems as well as the daughter is a Down syndrome's child… I was dizzy and fainted. It seemed like sinking and falling down directly to a deep valley… My husband tried to support me but it could not much help. Because I was so shocked and wondered why it happened to me. I confused and thought that I had done everything good and prayed for good things in my life but why this thing happened. By that time I was thoughtful and gave up for everything… I knew about a Down syndrome's child from the information received during pregnancy. Although, I tried to console myself that god might not be cruel to me but when I faced that situation, I was totally disappointed… I thought forward about the baby's life that how long the baby would be survived…

Kwan's mother is a representative among mothers who engages in a high economic status and high education who differs from the poor mothers. Namely they are not living in suffering from poverty. However, having a Down syndrome's child was an unexpected event and made them pain and suffer.

5.1.4 Down syndrome child …valuable life or worthless object

1) Life value and different way of thinking

Bee's mother : "It was bad enough for me for having a Down syndrome's child, but the more painful was from the words of doctor and nurse. They might acquaint to the sickness and death so that they treated body and life like as an object. So they were careless about their words and reactions to the client. I was hurt because of those words. . Instead of consolation, they blamed me about being absent in investigation as I was old and graduated in high education. They've never thought that none want to have an abnormal child and this was not only my mistake but it's of them too. And also they said that a Down syndrome's baby is ugly, worthless and likes rubbish of

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society… They gossiped among themselves and then stared at me. I was so angry when they reacted like my baby was worthless, they should gave me advice instead of those stupid words and gestures…"

Kwan's mother : "I never thought that doctor who took care our life also had a negative perception with a Down syndrome's child. I expected in a kindheartedness of doctor to keep our long life. Conversely, that young doctor said careless words with his insulting face, I still remember that face and he said that my baby might not be alive more than 3 years. I was very angry what he said seemed like that and he also did not want to do any treatment for the baby. It might be useless if he thought with economic concept. From that doctor's words, I was hopeless for survival of my down syndrome's daughter. I felt disappointed by his expression. I wondered whether in a medical school was interested in and taught about abnormal baby or not, why that doctor expressed like he had never found a baby like my daughter before. Both doctors and nurses are the same, they did not encourage me but they said me with the words that made me felt angry, under pressure and indignant… I nearly was mad and had the psychological problem. I sometimes needed to meet a psychologist and took sleeping pill to help my sleep. It was really terrible for my life. Is the role of doctor to treat human being or not? He should not predict or valuelessly judge a life. My baby was a worthless object in his eyes but not for me. Was it wrong that I did not have investigation and finally I got an abnormal child? Everyone had their own reasons which the doctor did not understand and didn't ask. Instead of support, he reacted like I did a mistake for not taking his advice. He should feel sympathy for parents who were looked with the suspicious eyes of the others to them and their children. In contrast, he ignored for that feeling. He did not understand the pain of parents who have an abnormal child. There nearly was no space for these children in society. Finally, my husband said that doctor did not realize the meaning of life. It was disgusting for him on a businessman doctor because an abnormal child could not be estimated monetary value. We could not access the costs to down syndrome's child …"

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> **Kaew's mother :** "…I could not resist to knowing that my baby was a Down syndrome's child. I cried like anything. I did not want to listen to the doctor. Doctor told me about my baby's symptom and then said that don't throw the baby away but if I really want to throw just tell him. He would transfer the baby to the Public Welfare Department… It was questionable that 'was the Down syndrome's Child totally unacceptable?' which made the doctor said like that… Fortunately, the grandparents did not agree, they wanted to take care of the baby…

According to Bee's ,Kwan's and Kaew's mother, it reflects to biomedical concept to life like a physical mechanism. Human body and life value are reduced to compare to only an object. The conception of a normal fetus is determined as an existence of human being while an abnormal fetus is recognized as a useless object. However, medical explanation on biological mechanism does not absolutely terminate pregnancy in both risk group and non-risk group which finally leads to an existence of a Down syndrome's child. This is a social experience that has been prescribed in medical definitions. On the other hand, those definitions and knowledge are not recognized by all mothers. They have own negative impression of a Down syndrome's child. It is hurt enough for most mother to know that they have a Down syndrome's Child due to their perception which constructed from social and cultural background. However, the more suffering is in medical service system through the communication between the health personnel and client that react to their child as a worthless object. Similarly, the risk group mothers have sympathy for having a Down syndrome's children, while they accept that their Down syndrome's children are human being and life that needed to take care. They, nevertheless, feel more disappointed with health personnel communication, reaction and expression to their children and themselves. Those people react like these mothers generate an existence of a worthless and unacceptable object in society which leads to mothers' embarrassment. From the study showed the suffering of some rich mother which was from the health personnel especially through the communication and the more suffering in the poor mothers' group.

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Down Syndrome has been changed from a valuable life to be an object that needed to evaluate into monetary and economical cost benefit analysis. This is obviously problematic for the poor as a result of many kinds of sickness which required expertise treatments so that it is a costly burden for the poor to take care of a Down syndrome's Child. The baby needs an intensive health care, therefore, the poor mothers have to struggle to access the treatments for healing the baby's deficiency. However, the services are not different. They recognize their humble and contemptible class from a low self esteem and insulting which are reflected from words, reactions and expression of health service system to them.

5.2 Medicine, Power and Suffering

5.2.1) Medical procedure as burden and sources of suffering

1) Complexity of Medical procedure

Taen's mother : "After doctor informed me that I got a Down syndrome's son, he appointed me for blood checking. He told me to have a chromosome checking. I wondered what was chromosome. He said that it is concerning blood, after checking, he could confirm the result of a Down syndrome's baby… I did not understand why I need that checking, but he said me to check so I was checked with thousands cost. Moreover, the hospital where I gave birth could not give me the checking, so my baby's blood was delivered to another public hospital… I thought that they might have cooperation with each other so that I took my new born baby to that hospital. In stead of making some references for me before… When I went there everybody was confused for what I would do, I told that I came for chromosome checking. They said that the blood I brought could not be tested. Therefore, they started to collect again. They did not refer to each other, I did not have any reference report. The official there complained a lot that I did not even have any reference report… And then they said me that the result will be disclosed within a month… It was terrible. Just think of it my baby was very tiny and I carried the baby for blood punctures again and again. It was so difficult to find

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the baby's blood vessel as baby was too small. During the puncturing, my baby was crying seriously till I was about not to let them do it anymore. In addition, they knew nothing about my case. They gave a phone call to the original hospital because nobody knew about me… I paid for 1,700 baht and they let me wait for a month… It was the most nervous time in my life during waiting for the result because I was afraid that my baby is really a Down syndrome's child… Actually, I lied to myself since I noticed that my baby face looked strange. My parents and others said that my baby was an abnormal one… But doctor suggested to have an investigation so it meant that he was not sure. Therefore, I also had not yet sure that my baby was a Down syndrome's… I prayed for my baby. I was curious that I might not be able to take care of my baby, how we would live… I was pretending to myself during waiting time for the result, but finally I could not escape from reality. I called them to get the result and the answer was 'yes, my baby was a Down syndrome's baby'… I felt disappointed.

Kong's mother : "…At first, I was alone when I knew about my baby. My husband was not available and my baby still stayed in the hospital. I didn't dare to tell anyone, just kept it with myself. The doctor said that we need to make sure from the result of blood testing. When I submitted the blood sample, a nurse told me to be ready for the result, shouldn't think that my baby is not a Down syndrome's. Conversely, I should think that my baby is a Down syndrome's… Anyway, I still thought that my baby might not be a Down syndrome's… Because, if I definitely knew about my baby so why I needed to go for a test to waste my money and time… To go for an investigation was extremely suffered as I had to bring the blood sample myself even just after my delivery. My husband was working so that I must to do it myself. I had to prop my belly that seemed like I was still pregnant. I was lost for I really didn't know where to take the blood to. There were not many people in that big building, it was so scary. To enter to the building, I had to deposit my ID card. There were tens elevators, when these ones opened and other ones close, it puzzled me. I did not know which one I should take to upstairs. I was waiting until someone came. I got to the tenth floor which there was nobody, there was just like a graveyard that I was walking. By that time while it was raining, I was downhearted… I was nervous for the

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whole month. I visited my baby from morning till the end of visiting time. I cried at hospital, but at home I pretended that nothing happened. When my husband asked about baby, I replied that baby was not healthy. I was afraid to tell him about Down syndrome's son… I prayed everyday before going to bed. I made all merits to help my baby… To keep the secret for a month made me feel very stifled. I had to control myself not to cry in front of my husband. Sometimes, I had to cry alone in the toilet… I kept the secret whereas I still expect about a good news from the result. And if I told him before then he must be disappointed and upset. But at the end, the result might show that my baby is not a Down syndrome's… I wanted to make sure before telling him… When I was going to listen to the result, it seemed like I was going to an execution. I was absolutely nervous and I was hopeless after doctor told me the result. I told my husband about my son accordingly. He said nothing. I told him more that doctor said baby got an abnormal chromosome, but he still kept on silence… Actually, he was curious and did not understand about what I told. So I told again that baby got a sickness as "Sayan". Then he got it, even that he still kept on silence. He, normally, is not a talkative man but I think that he also felt disappointed…"

Phing's mother : "Doctor said that the baby was abnormal, I was upset and worried about that. He suggested to have a blood investigation. By that time I wanted to do anything as the doctor said though I had to pay. I did not want my baby to be as the doctor said. The previous result might be wrong… The hospital that I gave birth did not have that analysis tool so they had to transfer me to another hospital… My baby blood was taken to that hospital but it did not work at the first time as it was clotted so they called to collect the baby blood again. It was very disgusting since my baby was too small. By that time the baby did not take my milk but still the baby needed to be taken to hospital for blood sample collection. There were many times of blood puncture, during the time my baby cried a lot till my husband was angry… They let us wait for the result to bring it back to the original hospital and the result showed that my baby is a Down syndrome syndrome's child… I was somewhat disappointed but not much as the first time I knew because I had already conceived of it. Actually, if I was definitely sure about the result, I would not go for that investigation to waste money and let the baby painful. There were so many punctures to collect my baby blood…"

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Procedure and measurement in medical treatment are set as rule or guideline for medical personnel. Similarly, the delivery of Down syndrome baby can be identified by medical personnel as the particular physical appearance of the baby. This can be indicated through physical visualization. Actually, it is not only medical personnel who can indicate a Down syndrome baby but also general people. Mothers are normally informed about a Down syndrome's baby after delivery and it can be recognized in both the mother and medical personnel. However, medical process has measurement to confirm the fact of sickness through laboratory test, which definitely all the cases are confirmed about the Down syndrome's babies… The confirmation test is one process that has been designated in a medical process. According to the confirmation of testing, this study indicated that mothers are lost in many aspects such as economical, social, emotional and mental. In the opinion of the mothers these are lost to mother that could not make it for the better circumstance. Beside, it gives more pain and even end up with confirmation on the such reality.

2) Medical rule as the obstacle of mother's love

> **Sor's mother :** "They reacted as if my baby got a hideous sickness. I was mad, just think of it that whoever wanted to enter my baby's room they did as that room was an alien's room. Doctor said my baby got infected so that everybody who would like to visit, had to wear mask including me. Moreover, I was not permitted to touch my own baby which it was too much… I was so angry at that time and scolded at nurses that 'why you did to my baby like the way to treat an hideous patient'… My baby did not get HIV so why everyone had to wear like that. At that time I was like a hen… whoever came to do anything with my baby I had to start expanding my wings and then pick with the beak…"

> **June's mother :** "My heart was broken as I really wanted to hold my baby while he was in an incubator. I tried to sneak my finger inside the incubator to touch my baby, unfortunately, a nurse saw me and then she scolded me that I was stupid to do that because my baby might got infected…"

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In addition, medical rule is an obstacle to obstruct linkage and attention between mother and baby. After delivery, it was discovered that most of the Down syndrome's child are in an incubator as well as get infected child in which mother cannot touch or hold as general baby. This situation created an extreme suffering that illustrated in Sor's and June's mother conversation. After waiting for 9 months, they need to touch, hold and embrace their children with love but they can't. Because of love push some mothers try to break down the rule though it risk to be scolded by the health personnel.

3) Doctor as the most knowledgeable expert in hospital

Sor's mother : "I brought up my baby as usual even he is a Down syndrome's child. He was about to go to school but after I took him to check at the institute… He was found that the bone of his neck was moved, then he suggested to send my child to a children hospital. The doctor did not tell about operation but refer my baby to another hospital for a specialist in physical therapy. And I went there as he suggested. By that time I thought that it might not take long time but after investigation, the doctor said that 'okay, go for operation'. He said confidentially as nothing serious. I did not prepare anything since I never knew that my baby needed an operation. The doctor said easily. So I thought if my baby got a good treatment he might get cured… Doctor managed for everything, he booked a room, bed and then had operation… Everything was fast and seem easy. But I didn't know it was good or bad. Normally the room had to be booked for months. Maybe because my husband is a solider and we got a health welfare… At that time, I thought I was lucky as everything were smooth. Doctor asked me to sign in an agreement form so I signed without reading and realized anything, for I strongly trusted in doctor… During my baby was in an operation room, I prayed for my baby to get cured with hopefulness… After the operation was finished, they took my baby to ICU. I stayed with him for around 1 hour and noticed that he was pale and become green in color. Therefore I called a nurse but she was still cool and told me that nothing wrong, it could happen with any patient after operation. So that, she did not do anything until my baby was

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> breathless and had convulsion. I again called the nurse. This time they were eager to do many things and asked me to stay outside… I didn't know what they did but only knew that my baby lacked of oxygen that made his lung deflated and finally she became a disordered child. She has been stayed only on the bed for over 4 years as well as had to use a lung machine supporter… At the first stage, I was about to die. Actually, I was hopeful but became hopeless accordingly. From a child who could walk, became only lie on bed … I stayed with my baby for whole day after the operation because doctor said we were hopeless, he might not stay any longer… It was like someone took away my heart. I was looking at him to see his final breath. I was disappointed to taking my baby to this hospital. This would not happen if I did not bring my baby here… Fortunately he survived from there… I trusted in doctor because he said like it was easy. My baby was a sample, when they did not success in operation they were not responsible for anything. They just referred my baby to another doctor. At least they should came to ask me about my baby instead of ignorance… They did not realize that our family life has been changed totally. We used to stay together at home but now my husband and I have to stay in hospital. We have slept on the floor next to my baby's bed and another 3 children were sent to stay with my mother. We do not stay together. It takes months or years to stay with the rest 3 babies. I lost my freedom. I could not go anywhere and couldn't think of traveling. Now I spend my life in hospital. I feel like living in jail and hell. I don't have future… Sometimes, I got sarcastic words. I have no idea that how long I have to live like this…"

Sor is the case of the more severe symptom which is the production of the knowledgeable doctor who confidences in own medical ability and treatment without participation of patient and relatives in making decision on treatment. The mistake from treatment leads the mother to be in a severe trouble as she illustrates by the words *"toknarok"* (like in hell). To stay in hospital for 4 years long, she thinks that it is a trouble caused by doctor who made her life totally change. The decision made by doctor at that time is a confusion and obstacles in her life which impact to change in her family life and emerge of suffering until present time.

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5.2.2 Poverty plus abnormality is as Marginality

1) The limited rights of the poor and Down syndrome's child

> **Bengi's mother :** "…I had health card and disordered people welfare card too. Nowadays I won't use it because it was not good in service even though the health office was closed to my home. I would rather buy medicine myself… Both the health care card and disordered people welfare card created problems because the recent institute that we went for physical therapy will no longer provide service for us then I needed to take my baby to hospital which closed to home. But this recent hospital does not refer to another one as they said they could do physical therapy for my baby. They have once a month for training. I was almost fainted because the doctor said that my baby need to be trained often. Therefore, once a month would not be enough. Moreover, they were not expert and there was no any expertise. So I didn't trust in them, if I could choose I would choose the better one… Like when my baby got intestinalitis, he stayed in hospital for a month but his sickness was not improved even they gave antibiotic. My baby was almost died, like he got a wrong medicine. So that, I could not sustain there then I had to take my baby out of hospital to clinic and came back home for months. Doctor at clinic told me to take baby to a private hospital but I said I couldn't support. So he recommended me to use a health care card. I replied that I already used it and quitted the hospital as my baby's symptom was not improved. If I go back again, they may not accept. Thus, the doctor at clinic accepted to treat my baby and told me that if my baby was improved, I should come to get saline as he is very weak but if he is not improved so I need to take him to hospital…Fortunately, my baby was improved… That made me more trustless in the treatment of health care card system…"

The poor Down syndrome's child should deserve benefits on childhood, poverty and disordered person that benefit for more honorable health care services and welfare. Conversely, they are limited in practical as the case of Bengi, Afifa and Pond. Bengi's mother had an experience of using the health and welfare card to receive the good service and treatment according to her right but it was so limited.

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For Afifa, her mother was so suffering for her daughter being limited the services because of the infectious disease and the poverty. She thought that it was unfair to her and her daughter who deserved to get the better service. Nevertheless, she surrendered to the fact of her poverty and her daughter's disability as these were limitation of their life.

> **Afifa's mother :** "I tried to take my baby for training but she was discharged early because the doctor said that my baby got TB… This was because my mom got TB and they stayed together whole day so that my baby also got infected… Doctor found the decease, therefore, he asked to stop training and waited till my baby recovered and if I could get school for her, I should let her go to school… He did not ask my opinion, actually I wanted to get my baby trained for she was not fully fine… Doctor did not understand my trouble… I'm not available to take care of my baby as I have to work everyday. I have no other choices, if my baby cannot go for training then I have to leave her with my mom. It is worsen. Doctor did not understand me, he may think that I do not give attention to my baby… So that, I tried to go to the new hospital even it is not better than the previous one but still better than do nothing. Doctor investigate again and came to visit my home…"

> **Pond's mother :** "I've never think of going to hospital myself since I was afraid of doctor. Every time I went to see, he blamed and scolded me… he scolded that I didn't pay attention to my baby, and I haven't had any card though I was adult so far. You see, I have been like this, my parents did not do anything for me so what I can do. When I got sick, I just bought medicine from drug store… To go to a health care center, my friend took me there or someone gave me bus fare or milk… I am scare of some doctors, I don't want to go… Like when you took me to hospital, if I was not feel sympathy to my baby I would not go. Everyone looked at me like I was an alien. The officials asked me about health care card and how I would pay. I disliked that question. I ignored like I didn't hear and then officials shook their heads. I wanted to disappear from there because I knew nothing. Last time, when the doctor checked up my son, she blamed me both her verbal and eyes that why I ignored my son. When she went out for a while, I was left there, scare, lost… As the time that you brought my son to see doctor, my son stayed in hospital for 3-4 days. I let the doctors

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do whatever he wanted to do to my son and then came back home… I have no idea whether my son was improved or what reason that he was discharged. They told me to go home so I left… I did not know what happened to my son they gave me medicine so I just mixed it with milk to feed my baby… but after 2 days, she was smothered by milk and then died…"

From the point of view of the mothers to the treatment process, they fees that their babies are seen as a humble population who are not gained attention from society and health care service. Although these babies should be access to health care service as common population or more in the benefits of disordered person. Practically, they realized that their down syndrome's children were ranked in the lowest class or marginalized person of society. They, therefore, have to neither encounter with pain from the medical system that has less attention in their babies and react with the Down syndrome's children without respect in human dignity nor understand in necessity and background of the poor.

5.2.3 No money, no treatment

Kwan's mother : "If I had had no money, my daughter would have died. For instance of operation, I was in queue up for operation at the famous public hospital. I had waited for years until I gave up, for I was hopeless for a long queue. When I was about to get my turn, there was another case that interrupted. I asked nurse and doctor why the other patient who came after but can do before. They said without guilty that that case was more necessary than mine. Then I realized and sensed that they passed over my queue as they thought my Down syndrome's daughter was not that worth… Therefore, I decided to move my daughter to private hospital to get operation. Surprisingly, the operation was done by the doctors from that public hospital. I'd expensively paid , more than a million baht. Don't you believe that after payment on Friday my daughter got operation immediately on Saturday. Only one day if we have money, but more than a year for waiting. It's is difference that can clearly see. Money can really buy everything, it is real God!. This made us trustless in government system… After the operation, my baby got many complications and needed long time for rehabilitation. Doctor referred to the public hospital. I daily paid for thousands on medicine and room…if I had had no money,

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> my daughter would have died. She survived just because of money… Even though my baby stayed in the public hospital, she would have died. One day, I just asked about the right of health care card that made them think that we did not have much money to pay. After then, they removed out some supporting equipments."

There are many questions from Kwan's family especially on treatment of Down syndrome's children who are classified as an abnormality and disability. In their opinion, medical system gives low value to Down syndrome's children than normal ones. That leads to less health care service for Down syndrome's children in comparing with common children. Accordingly, Kwan had to be in a queue for long time in the famous public hospital until her family realized that doctor would not do operation for her and she would not survive as doctor said… They thought that money is real God like a miracle to buy life, medical service and time. While the poor Down syndrome's child cannot afford to access to services other than basic health care services provided by government. However, they still have difficulty to access even those basic services according to the conditions of life and poverty. Rung's and Kong's mother are examples of poor mothers who believe that because of without money make them lack of bargaining power, hastening procedure and choosing their desirable treatment method. They have to mainly follow the doctor's decision.

> **Rung's mother** "Operation and treatment cost was very expensive, I could't afford to pay. It is very difficult even to make a living… I used the health card, 30 baht, but sometimes I have had to pay extra. It still be much for me even not that much money… I still be waiting, even I have waited for years. Repeatedly, doctors and nurses were changed but my baby had not got operation yet. I endured to suffer privation and spent my almost time to wait even without aim. Anyway, I never miss the appointments because I have no other choices… If I win the first prize of lottery, I will go to see the best doctor. I will not wait like this"

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> **Kong's mother :** "Doctor said that I need to use a lot of money to operate my son's heart, so that I should use a health card… I tried to go but it was uncomfortable as It was so far and doctor said that he could not do because my son was very young and weak. Moreover, the equipment of his hospital was not modern for the operation so my son would be transferred to another hospital. At the first, I hoped to see him recover by himself but it seemed to suffer hardship. I have no choices. Finally, the severe symptom of Kong pushed me to decide to go to the hospital with the right of health card. It was not comfortable but I have not much money. If I have money, I will go to a good hospital near by home instead of going there which is so far… "

Summary

The aboved results indicate the influence of poverty which limit the opportunity of down syndrome child's mother to access the medical institution and treatment procedure. For some mothers who can access to the health service system, most of them were not happy under the relationship between them and health personnel. The communication problems which based on the different body of knowledge, perception and attitude to Down syndrome and the other disability. The gaps of relationships between medical service system and clients (mothers) as well as medical personnel and Down syndrome's family which cause the problem on disparities between medical and local knowledge. Medical knowledge is abstract which hardly understood and linked with the way of thinking of the poor that focus objectively in making a living. Therefore, medical information/knowledge are ignored by the poor as it is inedible. Additionally, communication problems were found in many aspects which are the differences between perception of Down syndrome's child in medical context and motherhood as well as family context. In biomedical context, Down syndrome child is seen physically as disability which is different from the mother's and family's perspectives. The different perspectives between worthless and valuable life originate divergence in moral justice as well as evaluation of life value in term of psychological and spiritual more than economic or productive judgment. Furthermore, the results reveal the many problems of

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medical service system such as the complexity of medical procedure, limitation and discrimination of medical service to Down syndrome's child especially for the poor group and monopolization of medical knowledge and health personnel in health care service including the treating decision. The results can be summarized as the figure 6. These are the conditions that have effected to to the emotional problems such as frustration, anger, stress, moodiness, sorrow, grief and suffering.

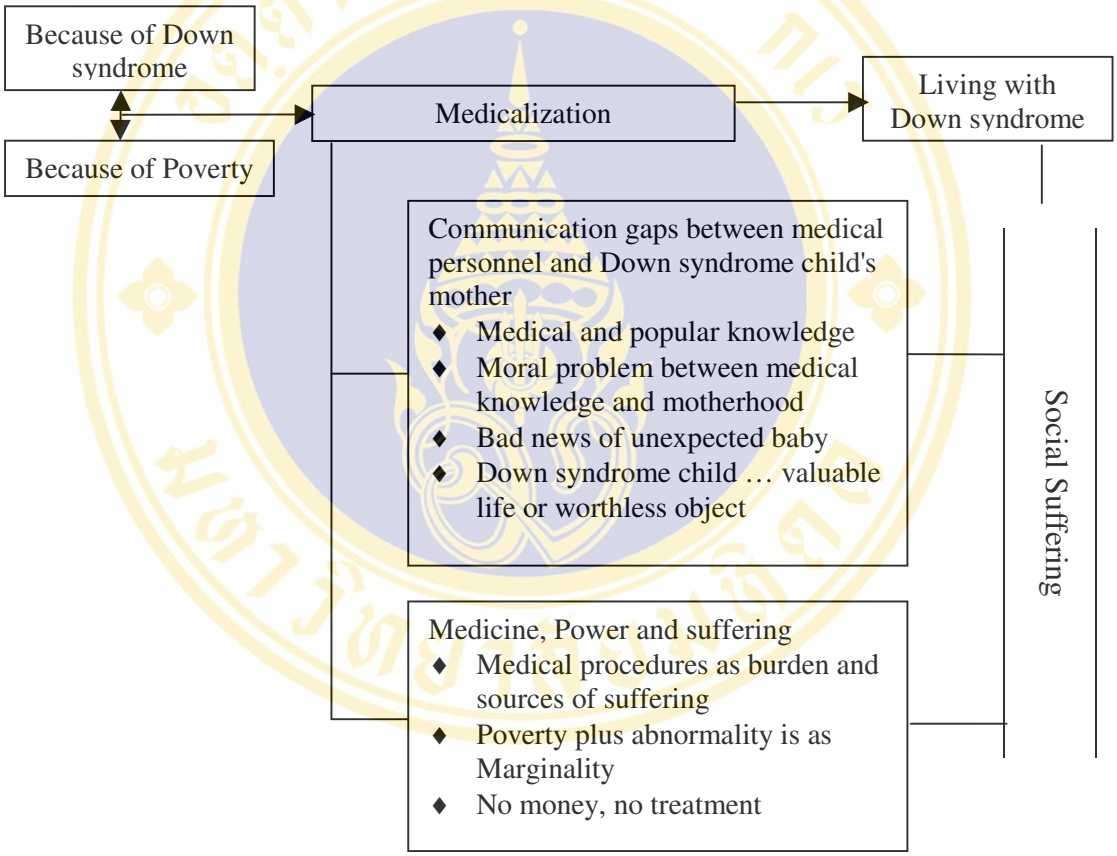

Figure 6 : Suffering experience of Down syndrome child's mothers under the medicalization

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CHAPTER 6
SUFFERING UNDER SOCIAL AND CULTURAL STRUCTURE

Chapter 5 presented the suffering of Down syndrome child's mothers relating to medical institutions and the treatment procedures on their child symptoms. This chapter presents the life experiences of Down syndrome child'smothers in Thai social and cultural context which lead to their suffering in two parts. They are as follows.

1. Structural Violence and Suffering : This part indicates suffering under social and cultural structure especially the problems on gender aspect which are composed of ; 1) Sexual violence and feminine Down syndrome's child , 2) Religious rules, Social rules and perpetual sin, 3) Social rule of family planning and women contraception, and 4) Down syndrome among normalized society.

2. Poverty and unequal accessibility to social services. This part reflects the economic class and the sequent problems to access health and welfare services are composed of ; 1) Unknown health card and unknown right , 2) Poverty and inaccessibility of health services , 3) Mainstreaming education and Down syndrome's child and 4) Life insurance system and discrimination Down syndrome's child.

6.1 Structural Violence and Suffering

The structural violence to femininity and motherhood are existed among Down syndrome child's mother especially for the poor. Normally, the violence was perceived in form of physical power such as beating, injury and fighting but the structural violence was in form of social and cultural rules which limited the ways of thinking and life, limited opportunity, the difficulty on decision making, frustration and suffering. The social and cultural rules about women role and right were socialized and accepted as norms that affecting the way of woman thinking and

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woman life without realizing or questioning on being done by the the inequitable power and taking advantage with the patriarchy ideology. These powers, social rules and religious rules, were disputable on womenhood, motherhood , the abnormality and the poverty.

6.1.1 Sexual violence and feminine Down syndrome's child

In the present of Thai society, families do not serious concern on sexual selection of children as seen in the concept of family planning that “Girl or boy is good but just two children are enough”. Though the value of the child's sex is changed but for the Down syndrome child's mother, she feels that having son will make her more happier than daughter. There is still an existence of sexual disadvantage which women are taken advantage and reputation. It has been acknowledged in Thai society that the patriarchal concept is still influential which reflects in sexual violence within family and society i.e.; rape and obscenity which may happen to both normal and abnormal women. It efforts the social danger to women and sexual disadvantage. Especially, the violence that happen to an abnormal women. Therefore, the mothers who have a Down syndrome’s daughter encounter the more suffering than the mothers who have a Down syndrome’s son.

Furthermore, disadvantage of female also reflects in health care procedure through doctor’s suggestion to mothers who have Down syndrome’s daughters that they should prevent their Down syndrome’s conception again.

It has been acceptable to have contraception in an adolescent Down syndrome’s girl as it can prevent social problems. Nevertheless, it is the suggestion that can be seen as a social violence to femininity and abnormality without dealing with problems from men. In the cases of Bengi’s and Kaew’s mothers, they accept the concept of contraception in Down syndrome’s daughter and overlook human dignity unintentionally.

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Violence to abnormality and femininity

Bengi's mother : "The doctor told me that if my baby is a girl she should have contraception…I am worry about this, because a Down syndrome's child is easy going, overacting, talkative…She likes to play with man, also gives a hug and kiss. She is very talkative but not with a woman…If she is grown up and still does like that, it will be very dangerous for her. I may need to always keep my eyes on her. I cannot trust anybody these days because even a father may rape his own daughter…My husband is also trustless, when he is drunk and want to have sex, he gets it right away. So how I can trust him. I plan that when my daughter is going to have period, I will take her for sterilization as the doctor said…Who can take care of her all the time when she is grown up. I am afraid that if I die before her, who will take care of her. Her brother?...To be sure, I have to prevent the problem beforehand. I am thinking that if I die I will take her with me as I am worry that none will take care of her after my death…When I'm still alive, I always be with her. But if I hadn't been alive, how she would have lived…"

Kaew's mother : "When she is grown up and going to have period, she need to have sterilization as the suggestion of the doctor. He suggested that I should get rid of her uterus for protection of pregnancy since my daughter do not understand anything and nowadays there are many wicked guys. They never feel pity for a normal or abnormal girl. When they are mad, they never realize that this is a woman or a dog. Once I heard the news about a lustful man rape a dog…Human beings are cruel and trustless these days. We are very concerned about our normal daughter. However, as for our girls , the concern us more because they can get pregnant without a marriage. It's better to be a boy…Actually, the abnormal daughter has someone to take care of her all the time. However, for safety, she should have had contraception…"

6.1.2 Religious rules, Social rules and Perpetual sin

To kill or persecute an animal or a living thing is forbidden in every religion. Therefore, contraception is recognized as breaking a religious rule, even though modern society recognizes it as a birth control in order to decrease the population of the country. On the other hand, contraception and abortion are an

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preventive measurement of sickness in the medical context. The number of acceptable children is set as a social rule. Thus, a family with 2-3 children has been advised in medical aspect in order to have birth control which mostly being done by women. Moreover, an abnormal pregnancy can be recommended according to medical aspect to have legal abortion in order to prevent sickness and social problems. On the other hand, this measurement is recognized as persecution of life in every religion. It is wrong in the natural principle as well as religious rules. Some of the mothers have been in a dilemma of following; the medical principle, social rules, or a strict religious rule. This can be illustrated in the case of Sor's and Afifa's mother. Both of them are Muslim. However, they surrendered to the medical reason that they may have chance to have a Down syndrome's baby again. Moreover, they also surrender to social concern on having 2-3 children according to the concept of "the more children , the poorer". Hence, they decided to have sterilization after having 3 children. However, they still perceive that sterilization is a sin. It remains in their conscience forever.

> **Sor's mother :** "Actually, I planned to have three children because after having a Down syndrome's baby I did not have sterilization as I intended to have more…You may wonder why I never give up or afraid of having a Down syndrome's baby again…I told myself that let the fate be. While I was carrying the third baby, the doctor had already realized that I needed to have my chromosome checked. This time doctor did not need to encourage me much because I had had experience. The doctor just told me to have it diagnosed. The result was that my baby was normal but still I was not certain as we could not expect on something that had not come yet…It was good hearing that my baby was normal. Then I asked the doctor to do a contraception for me. The decision on having sterilization was due to a heavy burden. I had no time to look after another children as Sor was staying in hospital. I had to ask my sister and mom to take care of my other two children. I also didn't have enough money. I therefore had to be in debt… Sterilization was more painful than delivery. Actually, I was not hurt because of sterilization but it was because I had committed sin. Muslims are not allowed to have sterilization …However, I had to do it. It is forbidden in my religion.

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> But if I did not do it, it would have been worried sick having another, especially a Down syndrome's child again…So, I surrendered and let the sin remain with me alone. Nobody knew about this…I am afraid that someone will know and they will scold me…especially if my neighbors know, it will embarrass me. Fortunately, I do not live in Muslim community…"
>
> **Afifa's mother** "After I got the third baby, I asked doctor for sterilization even I realize that it is a sin in my religious rule. But still I did it. My mother also knew about this but she did not blame me she felt pity for me. She knew that I worked hard to make a living of my children alone. My mother was also in trouble with me since she had to take care of my daughter when I went to work. Having many children gives me a heavy burden. However, if I had known that my baby was abnormal during pregnancy, I still would not have abortion as she was my baby. Abortion is more sinful than sterilization because I do not kill any life for sterilization. …I surrendered to a sin otherwise my life would have got more trouble. Both having sterilization and not are the suffering that I cannot escape…I prefer being a sinner alone to bring suffering to other ones. The new baby would also suffer…I was afraid to tell anyone even my husband because he is a teacher teaching on religion. If he knows about this, he will be frustrated…It is very difficult for me as I am a woman and mother. He is a man who has less responsibility. He stays in the other house. He never realizes how hard we are living…"

6.1.3 Social rule of family planning and woman contraception

According to National Policy on population control, the Ministry of Public Health and related organizations promote and encourage the public to limit the number of children to 2-3 children as a countrywide social rule. Similarly, the key informants decide to have sterilization after having 2-3 children no matter he/she is a Down syndrome or not. The main reason of sterilization is a heavy burden as well as high cost of having many children.

However, the study indicates that social rule mainly influences and takes action on women as women have to decide or bear contraceptive burden as illustrate in contraceptive pills, rings and operation. These are being done on women alone. They only resist on physical trouble and painfulness from contraception

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without questioning on why has to be a woman, although there are other contraceptive measurements which can be done in men. Namwan's and Fluke's mothers are the case study of this circumstance.

1) Contraceptive pills and operation on women

Namwan's mother : "I planned to have only two children as I cannot take care of them alone…During the prenatal care I told doctor that I wanted to have only two children. But after I got the second baby, the doctor did not provide me contraceptive operation as he might have seen that my baby was not strong…I took contraceptive pills discontinuously, therefore, I got the third baby...I tried many ways to take off my baby during pregnancy. Although my mother sent me an abortive medicine from countryside but still I was not successful. So I had to let the baby born…After giving birth of the third baby, the doctor told me to have sterilization …I did not consult my husband. He did not know or response to this. When he wants to have sex, he never cares for having a baby or not. I have to be careful myself…I am bored to be careful so I decided to have contraception. My mom told me for that she was afraid of I might be mad. But I was more afraid of a heavy burden and starving…"

Naey's mother : "When I was carrying Naey, I did not prepare for pregnancy. She is a second child with my present husband. I planned to have contraceptive operation after this second child, otherwise I might take wrong pills and unintentionally get another new baby…By that time I was not much aware to taking contraceptive pills. So I got this baby…Firstly, I wanted to have abortion but could not get anywhere as my pregnancy was mature. I did not realize that I get pregnant since my baby did not move…I consulted the doctor to have abortion but the doctor did not allow since it might be harmful as my pregnancy had been developed for 6 months. I went for prenatal care late…Therefore, I just got contraceptive operation just recently. I would have had sterilization before if the doctor had not been worried about the survival of Naey…Having too many children is a heavy burden. I have to be responsible for both my children and husband…To tell him to go for sterilization is impossible. I told him to do it but he denied me because he believes that he might be weak..."

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2) Contraceptive rings on women

Fluke's mother : "Firstly, I was afraid of contraceptive operation so I used contraceptive ring. I had used it for 10 years without any check since I had never thought that it might be unfixed. I had already had three grown up children. I therefore never thought of having another child at my old age. I got pregnant despite the contraceptive ring was still inside…Therefore, after I gave birth of the fourth baby, I had to have contraceptive operation even though I was afraid of it. But I was afraid of having baby more than that. I was too embarrassed to be pregnant at the old age…My husband will never go for contraception. He is coward and irresponsible for anything…"

6.1.4 Down syndrome among normalized society

Having a Down syndrome Child…Unforgettable experience

Mothers accept that to have a Down syndrome's child is a cruel experience and a nightmare in one's life as well as it is still remained in their subconscious to fearing and worrying about their daily life. They had tried to avoid having this experience with their families or fellows. As far the group of mothers who are older than 35 years old that plan to have more children, they have been assured to have amniotic fluid checking for the next pregnancy. While another group does not prefer to have more baby as they are afraid of having a Down syndrome child again. Taen's mother is the case of mother who is afraid of having a Down syndrome's child. It has effected on her daily life such as having sexual intercourse. Similarly, Linda's and Namwan's mother said that if they had known that their baby were abnormal during pregnancy, they would have had abortion.

Taen's mother : "After I have a Down syndrome's baby, I have been afraid of having sexual relationship with my husband as I am scare of having a Down syndrome's child again…It has still remained in my mind…"

Linda's mother : "It was an improper birth control. So, I got unintentionally the third baby who is a Down syndrome. And when I got the fourth pregnancy , I went for prenatal care at the new hospital.

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Because I was afraid that the old hospital might have blamed me that I've already got three babies and one is a Down syndrome but still I did not stop…I went for prenatal care when was the fourth month of pregnancy. I told the doctor that I have one Down syndrome's child so I wanted the doctor to check the fetus as I was worried about having another Down syndrome's child again. However, the doctor did not check and screen for Down syndrome because he physically had diagnosis and found that my pregnant development was normal. I did not know what to do but listening to him…At that time, I was totally mad and afraid of having a Down syndrome's baby again but I was not dare enough to have abortion…Right away after delivery, I asked doctor to check my baby face whether normal or not. Doctor was laughing and told me that I was lucky, my baby was fine. He said that not many people were lucky like me. And then the doctor let me have contraceptive operation after that because he said that there was a risk to have a Down syndrome's baby again…"

Namwan's mother : "I was scary of my third pregnancy. Actually I had not wanted to have any child. When I got the second baby as a Down syndrome's child (Namwan), the doctor had not allowed me to have sterilization. He might have thought that my baby was not healthy…But I had been in trouble as my eldest child was naughty and this one was a Down syndrome. I did not pay much attention on the Down syndrome's child. I even did not go for development training or practicing. I just let her lie down in bed…It was on improper birth control. I therefore got another baby…The doctor checked properly because I have had a health care welfare. Anyway, I felt uncomfortable and was worried about my baby…After having the third one, I told to doctor to do contraceptive operation for me, no more baby…"

6.2 Poverty and unequal accessibility to social services

6.2.1 Uncoverage of Health insurance

Presently, health insurance is provided to cover all of the Thai population. As for the poor, the system has been changed from health care service through the welfare card for the poor into the system of healthy for all through health card or golden 30 baht card. However, as a result of poverty and illiteracy, there have been

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several procedures and conditions on using the card which obstruct the poor to access to basic health care service. Those conditions are the selection of health care center and referring system as well as the requirement of providing basic health care service.

1) Unknown health card and unknown right

National Policy assures that every Thai population is provided at least 1 health insurance. Unfortunately, some of the key informants do not know about the health card due to illiteracy, poverty and the migration that is mainly a physical migration without documentary changing. Some of the key informants do not know about their benefit on health care, or even the existence of the health card which is the basic public service for the poor. They do not know that they deserve to have that card. Moreover, they have never seen it and do not know how to get it. This can be clarified by the conversations with Boss's and Linda's mother.

> **Boss's mother :** "I never have this card. I don't know how to use it…If I have any health problem, I just buy medicine myself or go to see a doctor at a health care center because it is not expensive…The doctor asked me if I had any card? I replied that I didn't have any…nor money. So doctor helped me…I really didn't know where I could get that card…"
>
> **Linda's mother** : "…I have been moved from here to there. When I stay here, I go to a health care center. When I gave birth, I went to Siriraj Hospital…But I don't have any card. I paid like a destitute patient…I didn't know what the benefit of the card was as I have moved out from my home town for a long time. I rarely go back home, even now my ID card has expired but still I have not yet gone for its extension…We live separately, my husband stays there and I stay here. I wonder how I can have it and what the benefit of the card is?..."

2) Without either ID card or health card

Health card is the rights of the poor but the worst of poor is no evidence of being Thai population which is absence of ID card. Pond's mother is an example of the woman who lives in a separated family. She stayed with her father in her

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childhood and moved to stay with her mother after her father got a new wife. She was discontinued studying and nobody paid attention on her citizenship. She does not have birth certificate, census registration nor ID card which result in not having the health care and all the rights deserved for Thai citizen.

> **Pond's mother** : "I don't have ID card. I don't know where my father keep my birth certificate. Since I moved out of his home, I have never visited him… When I was at school, there was no problem. And when stayed with my mom, I did not give attention on the card, so did my…I never vote because I don't hold ID card…I can live for 26 years without the card…When I went to hospital for delivery, I told them that I lost my card. They blamed me and I just ignored their words…"

3) Having a health card, but can't use

Some of the key informants have the health card but it cannot be used as it was issued according to their original hometown which means that they have to go to the health care which mentioned on the card. Therefore, their card can't be used when they are sick as they have already moved to stay in the city. Consequently, they need to take care of themselves by buying medicine or seeing doctor at clinic.

> **Rung's mother :** "I have the card but I have to go to Kanchanaburi because I haven't changed my address in my census registration…Fortunately, I am not often sick. So I don't concern much about the card. But I have to get it for my baby because if I need to pay a lot for her treatment, I will be in trouble. My husband puts my baby name in his friend house so that she can get the benefits from the card…'

Moreover, some of the key informants who are from Bangkok and vicinity provinces, have the health card but there is the condition which they cannot get the benefit from it as the health care center indicated on the card are far away from their house. As a result of having no chance to choose the place for themselves, therefore, the poor who hold this card cannot travel to receive the services. Since traveling means expenditure which is higher cost than paying for treatment cost at the place nearby home.

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> **Kong's mother** : "I am rarely use the card because I have to go to Klang hospital which is very far from here. I could not choose the hospital myself. If I go there, it means the bus fare and food cost that I have to pay…They should have provided me a closer hospital…In case I get little sickness, it is not worth go there. The bus fare is even more expensive than payment at the clinic nearby…It is not comfortable. Therefore, if it is not necessary, I will not go as there is too far. Moreover, they cannot treat for every sickness, in case that they cannot treat again they will refer to the further hospital…"

Mothers who has health care welfare under government benefit, they also face another obstacle, officials and cannot access to the card. As illustrated in the case of Namwan's mother, her husband is a low rank soldier. She relies on her husband salary which is uncertain. Therefore, her baby sickness is not taken care of satisfactorily.

> **Namwan's mother** : "…Even though he has a government official card, it is not free for everything…We have to see the doctor at the army hospital so that we can get benefit. But to go there, it is costly and I have to carry my baby awkwardly on the bus. Just imagine, I give up for that…If it is not a serious sickness, I will not go because I have to pay more on food and other things…If I'm just having a cold, I would rather see a doctor somewhere around my house…"

6.2.2 Poverty and inaccessibility of health services

The poor Down syndrome child'smothers acknowledged the importance of treatment and development practices which have to start from the Down syndrome's baby childhood and need to be done for continuous development. Although they realized this theory and really desire to take their baby for development practices. These poor mothers can not afford to take their children for development practices and the main reason is that they do not have enough money to pay for the cost of traveling and the practices. In addition, they cannot take a leave from their job since it is very hard to find job and they need to work for making a living in a city

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1) Limited choice for the poor to access the health services

Poverty is an obstacle which impact on accessibility to the services of the mothers. According to a heavy burden in both at home and at work. Although the health services are not much costly they can't afford the other expenditures i.e. traveling, food and the extra payment that the card doesn't cover. These are the obstacles of the poor to access to health care services. The instances of this case are Namwan's, Bass's and Pond's mother.

> **Namwan's mother** : "My daughter has never had this practice, but stays at home. She just lies down weakly like this. I take her to see a doctor only when she is seriously ill…A hospital is too far away. Even though we get reimburse for the treatment and practice. I can't afford the other payment. I need money to go to a hospital, only taxi fare it costs me hundreds as I cannot take her by bus. We don't need to pay for the treatment but still there are many other payments…I just bring her up according to fate, I let her lie in bed like this. I don't have time to go for that practice. I feed her at the meal time…Only when she get sick, I will take her to see a doctor…The doctor blames me every time I see him that why I never take my daughter for the practice…I don't know how to tell the doctor that I don't have neither money nor a supporter…I have to ignore for his words…"

> **Bass's mother** : "I don't have time to take my baby for the practice although the doctor at Chulalongkorn Hospital has made an appointment for intestinal treatment and operation. I could not afford to go. My son has worn a diaper even now…I have to depend on my mom as I work for two shifts everyday without and holiday. My work started at 6 a.m. and ends at 12 p.m. everyday. If I am not too ill, I have to work. I take a sick when I am badly ill. I will lose my daily wage if I take a leave…My mother has to take my son to see a doctor for me. I feel pity for my mom as she also has to work as a waste picker. If she does not pick the waste to sell, it means everybody does not have any food to eat on that day…My mom seldom takes my baby to see a doctor because our house is far away. It is difficult for a doctor to contact us as I don't have telephone if the appointment has been changed…However, my son is good as he practiced on his everyday life with his grandma. He goes everywhere with my mom. She carries him on her pushcart to pick the waste and he meets many people each day so that he is not afraid of people. However he has to avoid sunlight and rain, he will get a cold…It

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seems like his practices otherwise playing with his elders and neighbors…I really don't have time…"

Pond's mother : "However I cannot even afford for enough meeting. So don't ask me about the practices… The doctor blamed me when I took my son to see him the other day. I cannot go often as it is uncomfortable. Moreover, I had to pay for the traveling. However, the doctor gave me money to go back home…She is annoying and foolish. Look at her, she is very skinny as she hardly takes food…I cannot take her for practice because it will take me whole day which makes me absent from my work. So everybody will have nothing to eat…I work and if I look after him at home. I just let him lie down in blanket and feed him the breast milk or the instant milk given by doctor when he is hungry…"

2) More choices for the rich

The Down syndrome's children from a poor family lack of opportunity to have development practice. Contrarily, the Down syndrome's children from a rich family such as Kwan, Bee and Wut are the comparison case which obviously reveals the distinction of development practice opportunity between the poor and the rich. The rich key informants have chance to choose the place for practice and they can explore the other choices that they think it is the best ways to improve their Down syndrome's child to become as similar as a normal child

Kwan's mother : "I took her to many places, wherever is good. Firstly I took her to an institute…in where there is an expert in this matter. But I felt disappointed after visiting them as the training was so hard. I sympathized those babies because most of them have severe symptom…I therefore took him to the Phumipol hospital (Air force's hospital)…This hospital is good. The officials there pay a lot of attention on practicing my daughter. It helps me a lot. It's comfortable, not costing and near my home. My mom always goed to learn how to practices, except when she is sick so that she can train my daughter herself, if they don't have the course…I also went to a famous public hospital…as my relative is a nurse there…they taught us for training. But actually we went there just a short time as it is too far… We also tried to go everywhere, the private hospitals and popular institute …Fortunately, I stay at home with my daughter

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whole day. I can train her as suggested by doctor…I also take her in society such as swimming, playing golf, going to grandparent home, going to church and going to shopping. She goes everywhere with us and she meets many strangers so that he can help himself and learns to serve and help other persons. Moreover, he can do many things by himself such as having food, going to toilet…I take him to learn how to play a Thai musical instrument also as I think he will have concentration…I try to train him as his normal elders…"

Bee's mother : "…I am not satisfied with a public hospital. I therefore normally take my baby to a private hospital or a clinic. They know how to talk to my baby…Fortunately, my relative is a doctor aboard. So he sent me books to read. I try to understand and try to practices my baby according to the books. I practices him myself and use every equipment for training. He likes computer so much. So I bought one for him so that he play game or anything he likes…As for walking practice, the foreign doctor recommended that he walks on the sand to touch a nature which will help a child to balance himself. Therefore, I usually take my baby to the sea. I often go there until my elder children feel bored of the sea…"

Wut's mother : "After I was assured that my son was Down syndrome. I called everywhere that provides special treatment for this type of baby. I took him to the popular institute…Training at the public hospital…I have taken him to many places because I think the more practice, the better. How can I ignore as I am a mother. I want my baby recovery. On week day he goes training at a public hospital with his nursemaid…on weekend, I take him to the private institute for training on personality, walking, speaking. It is a private course with high cost. I pay as I hope that he will be rehabilitated…Other persons recommended me for supplementary food of Amway company, they said that it is good for brain which is good for child development. I decided to buy it and it is really good. However, it is very expensive. The discounting price is around 5,000 baht per month…Presently, we have not gone to the public hospital…because the doctor said didn't speak politely. So, we only go to the private hospital and institute…"

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6.2.3 Mainstream education and Down Syndrome's child

Thai citizens are activated on human rights and freedom after the Thai constitution was promulgated in 1997. Those rights include the rights of the disadvantages and disabilities to access health care service and education. The obvious action indicates the acceptance of disabled person to a mainstreaming education is the policy on compulsory education in 1999. The administrators and responsible person related to education announced that "the all disabled persons who want to study can access the right to study in any school". It was the hopeful statement for the Down syndrome child's families that their children will be acceptable and educated as common children. However, the mothers who have a child of school age indicated that the policy is unpractical. There are many of the Down syndrome's child who are not acceptable to study at school age. Moreover, economical problem is one of the supporting factors which make the Down syndrome child's families to surrender to obstacle of the system and allow the child to learn from the real life under poverty cycle.

1) Incompatibility between Educational policy and practice

Most of the mothers have had high expectation on the educational policy of the government. Therefore, they take their child to apply to a school. But in practice, it is not as easy as expecting. They do not allow the Down syndrome child to study in a general educational system. In stead of flexibility, they construct a rule which impact to schooling of the poor Down syndrome's child as the case of June's and Afifa's mother.

> **June's mother** : "It is very problematic on schooling. Luckily, at the preliminary level, the teacher took pity on my daughter and the school director accepted, therefore my daughter was accepted…I think it was a booming period…when she was about to go to grade 1, it was very difficult as the director had been changed and the present director did not accept my daughter even thought I went to ask him but he confirm on his decision. I asked him why at the preliminary level my daughter had

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been accepted and why not grade 1…he said that if he had been the director at that time he would not have accepted my daughter to be his burden. He said like my daughter was very hideous…I wanted my daughter to study there as there is near my house and my daughter like to study there…One reason that he did not accept my daughter was that I did not have money to donate to the school. He said indirectly that he needed a new air-condition. And he asked for 60,000 baht for donation. I said that I would pay by installments because I didn't have that much money, I had to work and collect money to pay for that…So he said that he would try to take my daughter to a class. She went to class for three days then I gave him money partly. And he said like my daugther's teacher had difficulty in teaching the class as my daughter was slow down her classmate…he said he wanted more money from me as that money he asked me before was too less. My husband was so angry that he took my baby out of the school…We comforted ourselves that if there was not any school for our daughter, so we will teach her ourselves at home. Then we try to explore for the schools that near my boarding. If it is far, we cannot take her there because we have only a motorcycle…This time, the new term has started, so she stays at home. Temple's school (laughing)…They will call us when there is a funeral, so I take her there to write, to play herself…I am disappointed on thet school. I thought that only the private school ask for money but public school also. How the poor can go to school. If it is not much for us, we still can collect those much money. But if it is much, then we cannot afford. Our job is uncertain, we only live from hand to mouth. My work depends on death man. Some host gave me extra money which I can make a living…I don't know the source of problem but to sue at the court is wasting time. Although government announced that disordered children will be provided education as normal children, I think it cannot be successful because school will say that an abnormal child creates problem…Although I asked them to have a pre-test for applicant of my daughter but they denied as they did not believe that my daughter can do it. To sue at the court is the waste of my working time…Previously, they accepted my baby as it might be at the booming period of the policy and school wanted to be famous. When the guests at the funerals saw and knew about my daughter, they encouraged me to complain to the Ministry of Education, but I didn't want to do it. It would be disappointing and wasting my time…The present problem is to explore the school for a Down syndrome's child…"

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Afifa's mother : "her elders are not difficult for schooling but for herself. There is a special school for this particular type of children nearby but it is a private school. I went there to ask about the cost, they collect for 1,500 baht per month exclude other expenses. After I knew the cost I gave up because I earn only 4,000-5,000 baht per month with three children to be taken care of…I tried to look for a low cost public school but they did not accept my baby. Teacher said that she could not teach the abnormal children as she might annoy other students. The teacher thought that she did not understand words so that my daughter will create trouble for her and other students…I tried to look for another school and they said that they felt sympathy on me and my daughter but they have a lot of children to look after and my daughter need a special care. And they didn't have time to take care of her specially…I want her to study in a general school with normal children so that she might be like normal children. I took her to the Mosque's school (Muslim) near my house but the school did not accept her …I therefore have no idea which school will accept my daughter…"

2) Educational Limitation for Down syndrome's child

Kaew got into a school for disordered students where her parents and grandparents do not want her to study there as they think that it might not support Kaew for her better learning or development. As a result of absolute rejection from the school that they want Kaew to enter, therefore, they do not have other choices with their idea that at least Kaew can go for studying instead of not at all.

Kaew's mother : "She was not acceptable in a general school as we took her to many schools. Grandfather took her to the same school as her sister which is a private school, after they saw my daughter, they shook their head and said that they didn't have a teacher for this type of child…I went to a temple's school…where her father and uncle is its alumni but they still did not accept. Her grandfather asked teacher that why the government announced that this kind of children are accepted at every school. Teacher have to accept…Still they did not accept my daughter. They said that just let her grown up more until she could take care of herself and took her to the school later. If we wait untill she is grown up, she will be foolish…Her grandfather did not want to annoy them. So he went to the aid center school in Klongtoey community. It is the special school for abnormal children

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with low cost and shuttle service. We have to accept as we have no other choices. No where wanted to accept her. I want her to study with her elders because she can play with normal children. I expect her to study in a general school but no schoole accepts her…My parents said that if she could not go to a school just send to study in the rural school but my husband's parent did not allow. They tried until she get the school. My husband's father said that it was fine for a special school like this one, as teachers understand these children very well because they had studied in this matter specifically. But the environment at school is horrible. My daughter is even better than many children. She can handle other children …"

3) Wealthy Effecting to Educational Choices and Opportunity

Bee's and Kwan's mother are rich mothers who have many choices for their Dawn's Syndrome Children. Although, mainstream schooling did not accept their children but their wealth helps them to have more choices and bargaining power to find the place for their Down syndrome's children to study with normal children in a private school.

Bee's mother : "I try to give her schooling according to her age and have a development similar to a normal children. We trained her until she was ready to go to school. Later on we took her to a famous private school. Although the cost of this school is very expensive but we can negotiate with the school owner for whatever we want. In case of a public school we cannot disturb them much as the have a lot of students so that they may not pay attention to my child…for the school that I get my baby in, I told them that I do not expect my son to pass the class but my goal is to have friends in a real society and finish a compulsory education. After that we will explore her skill in order to support that skill. It is fine to pay extra money as I pay more to the assistant teacher because she has to take care of my son specially. .. Bee will study according to her age like general children. But she may not pass an examination as other general students. She is very good in reading. I think she can understand English because I try to teach him and take him to English course with a foreigner teacher. I prepare him to get use to English because I plan that after completing compulsory education, I will take him to study aboard. I believe that the school over there may have more experience on teaching this special type of children. In Thailand, there is not much attention to these children…"

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> **Kwan's mother :** "I explored many schools for both a general and special school. There are advantages and disadvantages in both of the school… Finally, I've chosen got this private school for my daughter. It was very lucky. The school director was sympathized to my daughter. I told him that I have to choose the school which accept both my elder child and this Down syndrome's child because we are family then we have to take care of the Down syndrome's child together. This school understand us because they follow Buddhism concept… But the director said that his school never have a case of teaching Down syndrome's child so that the school need mother to accompany the Down syndrome's student. I look after her at school all the time. Actually, it is a school policy to encourage participation of parents. After taking her to school, I help teacher and school, I work as an assistant teacher. I sometimes help them for teaching and doing school activities among teachers as well as other parents. So they get benefit from me as it seem like they have more personnel in the school. Moreover, the school is also benefit from having experience to take care of this type of children. They accept more Down syndrome's children to study afterward…When my daughter is sick, I don't take her to school. For example during she was having treatment on her head, she stopped studying for years. She started studying again after recovering from the sickness. The school allowed her to continue her study…I do not expect her to pass the class as a normal student, it depends on her physical conditions and health. Normally, she studies for two years in one class…"

4) Indifferent limitation either the rich or the poor Down syndrome

Kwan's family is not poor but she has been refused by a private school as she is a Down syndrome child. Her parents and grandparents did not expect that the private school would not accept her daughter as they had believe that the school understood and sympathised the family with a disordered child. That rejection leads to a great painful and disappointed to the family.

> **Kwan's mother :** "It was very difficult to get a school. I tried to get the school which accepted both children. The elder child is fine because she is normal and smart. But the younger one is an abnormal one… I want them to study at the same place because I want the elder child learn how to look after her sister. We hope that when we die, she could take care of her sister. Anyway, it was so difficult to get a school because everywhere can accept the elder one because she is a good student and skillful but not for the younger one… I went to a religious school where I thought it might not be a problem but they

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said that they are not ready to teach this type of child and they don't have special teacher. I begged for them to accept my baby but still they did not. I was totally disappointed as I thought they had had a kindheart according to their intention. Contrarily, they only think about business. They want to accept only normal students…I do not expect my Down syndrome's daughter to be a good student but just want her to have friends and society. She was rejected although we had money. They did not want to accept because they did not want to bear any burden…It must be worsen in case we don't have money so don't think about an educational opportunity…"

6.2.4 Life insurance system and discrimination Down syndrome's child

Normally, the person who are indicated as having a good living status must have met a the salesman from life insurance company. Perhaps, someone might have been contacted by many companies. Especially, children are the favorable target group for those companies as there are low risk for sickness and accident in children. Moreover, there is a long period for insurance premium payment. Sometimes, people decide to buy the insurance only because they cannot resist on persistence of the salesman. However, this circumstance happens to only normal people, not for the Down syndrome's children even though they are in a rich family. This case can be illustrated in the conversation of Kwan's mother.

Kwan's mother "…All of our family members are provided a life insurance as my husband is careful. He said that we were not a government official so that we have to insure our children life. Like my eldest child, right after she was born we bought her a life insurance which provides health care also, the insurance premium is hundred thousands for each year. My husband has two insurances, one is provided by his company and one he bought himself…We just say that we want to buy a life insurance, they will immediately come to us. What we need to do is just pay for the premium…But in the case of my Down syndrome's child, we contacted to the same company. After we told them that my baby is a Down syndrome, they said that they have to check the company rule and the result was she could not get the insurance…it was funny, they may think that a Down syndrome's child is a disordered person or risky for diseases. Perhaps, the child may die before they gain benefit. So they did not

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> allow…It is business, their goal is benefit…therefore, they consider to refuse an abnormal children. This reflects that they look at this type of children as an object not a human being. In economic point of view, they think that if they accept this child it is risky for less benefit or lose in investment…It should have taken into account as the government stipulates that the disordered person are equal to common person, is that true or not?...We can be illustrated obviously through the life insurance system. Anyway, they are a private company. So they may not give any attention to the parents of the Down syndrome's child life. They only think of benefit and lose in investment…"

Summary

Social and cultural structure context which is structural violence such as direct and indirect sexual violence in society reflects to mother who has a daughter as a Down syndrome. They are plagued in fearfulness on taking care of the Down syndrome's child. This indicates the problem concerning both the femininity and abnormality. While the socio-environment aspects such as religious rule and social rule on having child are the social and cultural structure which they are influenced by patriarchy concept. Therefore, the rules in society are originated by the following concept. The disobedience of the rules impacts directly on mothers' emotion and guiltiness. Under the social atmosphere which is influenced by the normal standard impacts on mothers who are recognized as a producer of abnormality. Therefore, they feel disappointed and guilty for living with their abnormality. Besides the social and cultural structure context, there is an economic context which is the relationship between poverty and lacking of opportunity for social welfare such as the absence of health care assurance, inaccessibility to development practices, lacking of chance to study in a general educational system and inaccessibility to life insurance as general people. Hence, the poor Down syndrome children in the social and cultural structure which is influenced by a patriarchy, is the condition leads to the disadvantage and limitation on living and accessibility to benefit which the Down syndrome's people are qualified to get according to their dignity of a human being. These results can be summarized as the following figure 7.

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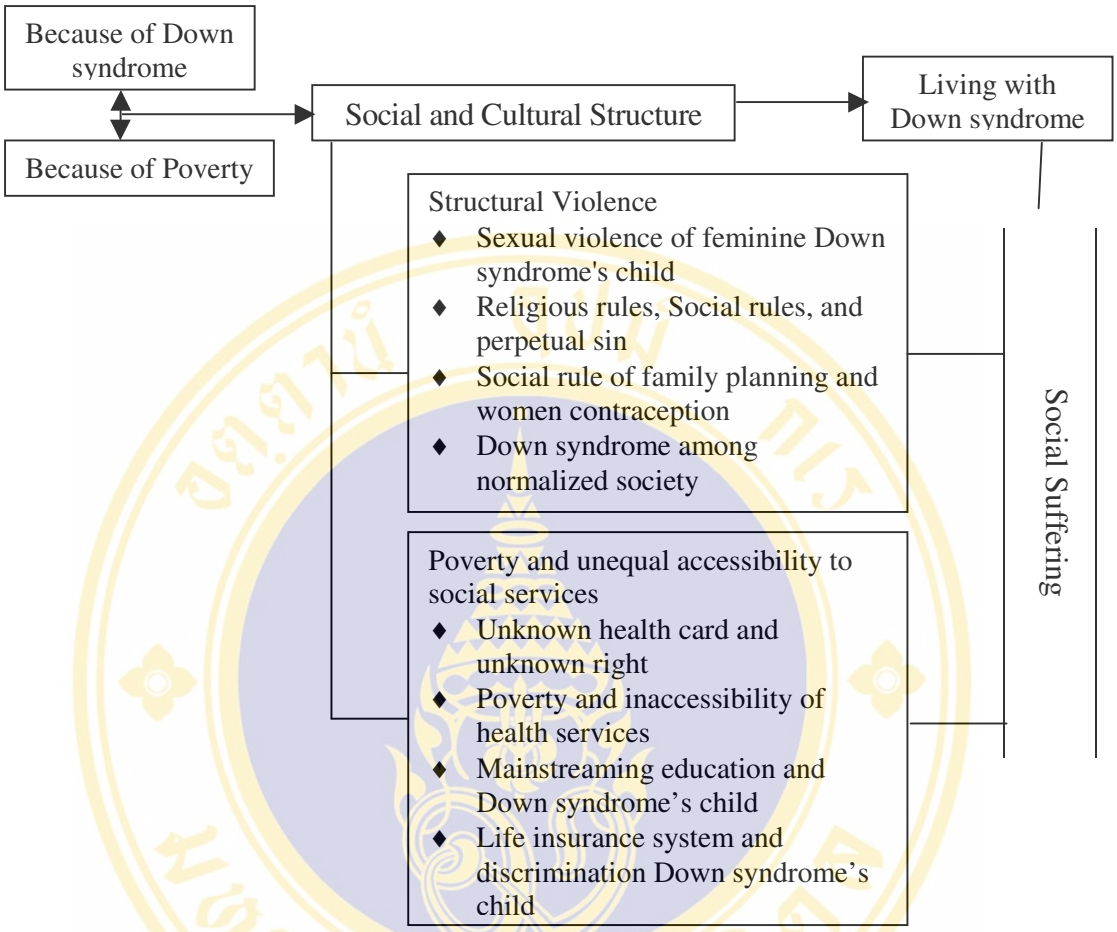

Figure 7 : Suffering experience of Down syndrome child's mothers under the Social and Cultural Structure

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CHAPTER 7
MEANING AND MANAGING SUFFERING OF HAVING DOWN SYNDROME'S CHILD

Medical meaning of Down syndrome is as a hereditable disease and chromosome abnormality that has effected to physical disability, intellectuality, and development by age. This medical knowledge is constructed under scientific medicine so that it's very difficult for the poor mother who is illiterate to perceive and understand. This study will reflect the meanings of Down syndrome in mothers' perspectives which are different in 4 periods of life experience of having Down syndrome's child ; prenatal period or pregnant period, giving birth period, checking and confirming period, and living with Down syndrome's child. Moreover, the study still found that giving meanings of Down syndrome in each period were different and they had effected to differently managing suffering too.

This results will be presented into 2 parts; (1) meaning of Down syndrome, and (2) managing suffering of having Down syndrome's child. In each part, the result's presentation divides into 4 periods of life experience as above mentioned.

7.1 Meaning of Down syndrome

7.1.1 Prenatal period or pregnant period

The most mother had prenatal care at the health office or hospital and this brought them relate to the health care system which had the different interaction between health personnel and pregnant mothers. The important factor which had effected to the meaning of Down syndrome and the different interaction, was the pregnant age of mothers, especially for the mother aged more than 35 years. 35 years is the cut point of risk age for pregnancy which is more risky for having abnormal

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child. . For the general pregnant mother, they hardly had frightened to delivery or giving birth the abnormal child because the physician and health personnel didn't give them the special knowledge, excepting the normal program. Down syndrome's child's mother always gave the meaning as their experiences, belief and culture. While, the risk mothers had more perception on the opportunity to have abnormal child. The different meanings which happened in this period were different as these follows.

1) Pregnant mothers aged not more than 35 years

The general pregnant mothers gave meaning of Down syndrome as their experiences, beliefs and culture. The most had not known Down syndrome before but when let them recall their past understanding, found as these meanings;

1.1 Mental retardation

Most of the mothers experienced and realized the Down syndrome but in different name as popularly called according to the disorder symptom on brain and mental which are "*punya-on*" (mental retardation), "*baa*" (mad) and "*oer*" (dullard), etc. It was mainly acknowledged and defined as mental retardation disease. It was resulted from ignorance on Down syndrome in society and this type of syndrome has recently been clarified. Thus, understanding of this syndrome was in the same type of mental retardation. Many mothers encountered the direct experiences with Down syndrome's child as family members or community member so that they have ever perceived and known as Meaw's , Namwan's and June's mother.

> **Meaw's Mother :** "at rural, the villagers call *'punya-on'* (mental retardation), *'oer'* (dullard), *'paroeu-patuoe'* (clumsy), fool, and include *'baa'* (mad)."

> **Namwan's Mother** : " My brother is also like this but I never know that he got a Down syndrome, just think that he is a mental retardation. We call that "*punya-on*" (mental retardation) or "*oer*" (dullard)… This type of babies are not treated, even doctor can not cure them… "

> **June's Mother** :" when I was young, at Korat province, grandmother called '*oer'* (dullard) and for me, I understood that it is *'punya-on'* (mental retardation),*'punya-nim'*(low intellectual quotient)and *'ngho* and *ser*' (dullard).

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1.2 Physical disorder or disability

Physical disorder problem of the Down syndrome's child, especially in the society which contain the disparity to access to health care services, extremely impacted to the understanding and the perception of Down syndrome in term of physical disability. It was due to muscular fatigue as the symptom which resulted from lacking of treatment or muscle developed practice. These children, therefore, cannot be able to use their hands to hold things nor walk since their legs are not strong enough. Hence, Down syndrome is acknowledged and defined as disabled person. Although, calling words are different but the meaning is similar which mean physical disability such as "*pikan*" (physical disorder), "*deang*" (paralysis), "*ngoy*" (palsy), etc. as in the narrative of Meaw's and Namwan's mother.

> **Meaw's Mother :** "for this symptom, general people will bring up the children according to fate… just let them sleep on shit and pee, saliva overflow from their mouth, and emaciated arms and legs… They are "*ngoy* or *pae"* (palsy) with limp body. They produce onomatopoeia sound and cannot take care of themselves. They are totally paralyzed. Actually, some of them are neglected until curl up."

> **Namwan's Mother :** "Her body is soft and also her legs. She can get the legs on her head and suck her toe. It seem like she does not have bones. She will be disabled, can not walk… wherever I place her, she will only stay there. She is now 12 years old but still cannot walk nor take care of herself… She just like her uncle (mother's younger brother) as he is now 11 years old but he is paralyzed, cannot walk. His arms and legs are emaciated and cannot take care of himself. "

1.3 Incarnated disease

Family and community members who have direct or indirect experiences on Down syndrome defined this syndrome that it is "incarnated disease" which is hard to find the reason and cannot be recovered like as the result of sin. The mothers of Down syndrome's children in this study are mostly engaged in the society with the poverty which has effect to lacking opportunity of access to knowledge and health care services. Those services include treatment and developed training. Thus the Down syndrome's children are lacking of developed practice to assist and survive

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themselves. Finally, they become a disabled person who has to rely on others as a person who gets chronic disease and depend on the surrounding people for entire life.

The belief of "*Karma*" in Buddhism markedly influences on the thought and meaning of Down syndrome's child which reflects to destiny of one's life. The belief in "*Karma*" leads to understanding on the origin of the action and any wrong action in the past or present that result in sequent abnormality in life that including having an abnormal child which is an unavoidable situation.

> **Bengi's mother :** "I used to see this type of child and I felt pity on their parent for having a child like that. They might have done something bad. I thought like that… "

> **Namwan's mother :** "When my mother got my younger brother as a Down syndrome's child but I did not know what disease he got. I never knew Down syndrome before. Mostly, we think that it is because of "*Karma"* and destiny of one's life. "

2) Pregnant mothers aged more than 35 years.

For the elder pregnant mothers, they have more chance to access to information on the risk to have a Down syndrome's child during prenatal care. Mostly, their experiences with the meaning of Down syndrome were not different from general mother which emphasized on intellectual disability that was mental retardation. The difference in meaning of Down syndrome was started after gaining information and advice from medical personal. Although, they perceived and realized more information but it created trouble, anxious and irritation on reality and the means of giving information. Meanwhile, there was different between the poor and rich mothers. It was because the poor mothers feel less anxious and pay less attention on the information as illustrated in the case of Mod's Mother. Similarly, Fluk's mothers also lacked of knowledge and did not understand the strange message from doctor's communication so that she was not worry about abnormality though she was pregnant at old age. While, the rich mothers were more worry on that matter as illustrate in conversations of Kwan's and Bee's mother.

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Mod's Mother : "I used to see this type of abnormal child "the *punya-on* child". Even the joker in TV that his name is Sayan… but I've never known that they were called Down syndrome's child… During prenatal care, doctor said me to be careful, but I was uninterested in the doctor's word. I did not even think of it. I just knew that these symptoms were *punya-on* but I did not sense and pay any attention and worry . "

Fluk's Mother : "I've just known about Down syndrome after giving birth. During prenatal care, doctor did not tell me directly. He just asked me whether I thought to do something. At that time I thought that doctor was worried with my pregnancy while I was having contraceptive ring. I did not think of Down syndrome's child during my pregnancy. I was just worry that the contraceptive ring might cause negative effect to my child. Formerly, I thought that this kind of child was the *punya-on* child. " "

Bee's Mother : "I knew that there was something wrong which one point that I sensed was because of we could not touch and carry our child. I did not understand why it happened with me because all of my sisters have given child at the old age. I somewhat knew about Down syndrome and mental retardation. During my pregnancy, doctor also suggested and gave me some information but he was not serious on that. Therefore, I did not worry nor thoughtful. Another reason was because I did not have any unusual symptom. "

7.1.2 Giving birth of Down syndrome's child

During giving birth, the mothers of Down syndrome's child defined the meaning of Down syndrome varyingly by their context. The study indicated that the mothers of Down syndrome's child are neither realized nor familiar with the word Down syndrome. Therefore, doctor and medical personal explanation to inform the mothers of Down syndrome's child that their child got Down syndrome. This explanation, however, was not providing proper understanding. The mothers defined 4 meanings during this period namely mental retardation, *Sayan* syndrome, physical disorder and abnormality. The differences of each definition of Down syndrome were varied according to their personnel background, perception of the syndrome and communication of medical personal. These differences had impact to mother's emotion differently as these follows.

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1) Mental retardation

Most of mothers perceived and understood Down syndrome as mental retardation. Down syndrome was a technical term in medical profession which was rarely understood by the mother of Down syndrome's child. Mothers mostly realized from their experiences and the visualized symptom as mental retardation. Moreover, there were the various perceptions on defining mental retardation which depend on their different contexts.

Sad news

The case of Phing's mother, who was poor and low education She perceived abnormality of her daughter from the physical appearance and she defined as mental retardation. Nevertheless, she was not troubled on encountering that situation since she passed through the more critical symptom of her previous daughter. Similarly, Namwan's mother felt somewhat disappointed as she thought that everything happened according to her fate. Moreover, she used to have experience of her own younger brother who got a Down syndrome but she perceived in the other name, *"punya-on"*.

> **Phing's Mother :** "Doctor called Down's Syndo (accent by the key informant) but I did not know the symptom of that. Formerly, I called as "panya-on" (mental retardation) as I knew before… I had knew this symptom as called "panya-on" (mental retardation). Before the doctor told me that my daughter was Down syndrome, I was curious that why my daughter face was like that. It was clearly seen, so that I thought my daughter was a mental retard. I even talked to my husband that our daughter looked like a mental retard, having a screw loose… It could be recognized on her face. After the doctor said, I was somewhat disappointed and so sad but just kept silence. I did not worry as I passed through even more serious situation."

> **Namwan's Mother :** "When the doctor told me that my daughter was abnormal, I felt sad because I knew the symptom from my own younger brother. I thought that she was like the mental retard and disabled child. I felt worry about a heavy burden on taking care of her since my eldest son was not much grown up."

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Extremely shock, scare and sad

Kong's mother did not see her son's face but she knew about abnormal symptom of her son through the nurse words. She was extremely shocked and frightened to know that her son was abnormal and got severe symptom. However, it was not the perception regarding to having a Down syndrome's child but mental retardation which was similar to *"Sayan"* (the joker's actor who got Down syndrome but most of people realize that he got mental retardation). Meaw's Mother, similarly, was shocked and seriously frightened after she knew that she got a mental retard's daughter.

> **Kong's Mother :** "The nurse informed me that my son was abnormal. I had not yet seen him so I just thought that he was not strong, or might has hard health problem. At that time, doctor told that Kong was Down syndrome but I did not know and realize about this symptom…Moreover, He said me not to have sterilization right away, just wait since my son was not strong. Meanwhile, I did not know that my son was Down syndrome. The nurse said like he got severe symptom and she also said that my son was similar to *"Sayan"* so that I realized that my son was abnormal as mental retardation… I was so sad for encountering that situation. My son both got severe symptom and also looked like a mental retard. It was too hard to endure. I felt like going to dying because It was unacceptable. I could not foresee the survival of my son and still he still be mental retard too. My heart was broken and it was like a drowned man. I loudly cried out, thoughtful. I felt more sad and want to die after seeing my son… "
>
> **Meaw's Mother :** "Firstly, I heard the nurse called my daughter that "Down" I didn't think about Down syndrome , but I happily was thinking of "down" (star) on the sky. But after they said that the same kind of Sayan, the slow developed person. That made me shock which I could not say any word, just crying out loud. I could not control myself. I thought too much, confused, and sad. I say honesty that it was unacceptable. I thought of the disabled child that slept on shit and pee. Really, this was named mental retard child who was ignorant…"

Although, Kwan's mother acknowledged about the risk and had the abnormal sign during pregnancy which referred to fetus's abnormality but she didn't think that it would have effected to her daughter. So when she confronted with reality

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of having Down syndrome's child through her husband words, it was still unacceptable for her and she was extremely upset to have a Down syndrome's daughter.

> **Kwan's Mother :** "My husband told me to control my mind and he said that our daughter got many symptoms and also be Down syndrome… I was shocked, and numb in whole body. The feeling at that time was like a man who was going to fallen down to the deep valley and it was like moving past at great speed. It seemed like I was faint and too much upset. There was a buzzing in my ears. I thought alone without paying attention to my husband words. I could not hear and understand anything by that time… Though, I was already preparing myself but still I could not resist for that. I thought that why my life was so cruel. "

Shock and denial

Wut's Mother did not recognize Down syndrome. She only knew mental retardation and Sayan syndrome. Therefore, when she knew that her son got this particular syndrome, she was extremely shocked unaccepted and denied on this situation as she thought that she have never done anything bad why it happened to her. Also, Taen's mother was shocked after knew that her son was like *"Sayan"*. She was attempting to think on her side that the doctor's investigation might be wrong because she thought that such a situation should not happen to her.

> **Wut's Mother :** "After I knew that my son was Down syndrome, I was shocked that how come he was a mental retard. It was totally unacceptable. I cried and raised my hands together on my head and questioned to the sacred power that why God let us be like this since I have done only goodness in my whole life… "

> **Taen's Mother :** "After the doctor said that my son was like "*Sayan*", I cried out loud. I couldn't say any words, just cried without stopping from hospital until I came back home. I could not tell that feeling of mine but it was scared and frightened. I never thought of this situation, why was it happening. I didn't understand why my neighbor, although, she was a drug abuse but her child was fine… It was unbelievable that my son was like that. Doctor told me to have blood test in order to confirm the result. It meant there was hope, as my husband and I did not have any abnormal symptom. It was impossible… "

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Anger and tension

Bass's mother got pregnancy during her husband was flirtation with another lady and lacking of responsibility to the family. She was unhappy to carry the son. Therefore, when she got an abnormal son, she was so angry and tension to face that situation of having a Down syndrome's child which her mother and herself realized that Bass got mental retardation.

> **Bass's Mother :** "If I tell other people that my son is Down syndrome they might be curious. Actually, they can recognize from his face as it is the same pattern. The person who has a flat face without the bridge of the nose. It is strange that these mental retard's children are all the same no matter born from whom…"

2) "*Sayan*" syndrome

Rung's Mother was another one who recognized abnormality after seeing her son but she was still due to ignorant to understand what happened to her son. Although the doctor informed her that her son was Down syndrome, she was not frightened or upset but at that time she felt amusing and compared to "Sayan" who is a joker with hope. Nevertheless, her elder sister was not the same feeling as her because she acknowledged that *"Sayan*" was a mental retard.

> **Rung's Mother :** " I did not frightened or upset when the doctor told me that Rung was Down syndrome because I did not know what it is. I just felt that it was a strange word that I've never heard. I did not feel any thing. I just realized that Down syndrome was containing various problems on dullard, ears, eyes, nose and heart after I brought him to see the doctor. It was amusing, I laughed with my sister as I thought of *"Sayan"*. She did not have eyebrow and the bridge of her nose. It was flat like it was totally pressed by the plough machine. I amusingly said to my sister that my son's face was like *"Sayan"* but she scolded at me that I was crazy to say as cursing the son like mental retard. However, I was not much scared as I saw *"Sayan",* because he was grown up, could manage to present himself on TV, speak and can earn money… But I never knew that there are other symptoms other than funny face… Dullard of this syndrome was very cute, just sits still and kept silence for whatever everyone said, I just realized the Down syndrome but I thought it was actually like deranged and so stupid person."

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3) Physical disorder

Namwan's mother had experience on having her own younger brother as a Down syndrome person. Therefore, she knew the symptom and recognized it as mental retardation and physical disorder. According to the family poverty and over number of children, it led her brother not to be taken care and abandoned to stay in the same position. This was a part of mother's belief about fate or "karma" so her brother was without developed practice. Therefore, he had the problem on movement which reflected too many calling name such as *"pikan*" (disabled), "*Deang*" (immobilize), "*ngoy*" (paralyze), etc. And when it happened to her daughter, she still knew and understood the same meaning as the past experience.

> **Namwan's Mother :** "Her body was soft and also her legs. She could even get the legs on her head and suck her toes. It seem like she does not have bones. She will be disabled, can not walk… Wherever I placed her, she would only stay there or moved by rolling without aim. She couldn't walk, and take care of herself. The others sometimes called her, *"Daeng"* (immobilize), *"ngoy"* (paralyze)... and if she was able to walk even improper so called "*I-pae"* (twisted leg man)…"

4) Abnormal symptoms

Sor's mother perceived Down syndrome in the meaning of abnormality which has never made her feel upset at all. This was due to her ignorant and communication of the medical personal that never allowed her to feel worried about seriousness of the syndrome. Therefore, she just realized that her daughter got abnormal symptom which needed a special care. Mod's Mother was also realized about abnormality of her daughter without frightening that the daughter got Down syndrome or any abnormal.

> **Sor's Mother :** "I was not frightened nor upset because I did not know about Down syndrome. I could not recognize the syndrome from his face. The officials at the medical center told me that my daughter got this syndrome and I thought that his usual syndrome might not be that serious. Moreover, the officials suggested me to take good care of him, so that it made me feel that her symptom was not serious… I was not worried and brought him up as usual. Until I came back home, my next

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door who was a nurse gave me some books. Therefore, I really realized about her syndrome by that time."

Mod's Mother : "I was not frightened. After the doctor told me that my daughter was Down syndrome, I felt like nothing happen. Conversely, it felt so glad that I got a daughter after I tried so hard for 10 years until having one… Moreover, I did not understand of what syndrome that the doctor said. I just knew that my daughter got abnormal syndrome but I did not know exactly that it was Down syndrome or what else…"

7.1.3 Checking and confirming Down syndrome

After the mothers was informed about the sad news of having the Down syndrome's child through the communication of the medical. Their emotion at that particular time was varied according to each context. However, the mothers needed to adapt themselves physically and psychologically after being known the sad news. The study found that after perceiving the sad news, only some mothers were advised to have children's blood checking for Down syndrome confirmation. Meanwhile, the mothers tried to seek the more information during that time which assisted to improve the meaning of Down syndrome more than the previous 2 period. However, this period was a short time which was only 1 month after delivery.

The period of children's blood checking for Down syndrome confirmation was advised to some mothers and it made them hopeful that the bad news sometimes was not true. Some mothers were partly believed but still expected that their child might not be Down syndrome. However, some mothers immediately believed in the doctor words because they related to the physical appearance of their children which appear to them. Therefore, they could recognize the abnormality or mental retardation of the child according to their experiences. During this period, some mothers could not ignore the symptoms of their babies, so that they tried to seek more information in order to understand the symptoms more. That reflected to the more meaningful of Down syndrome which overlapped with the period of accepting the Down syndrome's child and facing the reality.

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Mental retardation… Upset of the truth

Taen's Mother disclosed her anxious and scare that the blood test would confirm an abnormal symptom of her son, therefore, she was afraid to call for the result since she was doubtful to accept the truth. After the Down syndrome of her son was confirmed by the doctor, she was so upset. Similarly, Bengi's mother was upset and angry with herself as well as her husband who made all the things to be like this. Also, Kong's mother was sorrowful during waiting for the result. She suffered from keeping the secret alone with fear and hopefulness and waiting alone for the positive result. However, finally she could not escape from the truth that her son was Down syndrome. This news made them upset.

> **Taen's Mother :** "I was not totally believed that my son got Down syndrome but I was also worried that it might be true. I was afraid of it because the doctor knew more than us so it should not be mistaken. I was worried about taking care of my son… I counted down to the result release date but when the day came, I dare not to call for the result… After the nurse confirmed about Down syndrome of my son, I was speechless. I could not do anything, just only cried because it was so much upset."

> **Bengi's Mother :** "I was worried during waiting for the result, but I believed that my daughter got the Down syndrome rather than not. Because I used to have a prophetic sign in my dream so that I thought Kwon-Im God intended to give this daughter to me… but another thought, I did not want to be like this. I could not stop worrying when I was thinking of a mental retard. I was anxious while was going to listen to the result and I was shocked when the doctor told about the result of having Down syndrome's daughter… but I was comfort myself to accept the result…"

> **Kong's Mother :** "I was so suffered during waiting for the result as it was unpredictable. Anyway, I believed in the doctor and I was pretty sure after looking at my son's face… but I dare not to tell my husband. Doctor recommended having confirmation test and I decided to have the test but the period of waiting for the result was absolutely suffered. I visited my son at the hospital and cried everyday. At home, I had to tell a lie to my husband everyday because I dare not to tell him. And also I avoided crying in front of my husband since I was anxious about his feeling when he knows the truth… On the day that the result was released, it seemed

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like I was walking to the execution area. I was so scared. After the doctor told me the result, I was very weak and could not resist standing… I totally confused for how to live, what to do, what to tell my husband. I cried after I met my husband, that made him curious. However, he was silent after I told the truth about the son. Anyway he was normally apathetic… I was seriously upset about the truth."

7.1.4 Living with Down syndrome's child

Some mothers were not received the suggestion to have confirmation test, that resulted to most of the mother to believe firmly that their children must got abnormal syndrome as the meaning defined in the former period. However, it was found that in both of the mother who were recommended and not recommended to have the confirmation test, and both believed and not believed in the doctor words, mothers were advised to provide treatment and developed training to their children. In this period, the mothers perceived, sought and accessed to information in various ways which included explanation of medical personnel and seeking by themselves. That information resulted in better understanding of the Down syndrome and more meanings of Down syndrome were defined. Meanwhile, mothers have adapted themselves physically and psychologically to the Down syndrome during this period as illustrated following.

1) Down syndrome

Base on educational and knowledgeable background of Down syndrome child's mother, it was found that Down syndrome was not a familiar word. Therefore, to receive the bad news regarding the Down syndrome's child resulted in different condition and feeding. However, after that period, most of the mothers received information and realized more through the information on Down syndrome given by medical personnel. Especially, the information on treatment and developed training which some of the mothers found out the information by themselves such as looking for the professional institute of this syndrome, receiving advice from neighbor and reviewing the documents concerning the syndrome. Those mentioned means to access the information reflected to the ability of those mothers to clearly understand Down syndrome. Though, many of them still recognized the syndrome as mental retardation base on their former experience.

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The instance of Bengi's mother, she thought that she realized the Down syndrome more because she took her daughter for training. She knew the cause of this syndrome according to the information given by doctor and she also knew how to practice to her daughter. Similarly, Sor's mother understood Down syndrome clearly from studying documents given by her neighbor. Although, she was totally doubtful about this syndrome before. Additionally, Phing's mother found that she understood symptoms of her daughter more, however, her perception to the symptom was limited and she still called this syndrome that "Down's Syndro (me)" during I interviewed her.

> **Bengi's Mother :** "I was just realized that the person we called metal retard for a long time, the doctor called "Down syndrome". However, it was different only words between doctor and me and we called the same symptom…"

> **Sor's Mother :** "… if nobody told me, I really did not know that my daughter was Down syndrome. The health personnel did not tell directly so the indirect words didn't made me understand. Even I brought him at home, I still did not know. Until my neighbor who was nurse, saw my daughter and she felt pity then she gave me some books to read. I knew more from her books and I found that it was the same as my daughter's symptom… so that I just realized by that time that this symptom named Down syndrome… Anyway, if I told the others that my daughter got Down syndrome, they must be curious and still recognize my daughter as mental retard."

2) Slow development

To access the health care services and developed practice, Down syndrome child's mother could have more chance to access to the information. In general, health officials always explained the symptom and comforted mother that symptom of Down syndrome can be developed. It markedly reflected to meaning of Down syndrome which was slow development and led to calling and meaning Down syndrome as slow development. Moreover, the mothers were satisfied and hopeful with this meaning because they felt that this meaning was a positive word, and suitable for communication with others without stigma to the child. The instances of this circumstance are illustrated in the story of Bengi's, June's and Naey's mother.

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Bengi's Mother : " … previously, I did not know, I saw the next door child who got this syndrome but we call mental retardation and I thought that symptom would remain the same in the entire life. That was because I did not know… until I experienced this by myself, then I just realized that this type of child can be trained though its result would be slower than other children. These babies were not hideous. We disliked them because we did not know. Therefore, public relation should be encouraged to educate people that this type of children were slow development who could be improved through regularly practice. While general children need to tell one or two time but for these babies may need ten and the results are the same."

June's Mother : "I was misunderstood for a long time that this type of children could not do anything. In the countryside, we let these babies lived according to fate without any developed program. But actually they are the slower developed children and if we usually train them so that they can be improved… they just need intensive care. But some parents do not have time, thus it is not progress. Similar to June, if she was not practice for sometime, it was obviously found that she could not do what she was able to do. Hence we need to practice her regularly…"

Naey's Mother : "… these babies are slow developed group but they can be trained as the doctor said that "the more practice, the more develop". Moreover, as young as they practice, as developed as they are… she could develop a lot and could do many things like general children. My daughter could even help me to wash the clothes and help me to do many things. And she even recognized when I am worried, she embraced me and wiped my tear … She would be better developed if she lived with normal children…"

3) Physical and intellectual disorder

Perception that Down syndrome is complexity of physical and intellectual disorder and it is rooted from many causes as these follows.

3.1) Social Perception

Most of the Down syndrome child's mother perceived Down syndrome as disability after giving birth from the health communication, checking and confirmation Down syndrome and the information during access to treatment and

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developed training system. Moreover, the health officials always recommended the mothers to register their children as a disabled person at the social welfare Department, Ministry of Interior in order to be provided the rights of the disabled. Down syndrome has been defined as disability in society. Most of the mothers, therefore, perceived this meaning from social process as drawn in the case of Linda's, Afifa's and Bengi's mother.

> **Linda's Mother :** "Doctor recommended to have a card for the disabled person after delivery. He said that the child could be benefited in the rights of the disabled… Then I got the card but I have never used it because I didn't know whether where it was nor what to be used for. For developed practice, I irregularly took her to practice , it depended on my free time. When I took her to school, doctor also wrote the letter to school to guarantee my daughter's right but they did not admit my daughter because they might think that she was mental retard."
>
> **Afifa's Mother :** "It was their system, when I took my daughter for training, doctor transferred to do a disabled card in order to have disabled rights such as free of charge of some treatment and training . I didn't know the other benefit. Sometimes, they sent me the letter to collect the donation and money about 1,000 baht for the disabled, but only once…"
>
> **Bengi's Mother :** "It was a system of disability so Down syndrome and mental retardation's children were transferred to have a disabled card. They told that my daughter could benefit from the disabled card in position of the disability. My daughter could get some free of charge treatment and have developed practice until discharge… But I heard that they will terminate this system and turn to use only 30 baht card. Anyway, I still do not sure about that."

For Bee's mother who is rich, she was not satisfied this system after the officials transferred her to the system of the disabled registration without any asking, telling and explanation. So when she brought her son to the professional institute of Down syndrome, her son was sent to register to be disabled person and have card for access to the disabled rights though she didn't offer to have it. She didn't want her son register to be disabled person and have disabled right. She thought that the health official worked as the routine without concerning to the different background of the client. She was bad impression to this system which made her

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angry with the impolite communication. However, because of the rich, she had other choices but it's different for the poor.

3.2) Because of poverty and illiteracy

Taking care the Down syndrome's child under poverty, illiteracy and time constrain were the limitation which had impacted to many mothers. They were not being able to take care nor developed practice to their children. Therefore, the children got fatigue and had the appearance which realized and understood by the mothers that they were the disabled children. In case of Namwan's mother, she was too frequent having children ,namely she got the second daughter as a Down syndrome while the eldest one was not grown up and then she was again carrying the third one. She, therefore, was extremely busy to grow up the similar age of children who were in naughty age. So, she had not enough time to take care of Namwan who is Down syndrome. Namwan was remained lie down whole day and night without any developed practice . Thus, she got fatigue and could not be able to walk. Similarly, Rung's mother understood the problem on ears and eyes of her son which reflected to the problem in communication and developed. Those are the physical disorder which the mothers were experienced. However, the poverty and illiteracy were the conditions that obstructed the accessibility of the poor mother and caused the coming suffering.

> **Namwan's Mother :** "Her body was pliable and also her legs. She could even get the legs on her head and suck her toe. It seem like she does not have bones. I had no time to take her to see the doctor or developed training as I took care of the children alone and they were so naughty. I just let Namwan lie down like that, no problem… She was a disabled child, can not walk. Wherever I place her, she will only stay there. She is now 2 years old but still can not walk, sit nor take care of herself, her arms and legs are emaciated. I don't know what to do. I've not time and no money too."

> **Rung's Mother :** "He had the problem on ears and eyes. He could not hear and see properly. Doctor recommended talking to him often with the hope that he might hear some days. I sometimes turn on the radio for him the whole day but it was not useful. Moreover, he couldn't see clearly, I really didn't know the cause. I did not know before, but after I noticed that he often crashed things when he tried to walk, then I took him to check and I just knew his ears' and eyes' problem."

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3.3) Disability because of treatment failure

Sor is the case of physical disorder, she could not neither walk nor sit. Her symptom caused by failure of operation of medical doctor. The failure changed Sor's life from a girl who used to be able to walk and take care of herself became a disabled girl who totally couldn't take care of herself. She must rely on the lung's assisting machine all the time. Sor's mother accepted that her daughter's life has been changed from the Down syndrome's child who had only the problem of intellectual disability to both intellectual and physical disability for the rest of her life.

> **Sor's Mother :** "Previously, she could be able to walk and self-care herself. She was about to go to school but the doctor referred her to have treatment for solving the neck's problem. He said that physical therapy will help Sor's neck to be certain, so that we won't worry much about her when she went to school. I brought her to see doctor according to the reference. I've never thought that she will become a disabled person, only lie down on the bed and can't go out anywhere as she was able to walk. If I would have not decided to have operation, he would not be like this. But the problem was because of the doctor who I trusted him too much. He was very confident when he decided to operate my son so I thought my daughter could be cured."

4) "Oer" or Dullard

Some Down syndrome child's mother recognized Down syndrome as dullard. This was resulted from the social experiences that people called the person who was insane or calls "*Mai Tem Baht"* in Thai Society. The word "*oer*" (dullard) was used to call the person who was clumsy, stupid, ignorant and physical disorder as well as intellectual disorder. They did not know that "*oer*" (dullard) is the medical name of Iodine deficiency disease. The followings are the example of this case drawn in the conversation of Meaw's, June's and Pond's mother.

> **Meaw's Mother :** "In rural, this type of child is called "*oer"* (dullard), *"pa raer pa ter*", "*maitemroy or maitembaht*" (insane), ignorant. Sometimes, they were included with those of *"baa"* (mad), *"bong"* (half-crazy)… their face somewhat looked like those of dullard person."

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June's Mother : "this symptom we could be called in many different ways, perhaps *"oer"* (dullard) like the insane person. Their faces also looked like clumsy."

Pond's Mother : "Grandma and other people called these children that *"oer"* like insane person, stupid or mental retardation or foolish."

5) Mental retardation

Mostly, the Down syndrome child's mother defined the meaning and called the Down syndrome's child as the mental retardation and/or the intellectual and neuro-psychological disease. That was because lacking of understanding of Down syndrome since this group of disease has recently been classified clearly in the society. Consequently, the understanding of Down syndrome in society still defined it similarly to mental retardation. Most of the mothers directly encountered the past experiences of Down syndrome which faced the Down syndrome's child in the community, society and mass media. The mothers, therefore, realized that their children with the particular face and symptoms were the mental retardation as Naey's, Rung's, Bass's and Kong's mother.

Naey's Mother : "Whatever you call them Down syndrome's child or what, they are the mental retard. Everyone knows that these are the mental retardation."

Rung's Mother : "just the symptoms of mental retardation ; dull, stupid, clumsy. They are like an insane person. They are called "mental retard" in the community."

Bass's Mother : "There is the child like this in this community, but already grown up. Everyone call him as mental retardation. Everyone calls him like that. In the rural area, they are called "*prasart*" (insane), "*baa*" (mad), "*bongbong*" (half-crazy), *"ting-tong"* (dullard), *"pun-ya-on"* (mental retardation), something like that. But when it happens to the nephew, my mom took side to say that he also got it but not that much as the others."

Kong's Mother : "Doctor said he was like *"Sayan"*. He was like an abnormal person which was called *"pan-ya-on"* (mental retardation). "

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6) Down as declining disease

This meaning is given by the understanding and interpretation the word "Down" in the name of disease "Down syndrome". In the case of Kwan's mother, she is an educated person so that she knows the meaning of the word "down" in English which means "decline" (negative direction) and opposite to the word "up" (positive direction). The meaning's comparison is the opposite side between negative and positive or bad and good. Actually, she did not know the root of this word "Down syndrome". However, in her belief, the name "Down" is not favorable and cannot be able to use clearly for communication on the symptoms and illness with the others, especially with the uneducated people.

> **Kwan's Mother :** "This name is very terrible. I really don't know why they call "down". There are many other names to call and everyone knows its meaning is not good. To call "down", everything is worsen and worsen. Why they don't call any other better names. I belief that not many people knows why it is called "Down syndrome" or where this name has come from. In Thai, naming is very meaningful, so we always name our children with the name that has good meaning. I dislike the name "down" because it will make the listener think further and this name does not bring the luck. It is just like we curse them everyday. The calling word should be understood by parents and not make them feel embarrass. Moreover, it should be the word of hopefulness and encouragement too."

7) *"Karma"* or Incarnated Disease

Since the cause of Down syndrome could not be explained and clarified for the Down syndrome children's mothers. They, therefore, tried to find out more meaning to explain the cause of the Syndrome according to their belief and cultures. The belief of Buddhism is markedly influential to the concept of "Karma". Karma is the belief that ones have done something wrong in the past which might be in both the past and the present life. And it is used to explain the unavoidable circumstance of having the Down syndrome's child. Karma or retribution which is worse, always be understood as the cause of Down syndrome. Not only the Buddhist person that finalizes the cause of having Down syndrome's child with "Karma" but the

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other beliefs, such as Christianity and Islamic, they have also explained with “Karma” too. These Karma are classified into 2 periods which are; 1) Karma in the past life which contains the unseen origin; and 2) Karma in this present life with the particular cause, origin and period which are comparable to prompt reaction of Karma.

7.1) The past Karma

There are the showcases of the belief in the past karma which are the case of Bengi’s, Kaew’s, Kong’s and Ping’s mother. They are all influenced by the belief of the past karma which was unseen of the neither particular happening time nor happening with whom. This belief is emerged unintentionally, though some mothers are the new generation with high education and living in modern lifestyle. While the cause of disease is not explainable, therefore, they concluded that the cause was because of “karma”. Actually, they themselves didn’t know the reason of that conclusion, since they did not totally believe in this concept. Similar to the Muslim mothers, they finally surrendered with the reason of karma according to the influence of social environment including husband, neighbor and colleague. Bengi's Mother, Kaew, Kong and Ping are example of the belief of the past karma which mostly influenced by family members namely grand parents, and surrounding people.

> **Bengi's Mother :** “I used to see this type of children and I felt pity on their parents for having the children like this. I thought that they might have done bad action or retribution… When it happened to me, I thought that what I have done wrong in the past life. It has had a revenge on me for that wrong. My child and I might have done something wrong together, we, therefore, become mother and daughter again in this present life. The monk at the temple also said that my daughter might still seek revenge me. Generally, if she was normal, she has to take care of me. Conversely, if she was abnormal, I have to take care of him for whole life. No matter what, she was born to be my daughter and she must be born. In the past, I tried to abort once but it was not success. She has to come one day because it is the past karma… We could not escape from each others. We were born to reimburse the retribution our deed and we need to reimburse them all, otherwise we have to owe each others eternally to the next life world. She was born for me to reimburse my deed retribution …”

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Kong's Mother : "It is either my or his Karma (the mother was crying). My boss said that it was my karma in this recent life or the past life which try to seek revenge myself. I think it is the karma of past life because I've never exploited or killed any life, even beating the fish head. In my life I have never persecuted anybody and my husband is even better than me, he has never complained nor blamed anybody. So I don't think that it will be karma of this recent life."

Ping's Mother : "The monk said to my mom that my daughter was her daughter in the past life world but she didn't let her birth so that she followed my mom to reimburse to her. Therefore, my daughter came in the position of her niece. My mother has to be the main caregiver who take care of my daughter. My mom has believed that this made her reimburse the past retribution. She took care of my daughter from childhood better than me. She said that she will try her best to take care of my daughter for not owing each other life anymore… Some fortuneteller said that it is the past Karma of my mother, and then they meet each others again in this life. She needs to do a good merit in 9 temples in the same day before the sun set… However, my daughter and my mom are very compatible, their relation is close more than being grandma and niece."

7.2) Karma in this present world

"The result of karma" is one dimension of the beliefs which is happened according to the wrong action in the present world. Some mothers believed that this is the result of the husband's karma which effects to children's life and become the karma of parents to reimburse their deed. In case of June's mother, she reflected her thought about the cause of Down syndrome's child by the unfavorable behavior of June's father during his teenage. Namely he used to persecute the other women and didn't response to his sexual relation and moreover he forced those women terminated the pregnancy. Bass's mother also believed that her Down syndrome's child was the result of her husband's retribution.

June's Mother : "My husband said that it might be the rule of karma and as the prompt reaction of Karma… He thought that he did many things wrong to his girl's friends and also forced them to have

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abortion. So this might be impact to our daughter in order to let him reimburse his deeds. Finally, it happens to our daughter. He, therefore, has pampered her daughter so much. He thinks that it is the way to reimburse for his karma. He admits to do his best taking care of our daughter and loves her so much. This aims to avoid the revenge in the next life world."

Bass's Mother : "Grandmother said that this syndrome is the incarnated or karma disease of our family. It might be someone who has done something wrong in the past life, so that it happen to my son for reimbursing our deeds… the grandma thinks that it might be her karma, thus she has to bear all the burden though it's so hard for her aging period. Therefore, she has never complained any word. For me, I think it is the karma of my husband more than I and my mom. I've never done any bad thing and my mother is a good person."

The mothers' thought of karma also be the karma of themselves as illustrated in Namwan's and Naey's mother. They think that it was because of their attempting to have abortion during pregnancy. Therefore, the children were born to take revenge, in the sense that the more that the mothers did not want them, the heavier burden to take care of the children.

Namwan's Mother : "I have child very frequently, I had two in one year, at the beginning and the end of the year. It was heavy burden to take care of the children since the eldest one was very naughty. I could not take care of them alone, even my husband never assisted me for that. And then I again carried this Down syndrome's child, so that I tried to have abortion. But no matter how much effort I tried, the baby was not discharged. My mother supported me by sending me the abortive medicine from the countryside of my hometown, but it was not success. The child was so strong head, therefore she was born as "pan-ya-on" like this. My husband did not know anything about my attempting of abortion. So it's possible that this is my retribution."

Naey's Mother : " My husband was not a responsible person, so that I did not want to have more child. When I knew that I got pregnant (Naey), I tried to have abortion in every possible way such as using the cloth hanger to dislodge the fetus, pressing by lying prone, and taking the abortive pill, but I was not success. Moreover my friend suggested to go to the abortive clinic, I went there but I was not dare enough to do.

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> When I gave birth Naey, Down syndrome's child, I believed that karma really existed. Because I was so bad during pregnancy, I got severe nauseatic in pregnancy. When giving birth, it was very troublesome as the infant feet came out first. It is because I didn't want her, so that she became like this. (Down syndrome's child)"

8) Hereditable Disease

Another belief of some disease is because of heredity so that the new generation has chance to be as their ancestor. It means that Down syndrome's children have to get the genetic transmitted from the parents, grandparents or the ancestor. In this study, it found that some mothers felt like they also had germ of Down syndrome as their children. They were worry that people in society will also think that themselves or anyone in their families had the germ of Down syndrome or mental retardation which transmitted to their children. The story of Kaew's, June's, Linda's and Bengi's mother is illustrated that abnormal child is represent the abnormality of parents or the sin which transferred from mothers to their children.

> **June's Mother :** "… When I sent her to school, some parents looked at me and my daughter with the strange eyes . Some children also called their parents to look at my daughter and loudly said that my daughter was *"panya-on"* (mental retard) and instead of blaming or teaching their children, they showed the gesture that agreed with their children. Moreover, their facial and physical expression was reacted like they dislike us. It was like me in the past life, I also felt dislike and objected this type of child who had strange face and a short hair cut. I felt very disgusting and I avoided to react with this child. But when it happened to myself I just realized. I felt guilty and really didn't want to talk to anyone when I drop down and pick up my Down syndrome's daughter at school. I tried to come back home as fast as I could do. I hated the strange eyes that looked at my daughter and me, it was annoyed me."

> **Linda's Mother :** "… I was in tension when I looked at her strange face… She made the others look down at me and didn't want to talk to me. Someone strangely looked at me and spoke with their children with the word that intention to reflect to me as the abnormal thing. The children did not play with my daughter and always annoyed her. Moreover, the neighbors might think that Linda got the mad blood or the

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> mental retardation from me. They also reacted disgustingly to me. It seemed like they thought that my daughter and I got the severe infections disease… I took her to the mainstream school, but she was rejected. Maybe, it was because my daughter was the mental retardation, insane in their eyes… They felt disgusting everywhere…"
>
> **Bengi's Mother :** "I sometimes mistrusted everyone. It didn't mean that I didn't want anyone to look at my daughter but they gazed at my daughter's face and differently react. They might think that my daughter was mental retard. Someone even told me directly that my daughter was mental retard. While, someone gossiped that I might have done something wrong so that my daughter become like this… If I heard it myself I had to resist immediately without any fear because I could not endure to that action."

The meaning of Down syndrome as the physical and psychological symptoms and karma are all reflected to the popular concept of sickness and illness. Those concepts include the concept of both the modern medicine which define the Down syndrome as the diseases and the concept of public opinion which belong to the religious belief and culture namely "Karma". The latter concept is transmitted to the society of the mother's life from childhood until present time. The mothers are formed and experienced directly in that particular belief. The meaning of Down syndrome resulted in suffering of mother who is as the creator of the abnormal child and the one who has to responsible for this burden as the position of mother. Especially, the meaning in term of cultural aspect which affixes the sin from children to mother. This leads to the deep suffering that is the root of the more troubled.

From the results of the meanings of Down syndrome, the meanings in each period of mothers' life experience of having Down syndrome's child, were different which were as the above description. Those meanings can be concluded and showed as the following figure 5.

However, this study indicated that all meanings reflected to psychological suffering of mothers as shown in the expression words namely anxious, tension, angry, upset, uncomfortable and mistrust. The various form of sufferings from these meanings leads mother to seek the various means for managing the suffering which will be presented latter on.

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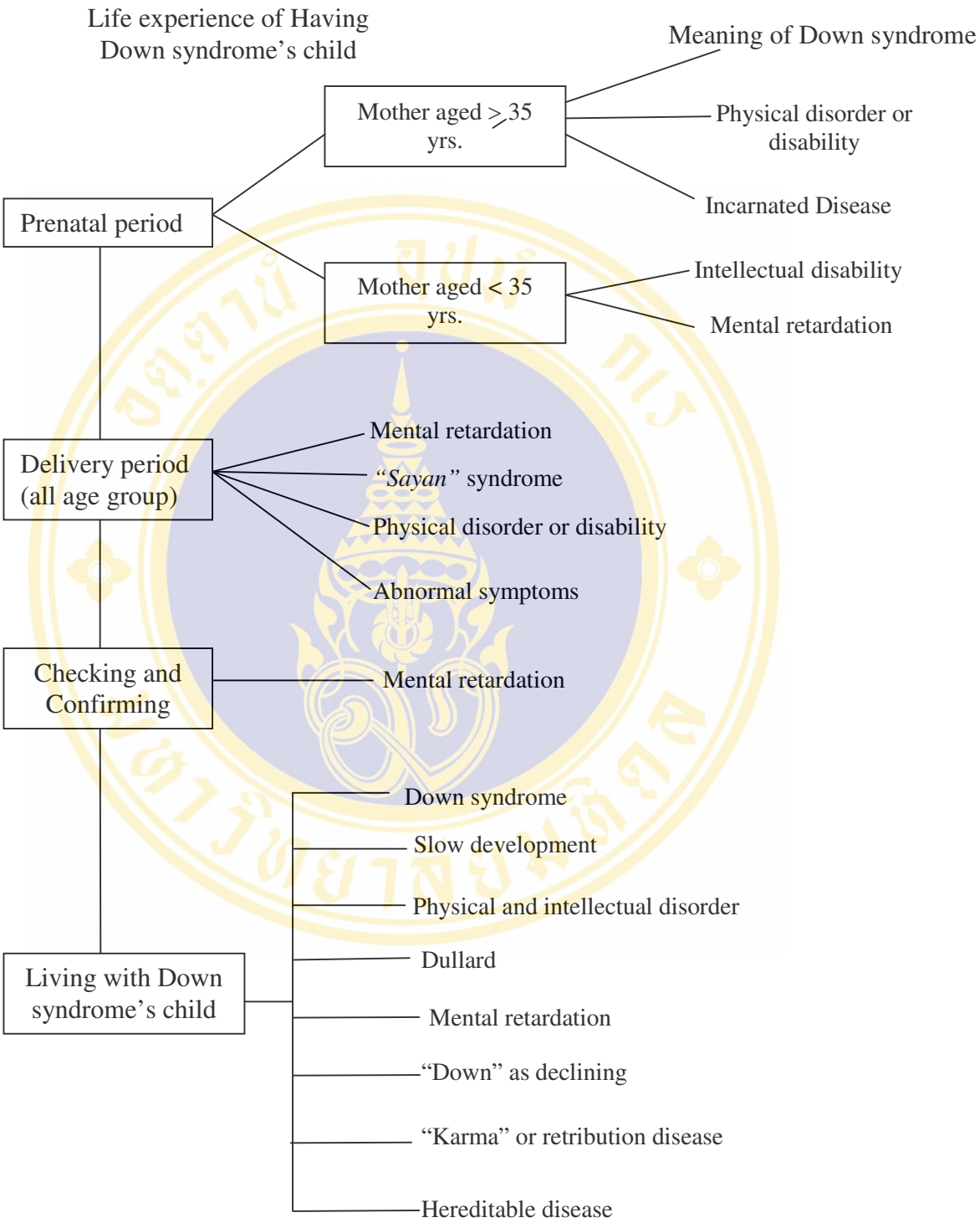

Figure 8 : Meaning of Down syndrome of Down syndrome child's mothers

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7.2 Managing Suffering as the Meaning of Down syndrome

The Down syndrome children's mothers encountered many experiences which can be classified into 4 periods of having Down syndrome child's experience ; prenatal period or pregnant period, giving birth period, checking and confirming period, and living with Down syndrome's child. The mothers encountered various experiences in each mentioned period which are shock, frighten of bad news, and suffering in many ways. However, they tried to manage their suffering in many ways until they could be able to live with the reality and suffering of having the Down syndrome's children. The suffering management according to the meaning of Down syndrome, it can be categorized into 3 period namely pregnant period, confirmation period and living with Down syndrome's child as these follows.

7.2.1 Prenatal Period

These poor mothers did not understand about Down syndrome or the risk of pregnancy at the old age. Thus, the mothers aged below 35 years old, who were not the risk group, were not worried about Down syndrome but they were afraid and anxious about the unforeseen present and future and the possible abnormality similar to the general mothers. They were afraid of the unperfected babies as compared in the Thai word that *"maikrob-samsibsong"* (lack of some organs). Mostly, the mothers managed their worry by their religion to comfort themselves. For the old-age mothers who were the risk group, they had chance to access to the more information of the risk of mother's age and an opportunity of having Down syndrome's child. However, there were only the rich mothers who had chance to gain the information from the private health care system, like Kwan's Mother who had explored the information seriously in order to understand and make decision on having the test as suggestion of the doctor. Meanwhile, she also managed her tension and stress through approaching closely to the religion by request from the sacred power.

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1) Request the sacred power

During pregnant period, most mothers had the experiences of request from the sacred power to have the desirable children such as desired sex, complete and perfect body and healthy. This mean influenced on the more comfortable of mothers, though they could not foresee the future. However, they felt warm and trust the sacred power for giving them as they request. The showcases are Bengi's , Mod's and Kwan's Mother.

> **Bengi's Mother :** "I requested the sacred power, and "Kwun Im God" for not having the wrong things to my child and asked for healthy too. Because I was old during pregnancy. I knew that it was risky and I still got a bad dream that "Kwun Im God" came to me with unbeautiful face. I was worried. So I prayed for the healthy child because I believed that the she was generous. I felt comfortable to do like that…"
>
> **Mod's Mother :** "I was very happy when I got pregnant. I did good merit and made many thank offerings… Even during pregnancy I still was asking for the healthy child… I requested at many places until I was not sure whether I made a thank offering for all the places."
>
> **Kwan's Mother** "I got abnormal sign during pregnancy I was worried. Doctor suggested to test but that even made me feel more suffered. It seemed like we got greeting from the lizard which is the bad luck sign in Thai culture. I prayed to my god, the Buddha and my husband also prayed to his God (Mary, mother of god) for my child… It was like one way of supporting our mind. When we felt uncomfortable, we really didn't know whom to rely on… and it was better than did nothing

2) Seeking the information

Seeking the information is one of the means to support the uncertain feeling and lessen worry of mothers during pregnancy. It was discovered in the risk group mother age more than 35 years olds that when they started entering to the medical knowledge field, doctor will advise on abnormality and the risk opportunity of pregnancy in the old mother. The study, however, indicated that there was not much education during pregnant period, except the case of Kwan's mother

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who markedly handled the power of knowledge. One of the causes of Kwan's mother circumstance was due to the complication emerged during her pregnancy that reflected to instability and worry. For her, to explore the information was the procedure to manage her uncertain feeling.

> **Kwan's Mother** "Doctor made me a remark, it seems like we got a greeting from the lizard. That made me feels uncomfortable. However, it was a virtuous intention as he wanted to clarify me, but after knowing more I became afraid… and they had the procedure which was abnormal test. In case the result of the test found an abnormal sign, then it followed by abortion… That made me anxious and afraid. I tried to explore more information for better understanding. Even I went to search for the book at the Rajanukul hospital which is an expert in this field… I understood more and realized that there was risk but not much. So that, it made me refuses to have the test. I decided to take a risk because the failure opportunity was not much…"

7.2.2 Being informed the bad news and Living with Down syndrome's child

The length of this period was depended on the doctor order to have the confirmation test. It was found that at the first stage the mothers of Down syndrome's child were shocked, frightened and avoidable from reality and tried to discover the means to free from the suffering and uncomfortableness in this period. There were various means as follows.

1) Seeking the information

While most of the mothers knew about their Down syndrome's child, they were interested in exploring the treatment procedure. However, Bee's mother, who is educated and rich, did not pay attention on understanding of abnormality of her fetus during pregnant period. But after she knew that her son got Down syndrome, she tried to gain more information for better understanding of the syndrome.

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Bee's Mother : "After I knew that my son got Down syndrome, doctor recommended me to go to the Rajanukul hospital. And I went there because I wanted to know more detail… I contact my relative who is a doctor in aboard, I consulted him for what to do since I got a Down syndrome's child. He explained and sent me some books to read. Whatever happens I just consulted him… my friends, who knew about my son, encouraged me and help me to find books and information… After I read the books from aboard, I found that there are the distinction between knowledge of the developed country and our. Down syndrome is not shameful syndrome and they can be developed as general children only needed more time. They can be improved, if the society gives them chance…"

On the other hand, the poor mothers of the Down syndrome's child mostly did not discover the information on the Down syndrome expert institute by themselves. There were only Wut's and Bee's mothers, who are rich, wanted to find the good institute for treatment.

Wut's Mother : " … I could not be still after I knew that my child got Down syndrome, I searched for the phone number of the expert center and called for more information about the further symptoms and what can I do?... They recommended me to go to Rajanukul hospital, they said that that is the expert institute for Down syndrome. At the beginning, I went there but it was uncomfortable because it was so far from my house. I tried to find out and contact some mothers who trained and developed their child until their child got a huge improvement. However, someone did not talk to me and even was angry with me for how come I knew their address and telephone number. She was angry because she didn't accepted that his son was Down syndrome. I also went to the famous private hospital and got more detail on the cost of treatment… ".

Bee's Mother : "… I tried to get more information that which institute was good in treatment of this child in Thailand. I went to… but it was not good that they included everybody as the destitute person and transferred to the supporting system. The officials investigated our profile and found that we were not poor, and then they blamed us that why I still wanted to get the benefit even I was rich. Actually, it was not my intention… mostly, I searched the information myself and if my son got sick, I will take her to the private clinic…"

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2) Seeking the treatment

Mostly, the poor mothers accepted after were informed by the medical personal about the Down syndrome's child, though they had the oppositional mechanism which refuses the happening circumstance. However, there were not the means to explore more information for better understanding of Down syndrome. While, they mostly tried to discover the place for treatment, treatment procedure or rehabilitation of the Down syndrome. There were many means as follows.

2.1) Seeking treatment as belief

The seeking treatment procedure was mostly base on the religious and magical belief. That was partly originated from the unclear explanation on the syndrome of the medical context. Consequently, it effected to mothers to find out the better understanding and management the circumstance based on the family's way of thinking, as presented in the case of Meaw's, Bengi's and Kong's mother.

> **Meaw's Mother :** "I could not stay still after I knew that my daughter got Down syndrome, I tried to find for where to get the treatment. Fortunately, I saw on TV then I wrote down the phone number and called them immediately. I told them my story and made appointment… we tried many ways like fortune-telling or magician belief. Mostly, grandmother handled those things for us but for me, I just partly believed it. My mother went to see the fortune-teller and told us what to do."

> **Bengi's Mother :** "I was like a crazy person, I visited every places where anyone said there were good. I asked the people who also got Down syndrome's child like mine and for what they did. I would do every means since I want my daughter got recovered. Even I went to see the spiritual fortuneteller, in Pukthongchai District, Korat. It was uncountable for the places that I visited… Nonetheless, the main thing was I praying to "Kuwn Im God" and went to the institute for developed training… Because the hospital that I gave birth recommended for this expertise institute. I tried to take him there. During practicing, I always ask a lot of question because I really want to understand and to see my daughter better."

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> **Kong's Mother :** "I, myself, did every method to help my son. Someone recommended me for the best spiritual fortune-teller, so I visited that fortune-teller even there were so far away. I paid for hundreds for the taxi fare of that trip and thousands for the fortuneteller. I paid a lot for the trip and the rite… My boss warned me that I might be cheated, but what to do as I wanted my son to be cured. Whoever told me what they had done well, I followed them all like to visit the monk fortuneteller, the spiritual fortuneteller… presently, I have stop, only waiting for heart treatment and training."

2.2) Seeking up-to-date medical treatment

It has been indicated that the mothers who found the severe symptom at the first stage of the child namely heart disease and gastrointestinal disease which are very crucial for survival, they preferred to find out the up-to-date medical treatment for their children. In this group, mostly, the transfer system of the medical treatment procedure was conducted. Conversely, in the poor group, this kind of seeking the high efficient hospital by themselves was not indicated. They were mostly in the waiting list under the queuing system. This system itself impacted to many of the Down syndrome child's mothers to quit their children's treatment at the end. However, some of them followed the doctor order or advice to transfer to the more expertise institute as illustrated in the case of Kong's and Bengi 's Mother.

> **Kong's Mother :** "… I gave birth at the Police hospital and the doctor suggested to have the blood test at Chulalongkorn hospital. Finally, after I knew the result, the doctor recommended to go to Rajanukul hospital, the specific hospital for mental retard which my son has been practiced until now… Presently, I am only waiting for the heart problem. I took him to the Police hospital for treatment but the doctor recommended to go to Central hospital (Klang Hospital) to get benefit from the 30 baht card in order to lessen the cost of treatment. But it was too far and uncomfortable. I went there but the doctor said there was not the particular equipment, my son had to be continued transferring to Vachira Hospital…"

> **Bengi's Mother :** "I gave birth at the Police hospital and they advised to come to the Rajanukul hospital. The doctor said that there is the expert in this institute and they pay kindly attention to the patient. Though it was very far, but I tried to go. So doctor said me to go to the hospital that was

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near by home because it was set as the policy for having treatment at the hospital near to home. Therefore, I followed the doctor word but that hospital was not ready, even there was not any trainer. Finally, I requested to take him for practicing at the former one."

For the rich mothers like Kwan's mother, it was found that there was the existence of discovering the higher qualified institute, though the higher cost had to be responsible themselves.

Kwan's Mother : "If I was still cueing, my daughter would not survive because she got very severe symptom. My husband tries to get more information about the good hospital. And then we decided to take her to the private hospital for treatment, even it was very expensive. But I preferred to pay, otherwise she would not get any treatment and died at that time…"

Bass was worsen than other babies as his symptoms needed to be treated through the medical procedure, but poverty influenced on Bass's life since his mother could not afford to provide him the treatment. Finally, she surrendered to her troubled life. Although, she realized that the only person who can cure her son was doctor, but still she could not provide the treatment for him seriously. That was due mainly to the economical condition. However, she believes that one day she will take her son for treatment.

Bass's Mother : "It is very troublesome like this (always excrete) because I have to pay for diaper. Moreover, it is annoyed me whole day and so smelly… I know that he needs to have a treatment. Previously, I let my mother to take him to the doctor, and doctor said that he needed the gastrointestinal operation… the mothers of body's stuff and operation, there is only doctor who can manage. How we can know all those. Doctors have their equipment so that they know about the problem… Formerly, I stayed for long time in the hospital but the doctor did not do anything, until I was removed the house. When I stay this far, then it is difficult for me to go to that hospital… I want him to be recovered. I plan that if I get some amount of money I will take him for the treatment. Unfortunately, now I don't have, so he needs to wait…"

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2.3) Information and Knowledge Exchange

Seeking the information among the mother of Down syndrome's child was emerged during the period of medical treatment system and developed training. In this particular period, the mothers were grouped informally through the appointment with the doctor. The exchange on information and experiences in taking care of the Down syndrome's child was raised. This exchange included; the formal one which the officials set up the group for sharing experiences among the mothers, and the informal one which was the communication among the mothers. This kind of information exchange assisted the mothers to be relieved, consoled, transferred knowledge and the method to take care the child. The exchange supported not only in the mental aspect comfortable feeling but also in the informative aspect which enhance the confident on taking care of the Down syndrome's child. The examples of this are shown in the case of Rung's, Meaw's and Bengi's mother.

> **Rung's Mother :** "I meet many mothers who have the child like mine. It is like there are the people who have the same destiny as me. Someone who understand each others… Sometimes, we tell about the funny story of our child, but some stories are not funny at all… It is good to see the others since I do not feel lonely, and lessen the tension. We bring food from home and eat together. We help each others during training. We became in the same mental status… and also I learn more like the heart problem. Many mothers have done and they said it is improved… that gave me hopefulness to keep on seeing the doctor…"
>
> **Meaw's Mother :** "When I go for practice, I will ask the mothers who can train their child nicely, and talk to them. I asked them for the method to assist their child to be developed well and I will imitate them. We always change our experience, ask and tell among ourselves. Also we recommend each others. This is good for training. We can be relaxed to meet many people and encourage each others. Suggestion and console… Perhaps, doctor let me to suggest to the others…"
>
> **Bengi's Mother :** "During practice and wait for development of our child, we, mothers, turn to talk to each others widely. My daughter developed well, so that some mothers asked me what I have done. Then I told them… Because we need to help each others. For something my daughter can not do so I have to ask the mothers who their child can do that thing… We can talk all the things as we are in the same boat, nothing to be embarrassed…"

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3) Comparison with the others' symptoms

After the mothers could not refuse the reality of having Down syndrome's child, it was found that recognition and knowing other Down syndrome's children and mothers was the method to relieve suffering and create encouragement for themselves as they found that they were not the only person who experienced many disease such as weakness in legs and arms which result in late walking, slow speaking or cannot speak, congenital heart abnormality, thyroid dysfunctions, respiratory tract problems and intestinal problem. Those diseases worried the mother on the symptom and seriousness of the diseases. Nevertheless, after seeing and knowing other Down syndrome's child, the mother did not feel lonely, but they felt having many people who got the same problems. Moreover, they got more encouragement through comparison with other Down syndrome's child. The comparison was divided into 2 types which are; (1) comparison with the worsen ones; and (2) comparison with the more developed ones.

3.1) Comparison with the worsen ones

Some mothers encouraged or consoled themselves by talking and looking at the other Down syndrome's children which focus on the ones who got the more severe symptom in order to feel that their own children were better off than others as show in Bass's Mother, Meaw, Naey and Sor cases.

> **Bass's Mother :** "Everyone saw my son, they said that it is bad to wear the diaper all the time. It is very annoying and problematic on expenditure for excreting all the time. But I don't have time to take him to the hospital. Moreover, I'm still curious whether the doctor will treat him… However, he is better off than many others. He can be able to walk and certainly helping himself. He can understand what I tell partly. But in some babies, they cannot understand the words at all, cannot walk, just only lie down weakly and dirty…"

> **Meaw's Mother :** "I met the same situation group, it made me feel that I was not alone. And to see the other children, my daughter got very tiny problem, just only the problem on speaks slowly while the rest are fine. Unlike other children I found, they lay down with the mouth full of saliva, could not more… my daughter is incomparable. When the

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institute carries out the function, my daughter will be the model, like superstar. When we come for the religious function, she is a charming son, everyone want to hold her…"

Naey's Mother : "… Naey is good, she understand, help herself and help me to do house work. When she sees me cleaning the dish, she will come to help me… You have to see at the Prapakarn Center (The private foundation), then you will see the severe symptom, it is very depressed. They sit on the wheel chair, unstable neck, overflow saliva, someone get convulsion. They are all severe… I used to take Naey to study there but just few days, she got transmitted from them. Instead of speaking, she spoke infirmly like them. It was not good… If I go anywhere, I can realize that my son's symptom is not that serious. Many children got even more, their parents must be worsen than me."

Besides comparison on symptoms, there was the comparison on the opportunity of treatment. In Sor's mother case, though the symptoms of her son was more serious than the others but she thought positively that she got better opportunity on treatment and living condition.

Sor's Mother : "Everyone felt pity on us that how I could take care of my daughter for 4-5 years, we were in trouble all including parent and child… Someone found that we were very distressed so that they recommended presenting on "Plod ni" program on TV… I thought we were not that much troubled as we can get reimburse from healthcare services cost and my husband get monthly salary, also we have place to live, even sleep in an ac room (laughing… sleep next to the daughter bed in hospital). Someone even worsen than us…"

3.2) Comparison with the more developers

Some mothers inspected the more developed Down syndrome's children as they were their model or goals. Furthermore, mothers were hopeful and encouraged on taking care and practicing their children as indicated in Bengi's , Naey's and Meaw's mother.

Bengi's Mother : "… I tried to look at the more improved children during training, and then I talked to their mother about what to do… I felt encouraging when I saw them could be able to do and hopeful that my daughter will also better."

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Naey's Mother : "I saw the better symptom babies, so I got relieved that my daughter would not be like this forever. I try to go for practice everyday as I have a model…"

Meaw's Mother : "We have to go for training often and then we will meet many people. That makes us feel encouraging because we will not think that this problem is only for us… Even my daughter is quite improved but still there are more. It means that my daughter will be better. That makes me want to be like those people…"

4) Suffering diluting to the others

Meaw's mother indicated that she is worried about bringing up the Down syndrome's child and her daughter's future, especially education. She thinks that it makes her feel uncomfortable and preoccupied with her thinking. Therefore, she believe that it is nice to take the child out for training and meet many people including the medical officials and the other Down syndrome children's mothers. Which allow her to release her suffering to the others.

Meaw's Mother : "I like to take my daughter for practice. To stay home alone is preoccupied with only me, just think lonely. It is good to meet many people and tell my story to the others, that make me feel better… other mothers also can express. Each one has chance to release the suffering, so that the more comfortable… at least we know that, there is not only oneself who is suffering…"

Bengi's Mother told that she usually reveals her troubled life on children, husband and others to the trainer. While the trainer becomes her consultant to suggest and help her when she get upset.

Bengi's Mother : "… I usually express to the trainer as I feel stifled and nobody to be told. I found that the trainer was very careful and friendly so that I expressed to her for the story of children and husband… Sometimes, I am telling with tear. She said that I can call her all the times and do not commit suicide…"

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5) Spirit of motherhood

Spirit of mother to protect the child is the psychological procedure which emerges during adaptation in the real situation of having Down syndrome's child. The explanation on mother-child relationship is the natural obligation and more profound than disability or abnormality to obstruct the love of mother to her child. The study discovered that the mother, mostly, offered their love to the child according to the spiritual of mother as well as sympathy. Thus, this kind of child was taken intensive care than the normal child as illustrated in the conversation of Bengi's, Kong's and Sor's mother.

> **Bengi's Mother :** "no matter deaf, blind or whatever, this is my child… I dare not to leave him. It never came into my mind. But doctors and nurses were afraid that I will leave him. While, I was afraid that they would leave my daughter, pay less attention to my daughter. (hands palm against palm over the head) I don't want to sound like I'm boasting, but I never leave my daughter though he is disabled. I was worried that when doctor found my daughter as a Down syndrome's child he might not take care of my daughter. Then I had to visit my daughter everyday as I was worried and felt pity on him. We were born to be mother and son, so that I have to do my best to take care of him. I think even if I die I want him to die with me as I worry about his living after my death…"

> **Kong's Mother :** "I used to read the news on mother left her child in the garbage and I thought that how she could do that. Her mind made of what. Even I am like this still I could not leave my son. If I left him, he must be dead, right?… even pig or dog, they also love their young, but for us, we are human being so how we can leave our child. He was born to belong to me as our offspring… As he is like this, I have to give more love and sympathy because he is unlike the others… I have to take care of him the best."

> **Sor's Mother :** "I did not know what happen to him when I gave birth, but doctor said to take good care of him, so I do… I also do even he did not tell. As he is my daughter… I love her like other children but I take care of him differently as he needs more attention… You have to see me when doctor said my daughter would not survive, I was mad. I could not stay still. I only thought of the way to love his life or if he had to die just want him to die with my

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hands… I was even more than the hen, I spread my wings while someone came close to my daughter and pick everyone with the beak. Since she is my own daughter, but they did like he is dirt, germs or monster. I could not resist… He stayed in the hospital for 4 years, I had to stay with him all the time, no matter how tired I was but I had to be patient for my daughter."

6) Exploring the Distinction of Down syndrome

Parents were realized and understood on symptoms and characteristics of Down syndrome's child after they encountered the truth of having the Down syndrome's child. Nevertheless, the parents did not accept the whole information, but tried to explore or create the different characteristics of their child from Down syndrome by the reason of to reduce severity of the symptom of their child which different from the general Down syndrome's child. Mother's of Meaw and Afifa characterized hair to be the distinction. While Kwan's mother distinguished on intellectual. For Bengi's Mother, Phing and Naey, they created the characteristics as the difference.

6.1) Face and hairstyle

Meaw's Mother : "It's good the she has a curly hair unlike a general Down syndrome's child. Normally, this type of child has the short hair in front, but her hair is not like that. Her hair is curly like a doll, everyone tell that she is pretty…"

Afifa's Mother : "When I dress her up nicely, everyone say that they she is hardly recognized as the Down syndrome's child because she has a nice curly hair. So that it make her different from other children who have the same hairstyle, while she is different…"

6.2) Characteristics

Some mothers found that their children is compliant and carry favor, similar to general children. Sometimes, they discovered that their children are more obedient and compliant, as shown in the conversation of Bengi's, Phing's and Naey's mother.

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Bengi's Mother : "very intelligent, fawn over. When I feel uncomfortable, he will come to hold me, kiss me and accompany me. It is like he knows that I feel bad… and he is understandable whatever I tell…"

Phing's Mother : "She is obedient, just naughty like general child. She is the sweetheart of her father and uncle. Everyone loves her because she is cute… My husband said that she is even better than general children as she is obedient and fawn over. When he just starts blaming, she will whimper him. She knows everything… I sometimes think that it was good that I did not have the test, in case the test showed abnormal sign and I have abortion it must be very regretful."

Naey's Mother : "She is smarter than the same age children. She knows a lot. When she sees me do something, she will come to help like wash the clothes, hang the clothes, and clean the dish… She can help herself, even better than a general child… and she can accompany me, when I am threatening and cry, she will came to hold me and wipe away my tear…"

For the educated mother like Kwan's mother, she pays attention in the child intellectual. She believes that Kwan intellectual quality is higher than other Down syndrome's children.

Kwan's Mother : "Normally the Down syndrome's child intellectual quality is lower 50 but I try to develop her. And I used to take her for the IQ measurement, she got 80. I think she is a special Down syndrome's child unlike common… "

7) Request the sacred power

Beyond the explanation of medical context or human being capability on causes and solution to treat the disease, certain mothers turn to discover other alternatives to pamper their feeling or to feel warm. That alternative is to rely on the sacred power beyond the nature base on their belief. This happens through asking for the miracle or rehabilitation of Down syndrome for their children. Furthermore, this asking includes the thank offering if the request become true. This circumstance rather happens in the poor mother. It was found the request at more than 1 place, meanwhile there were also other means which were managed at the same time, as presented in Kaew's Mother and Rung cases.

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Kaew's Mother : "I requested from Phra Phrom. Grand father said that Phra Phrom is powerful. I prayed to make my daughter get recovered, if what I request become true I will give the thank offering like Thai Dancing show, and preferable food… I did not totally believe but it was better than do nothing. IT was unseen… The grandfather also request, he believed and knew about the preferable things to offer for thank offering rite…even my parent at home also have done this, they requested form many sacred places…"

Rung's Mother : "I asked and pray from everywhere… but mainly at the Sothorn Buddha in Chachengsao. But I was not sure whether I asked for the right way as I was unfamiliar for that … I was afraid that I prayed wrong as I have taken my son for practice for long time but she is still not improved. I plan to ask from the sacred objects again… if my son gets well, I still don't know whether I can manage the thank offering correctly, I don't remember that I offered which things at which places…"

8) Rely on religion

When the mothers have to live their life with the truth on having Down syndrome's child, mostly, they accept and turn to rely mentally on religion, merit, religious rite and praying. This religious obligations lead to the more comfortable feeling and hopefulness that the good merit will result in the better improvement of the children in this life or to be born as a normal child in the next life. This can be illustrated as Kong's Mother and Bengi cases.

Kong's Mother : "I pray every night for him to be improved. I do a good merit at temple every Monday (the off working day) since I have him. I always cook food and offer to temple. It makes me feel good. And it might help him to be better in case he still have goodness in himself. And I also offer to the ones who seek a revenge on me, in case I have done something wrong unintentionally. I ask for them not to revenge me…"

Bengi's Mother : "I never miss the worship day, I have to go to the market to buy flower and other things to pray both the Buddha and Kown Im God. And I never eat beef. This thing is unseen so they gave me like this, I believe he will be improved… I do with hopeful and believe that the god will help my daughter to be recovered…"

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9) Shifting meaning from negative to positive

This study indicated that the mothers do not remain on the suffering while they encounter the reality on having Down syndrome's child and bearing this burden for the entire life. On the other hand, they try to explore the new positive meaning of Down syndrome in order to step out of the suffering base on religious belief and culture which overlay by beyond natural power and sacred articles. Certain mother's shift the negative meaning of Down syndrome to positive meaning that is from the suffering of Karma to the special children namely god/angel and the measurement for relieve the bad Karma. The new meanings change the suffering to happiness which compares Thai as change from the forehand to the backhand.

9.1) Offering from sacred power

Bengi's Mother expressed that she got prophetic sign of an abnormal fetus during pregnancy because she had a baby dream. It was like the sacred power told her in advance that this child will come to her for pay back of her bad deed. Although, she experienced many problems in her life but she still believe that the child will assist her to pass from hardship. She, therefore, take good care of the child until someone found that it beyond her limitation on economical status.

> **Bengi's Mother :** "During pregnancy I dreamt that she was born with one hand. I also saw "*Kuwn Im God*" in my dream, but her face was not beautiful as usual… I asked for a daughter from the god and the god nod in assent… So that I believe that the "*Kuwn Im God*" came to my dream to give this child… I used to have abortion once but still she come, her destiny is to born… the monk at the temple told that she seek to revenge me. She was born abnormal, I have to take care of her but if she is normal, she has to take care of me… Therefore, I have to take care of her the best in order to pack back all my bad deeds… when I go for training, I try to buy the best equipment as the doctor said even I don't have money until someone said that I am too much… but she also help me like when I don't have money for school fee of my children, I won the lottery as she pick for me… "Kuwn Im God" might sent her to help me to relieve my hardship, like the god never leave me… since the god give me this daughter so I have to take the best care of her…"

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June's Mother discovered this special meaning after she seriously remained in the suffering after the confirmation of Down syndrome's daughter. She lived her life without happiness and could not accept of having an abnormal child. Nonetheless, her husband defined the meaning of the child as the representative of his bad deeds. Moreover, she became strongly believe when the famous spiritual fortuneteller said that her daughter is a special child who needs an intensive attention. That has changed the opinion and reaction of herself and family members to the child.

> **June's Mother :** "My husband said that he feel regret to our daughter, as it is not the false of the child but it is the Karma rule which he need to pay back his bad deeds to the women who got pregnant by him during his teenage and he also forced them to have abortion… so that this daughter was born to take a revenge. My husband pampers her so much and takes care of her more than me. And he believes more after he met the spiritual fortuneteller who said the same thing as he think. The daughter was born to let us pay back our bad deeds in this life. In addition, the fortuneteller said that this daughter destiny is strong, so do not hit her, take good care of her… especially mother, cannot hit her absolutely because the destiny is not compatible. But my husband destiny is strong like her, they are compatible, so my husband can hit and blame her… It somewhat true as she is very disobedient to me but my husband. My husband pampers her so much."

According to the belief that Kaew is a special kid because she was given by the sacred power, so that she has the six senses to contact to the sacred power. The belief is strong especially in the grandparent, therefore, she is taken care intensively by the grandparent. They please her specially and take care of the child instead of her own parent.

> **Kaew's Mother :** "Grandparent takes care of her like she is a god. They please her so much because they said the *PhraPhrom* gave this daughter to us. The grandfather believes in *Phraphrom* strongly. He said that he requested for a nephew but when he got a niece so it mean the god wanted to give a girl… he please her like any thing as taking care of an angel. He cooks the favorable food for her everyday. At night still take her out to have food. Normally, he blames to anyone who uses a lot of electricity but for this niece, he turns on the ac for her to sleep well. He manages everything for her like to see the doctor, to

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take to school, to take to department store. We parent never be bothered… and my daughter is strange, she like to the Buddha image and when she see monk, sacred objects or temple she will pray herself. It is strange, like she has some sense…"

Sor's and Kaew's mother defined the new meaning of their children base on their religion. The children, therefore, is the special person or gift which given by the god which reflect to the obligation of mother and family members to accept this valuable gift. Thus they both defeated hardly with the severe symptom which need long time for treatment. However, those meaning according to their belief resulted to the ability to stay with suffering and shift the suffering to be the power for living.

Sor's Mother : "I have to look after my daughter whole day and night. I accepted that I was extremely tired for living in hospital as a home. But in our belief (Muslim), child is the special gift from god. We have to take care of him the best no matter whether he is Down syndrome. He is the truth in living or death, the truth which we were thought that it is common. It is not awful. So we are not afraid of death and resistant. Ones see my daughter condition… everyone said similarly that how I can resist for 4-5 years. I sometimes also think but if we believe that he is given by god then we can be resistant and acceptable…"

9.2) As god or merciful child

Kong's mother is one example of shifting meaning of Down syndrome's child from compassionate to the new meaning of being "God" or the merciful person. It is the inversion from the belief on suffering from Karma to the happiness on the merciful person. According to the past experience that she compared the suffering of having Down syndrome's child as the heart broken painfulness and like walking alone in the dark graveyard. Lastly, her suffering was stronger after she lost her son forever. The death was the lost and brings up the sorrow which made her wanted to die together with her son. While she explored the new meaning of Down syndrome's child as a god, therefore, the suffering and sorrow was relieved and contained with delight instead.

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Kong's Mother : "My boss said me to that it is the good Karma as this type of child was not born in everyone… I tried to take the best care of him as he is my child. My heart was broken when I knew that he got Down syndrome. But when he escaped from me (died) I didn't want to live. I was totally in despair… But I was better who the monk told me not to regret as my son was god, he was higher than we. I cannot take care of him. He just comes to pay back for his deed, and when it was over then he left… It seem like I have a good merit as the god pick me… the monk said that he was born on 19 and also died on 19. That was not accidental. The monk said me to control my mind because the son was not actually mine, he just picks me to be born and I took good care of him. I got the good deeds as I took care of him while he was born… It might be true as the date was the same. I do a good merit every Monday in order to dedicate to him…"

9.3) A child from the past world

Ping got Down syndrome together with the central nervous system disorder which reflects to the controlling of her organ, so that she cannot be able to sit or move her body herself. Ping's mother surrendered with the western medical treatment which is a heavy burden to take of the child. Fortunately, her mother assists her to take charge of taking care the Down syndrome's child. That is because the grandmother thinks that this Down syndrome's child was her daughter in the past life who seeks a revenge on her in this life.

Ping's Mother : "grandmother take very good care of her. She takes her to the doctor and practice everyday. My mom was a nurse, so she takes good care of the daughter. She cooks the food very perfectly… grandmother loves her a lot, she never go anywhere as she worry about her niece. They never separate, sleep together… She believes that my daughter was her daughter in the past life that she used to reject so in this life my daughter followed her to seek revenge… She just went to make a merit in a temples as it will be good for extension of child life and everything will be better then we did… grandmother do every way as she think that this is her daughter so that it is lucky for Ping… as grandmother think like this so that she never feel suffered but encouraged to take care properly."

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10) Death is the end of Karma

The belief on the end of Karma as mentioned in the 8th means which believe that taking care and looking after of the Down syndrome's child is the means of pay back one deeds, whether no matter the child get recovered. However, the concealed thinking is the timing of the end of Karma. Certain mothers believe that to recover from Down syndrome during alive is the end of Karma, while some mothers consider that the end of Karma will emerge while one of each side (mother or the Down syndrome's child) expire. The meaning of the death is the end of Karma, mostly happen to the mothers whose her child has a severe symptom near to death as well as she also lives in the trouble life.

Sor's Mother is the case of the mother who still take care of the severe symptom daughter with patience. Although, she believes in Muslim, but she also believe in Karma that the death is the end of Karma. This death is categorized into 2 forms namely; 1) The death of mother means the end of Karma of mother; and 2) The death of child means the end of Karma of mother and child.

> **Sor's Mother :** "just only wait for the death of each others, by that time the Karma will be ended. I don't know who will die first… If he dies before, our Karma will be ended, he will not be suffered and I will not be remaining suffered anymore. That will be the end of Karma of both my child and I… But if I die first, that must be thoughtful as my Karma will be ended but it might be his Karma or the others…"

Although, the belief or the death is the end of Karma which means to live the rest of ones life with delightful from fetters. However, the real situation of the death is absolutely grievous and leads to the exploration of the repeated meaning on the end of Karma as shown in Kong's mother case.

> **Kong's Mother :** "… I used to think that to die is to end the Karma… but I tried my best, I did not want him to die… after he left me, my heart was broken. I did not want to live, I was totally in despair. Early, I could not control my mind, I could not eat nor sleep… I also consoled myself that he ended up his Karma and did not want me to be troubled… I feel better now because the monk said that he was an angel who was born to pay back his deed, when it was over then he left… After his death, my heavy burden was relieved. I feel comfortable, otherwise I would worry about him everyday, but I could not stun…"

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Another example is Pond mother whose the death took away her child. She believe that she was frightened when seeing her son was choked by milk and then dead. To the question that is the sorrow emerges for that death, the answer was only silence and the strange expression on the corner of her mouth which the author used to see during her telling about her story from childhood until now. During interview period when her daughter still alive, she used to scold at her son that "when you will die, don't be stupid, you don't know that I am in trouble. " Therefore, when the death step on her son, she did not have any tear nor sadness but she felt relieved for free from taking care of the son with her hardship, sickness and facing with the medical personal. For her, the death of her son is the end of Karma.

> **Pond's Mother :** "I felt somewhat sad, but what I could do? So, just think that it was the end of Karma… I did not cry, cry for what… because she was not strong, never developed, she did not eat so she was smaller. I also could not afford to take care of her just did according to fate… very difficult to manage when she got sick, I did not have money to buy medicine or see the doctor… I felt as home to see the doctor and afraid that he would scold me. If she still alive I would try to take care of her, but it was good that she has gone… even she survive I cannot help her much. My burden was over. So I can work more, otherwise it is difficult to go anywhere…"

11) Sharing burden, sharing suffering

Generally, the suffering of the Down syndrome's child family, mother is the one who bear the heaviest burden to take care of the child. Moreover, she is the one who is the most suffered. However, there are supports from family members and relatives which are meaningful to relieve or dilute the suffering from mother. In the family that mother has to face to the problem of Down syndrome's child alone is more suffered than the family which has supports from the surrounding people namely husband and relatives, on the supporting in physical and mental manner.

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11.1) Husband's support

a) Assist to take care of child

June's and Sor's mother are getting greatly support from their husband to take care of the Down syndrome's child. That support is direct in term of physical action and indirect in term of earning money and providing the facilities for taking care the children. That reflects to the encouraged feeling of mother on taking care the child and living peacefully with the Down syndrome's child.

> **June's Mother :** "… It is good that my husband believe that this daughter was born because of his Karma. So he helps me a lot to take care of the daughter. Like in the day time, I have to help his mother to cook, so he takes care of the daughter, watches TV, or goes out for sight seeing, buying things or sweet… He also helps me to do housekeeping work like washing clothes. He can do it, take the daughter to see doctor, to school. He does his best for the daughter… He everything to the daughter first. He pleases her so much… so I am less tired."

> **Sor's Mother :** "If it happen to other men, they must left me and children alone. It is so boring; I really have no time to take care of him. He has to take care of himself… when we look after the daughter at the hospital we just sleep next to the daughter bed, at night we close the curtain and sleep… if I am too tired my husband will look after the daughter at night… It is good that my husband is nice. He never request. If he is not got, he would leave me alone. For some men, they will leave me to have a new wife but this man is good, help me to take care of daughter… everyday after work, he comes to accompany the daughter. On the day I go to work and come back late he will look after the daughter first… that made me feel more encouraged…"

b) Main economic supporter

In some families, though the husband do not directly assist for taking care of children but he do indirectly as the main person who earn money and provide the facilities for taking care of children. That result in mother feel not much upset nor suffered on taking care of the Down syndrome's child. The example is notified in the case of Rung's and Kong's mother.

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Rung's Mother : "No need to ask him about taking care of children, he knows nothing. He only works. He goes out to work at night and come back late morning then take rest and in the afternoon he will again go out to work. I feel sympathy on him that he has to take care of the expense alone, but he never complain only work. It is somewhat good… He gives me all money he earns. If the things at home finish he will drive me to buy. No need to worry about the comfortable things likes diaper, milk, and else, he buys all the things. He loves family and children. But he is not a talkative man, he is quite dull… I have to manage about my son myself like taking care, training, seeing doctor. He never knows what happen to the son… his duty is to earn and the main person to support the family. It is good that he does not play gamble, drink nor roam around…"

Kong's Mother : "… My husband is quite silence… it is good that he gave me all the money he gain. He never blames me to buy things like I hire my aunt to look after the son for 5,000 baht/moth, he never complains… He never complains on the expense on son. His duty is only earning…"

11.2) Grandparents' and relatives' support

The support on taking care of the Down syndrome's Child is mostly receiving the great support from grand parents who assist for both physically and economically. That greatly reduces the heavy burden or suffering of mother to take care of the Down syndrome's child. As shown in the case of Bass's, Kaew's and Afifa's mother.

Bass's Mother : "… If my mom never help me I would be dead. He has relied on the grandmother since he was born without the grandmother, I would leave him die in the hospital as I had no time, and I had to work. My mom visited him everyday even she had to sit whole day and no money but she borrows from the others to visit my son. I also felt pity but I did not know what to do. To leave in the hospital, my mom could not do that, she said her own nephew, she felt pity on him… my mom is very strong, she is a hardworking lady. She alone supports tens people, but she never complain… she goes out to scavenge the waste and also take my son (Down syndrome's child) on the pushcart with her…"

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Kaew's Mother : "… Fortunately, grandparent love their niece, they please her like she is an angel. No one can annoy her, grandfather pampers her a lot. Even taking her to see doctor, he also does that. My husband and I don't need to be bothered. To take her to school, he manages everything. Whatever the daughter like or want, he buys for her. Sometimes, he spoils him too much until I have to stop him… My parent wants to take care of her but he does not allow. They fight to take care of the daughter even my daughter is like this… My husband and I do not have much time to take care of her. At night we have to sell things till morning time. My daughter sleep with her grandfather, it is like grandfather stuck on the niece… Even aunty also plays with her at night, she is not married, and the children like to play in her room…"

Afifa's Mother : "… if I am alone, I still wonder that how I can take care of the daughter. No need to ask about my husband as he never stays with the daughter. My children feel unfamiliar with him, especially this daughter… they familiar feel familiar with grandmother because she brought up everyone from childhood. If my mom gets sick, these children cry seriously as they are afraid that she might die. So that they help to massage her… I totally have on time to take care of the children. I have to work and earn to support now. But I rely on her for looking after the children at home. That I don't need to pay to hire the others. Sometimes, the aunt-in-law also helps to take care of them."

11.3) Sibling's Support

The poor mothers need to work for making a living of family. Therefore, in some families, mothers have to rely on the elder children to look after the younger one. For instance, Phing's case, she has the elder sister who was born by different father, to take care of her from dust till dawn. Until the mother come back home, that is the time for her to leave. For Bass, he has young elder brother and sister look after him instead of grandmother after their schooling time. While, Naey has the 11 years old elder brother takes care and takes charge instead of mother during the working time of mother at night.

Phing's Mother : "Only the step sister but she takes good care of her younger sister better than me. Their ages are quite different, so everyone think that they mother and daughter because she take good care of my daughter. She manages everything like take her to see the doctor, cook for her…"

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Bass's Mother : "… the elders help me to take care of the younger after come back from school. They study in primary school but I can rely on them. The elder help to take bath, powder, dress up and then take the younger to play. If someone who have a dirt hand want to touch the younger one, the elder sister never them touch… but still I have my mother also"

Naey's Mother : " Tuk help me. It's good the elder brother help. When he was 10 years old, he help me everything because I have to work for supporting family. I have to work for 2 shifts then it will be enough. My job over around midnight… in the afternoon I have to pick my son at school and bring him back home. After that Tuk manage to look after his younger sister. He feed food and milk for her… I have to leave 3 children to stay alone. It is good that the eldest one is very responsible, take care of younger ones, do homework. He hardly goes out to play like general children… they sleep themselves at night. Sometimes, I came back and found that they sleep in front of the TV, without the mosquito net and full of mosquitoes bite… I really don't know what to do, but this much is helpful for me…"

Meanwhile, some mothers experience the cruel suffering and hardship in their life since their husbands are not performing the expected duty of family leader, lacking of responsibility nor supporting the mothers in practical and emotional support. The mothers are, therefore, facing the trouble on taking care of the Down syndrome's child and feeling lonely to bear the heavy burden alone. For instance, Namwan's and Naey's mother are living in a single family that including husband and children. However, the husbands do not share the burden on taking care of children, on the other hand, it becomes a heavy burden and increases the suffering to the mothers.

Namwan's Mother : "… I cannot rely on him, especially to take care of children. He does not even hold the daughter. It's only good that he is a solider then he can get reimburse for health care expense. But he never bother about children, what they eat, how do they live. He works in another place and will come home only on weekend. But he never helps me for anything just let me look after 3 babies alone. Anyway, auntie and grandmother help for food that makes them not to starving… His salary is not left to me, he is a social man, outgoing, and also going to the serviced girl… He is very happy, never worry about children but for me, I cannot go anywhere. I have to stay home all the

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times. It is hard for me, like this daughter (the Down syndrome's child); I never have time to take care of her. So I just let her lie like this. I don't know what to do, and still I have 3 children with the similar age. They are naughty… Doctor always complains me when he sees my daughter, he said why I let my daughter like this, and never have any practice. I don't have time to practice her. I almost die… My husband never bothers. He is self-centered. When he comes home, I cannot deny him for that (sexual intercourse), and if I do not have a proper contraception then the problem emerge (pregnancy)… he only give me the trouble."

Naey's Mother : "… my husband is irresponsible, only drink with friend. He never worries about children, never help me at all. I am busy alone for both work and child. I get up early and then prepare for children to go to school like clothes, food and then I go to work. In the afternoon I have to pick the children from school and let the elder son takes care of the younger, and I go back to work again. My job finish late night… I cannot rely on my husband. His work over in the afternoon but never come back home right away. He drinks with friend's everyday. When his money is finished, he takes mine… He never worries about our living. It is useless to call him. His word annoys me… It makes me feel more tired. To earn for children is not enough, I have to support husband also. If I never worry that my children will have problem, I would quit from him. Stay alone is even less troubled… Because he never helps me for any single thing, only drink and disturb the others. He hit me and children. He stretches me and if I never allow him, he will hit me. He is worsening than animal when he in drunk… Sometimes, he scolds me at the shop (working place)… everyone feel bored."

Pond's Mother is the woman who take care of her Down syndrome's child alone in the unauthorized room which lacking of electricity, facility and security. She pretended the she feel familiar to live alone with her son and the uncomfortable environment as shown in her careless action to everything surrounding and the regretless words. Nevertheless, when talking about her troubled life, sickness of her son and her future with tear in her eyes. Frequently, she turns away her face or avoids looking to the author eyes. I, therefore, believe that it is grievous for her lonesome life.

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Pond's Mother : "… I never expect for supporting from other people. I live like this since she was born. What I can do? Since her father left me until she was still in my tummy. He never knew that I got pregnant. Just let it be, he wanted to go, let him go. I can take care of my son… I take care of her like this, according to fate. She takes milk from me and the supplement which doctor gave. But she is small because she does not want to have milk. I don't understand her, she sometimes cries, stupid… I try to find job to work at home during day time. Someday, I got the job to make the chicken stick, just earn for food. At night, I work at Karaoke shop and let my son sleep alone. I cover her with mosquito net, and feed her milk but if I don't have milk, I will feed her the water mix with rice. Sometimes, she cries out loud, my next door comes to look after her, or I come down to see her… I have to support myself, don't know what to do. I have no where to go, so just stay like the. I get use to it…"

12) Trajectory over the obstacles

The consideration to win the obstacles in order to move toward the dream which target on the success of their children in Education and career similar to general children is an idea of the rich mother who dares to challenge to society. Since, there are lacking of attention and opportunity to develop like general children for the Down syndrome's children. The trajectory over the obstacles of the Down syndrome child's mothers refer to the model from aboard and they wish to move toward that model through discovering the best information and alternatives for their children. This challenge offers them encouragement to come across all obstacles with strongly confident that the children will be able to do such as study in the higher level, the great artist, etc. The showcases are Bee's , Wut's and Kwan's Mother.

Bee's Mother : "I try to discover for her talent. I don't think about academic matter but she is good in computer. She plays game for a long period like general children and likes to take things out, doing like fixing it… and she likes to draw the picture. I think that at least she should study till the compulsory level and I will send her study aboard afterward. Over there, there is the special institute for this son. She might become a genius in her interested matter. I try to support her on what she likes…"

Wut's Mother : "… I believe to support him to be smart. I realize that he has slow development, so that I advocate him in both training and

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supplement food which good for brain from Amway. It is expensive but effective. I think he is improved unlike other Down's Child… Maybe, one day he might become the country leader. I do my best for him as I will have no more children, just only this one, but I will take care him the best to erase the insult of the others that the Down syndrome's child cannot study…"

Kwan's Mother : "… many important persons in the world are somewhat abnormal. This type of child is talented, what we need to do just let them show their power. Sometimes, we block them as we believe that they cannot be developed and then obstruct them the opportunity as general children… Actually, they can do many things more than general children, like pick up small things, draw. She can draw very detail that means she has something special… understanding, giving opportunity and alternatives, she might be better off… and moreover she is innocent, pure, illusiveless… that gives her a happy life and I just observe to support her…"

13) Group empowerment

Suffering management of the poor is mostly in the individual and family level. There were not observed on grouping for protecting the rights of the Down syndrome's child and family. However, in the comparable group of 4 mothers who are rich and better off in social opportunity, it indicated that only Kwan's mother and her husband is the only case which consider and attempt to fight for group or network of Down syndrome's child through the medical personal. They aim to encourage the communication, receiving information, knowledge exchange among families, creation of friendship supporting activities, and the acceptation of Down syndrome from society as well as providing more public area for these children in both the conceptual and practical aspects.

Kwan's Mother "We try to encourage grouping of Down syndrome child's family. We have to overcome it and claim the rights of the Down's Child… we have encountered so many pain. If we can group ourselves then we can help the others not to face the same suffering like us… We try to encourage the doctor to form the group, at least it help to comfort each others and lighten the hope for parents… activities of Down syndrome club, like to handle the activities in each region, my husband can be the guest speaker."

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For the family which the Down syndrome's child have sever symptom, doctor can ask me to encourage them… it is a good merit… if we can form the group, that will enhance the understanding of people in society on the Down's Child, even it is not easy but I do my best… Now we have a small group, we can gather only the middle class people who don't have economical problem. The poor have no time to participate, I feel sympathy on them, because they don't have time… recently, we have rather less information in our country, moreover we lack of the proper information system. Doctors, themselves, never know the number of these people, I really want to know the real situation…If we can gather together, contact among ourselves continuously and provide the clear information. Moreover, when there are the benefits of the Down's Child, then we can let everyone know. If we know the number, that is beneficial for negotiation. Society will pay attention more on us and will not overlook us".

It is noted that the rest 3 mothers in the rich group, they do not interested in forming the group because they think that it is private matter and they will fight alone. While in the poor mothers, the idea of forming the powerful group never come to their thinking. They only indicated about the informal group which gathered during conversation while receiving the health care service at the health care center at the same time. That was the temporary group which led to friendship, information exchange and participation in the treatment activity or development practice program of that particular institute. However, the group was disintegrated at the end the program. Therefore, it is far beyond of the poor idea to establish the group as reflected in the conversation of Meaw's and Bass's mother.

> **Meaw's Mother :** "Even myself. I almost cannot be able to live my life, how I can help the others. Time is also constrained for me, I never be there for training every time… It is enough, I just rely on myself, no need to depend on someone else…"
>
> **Bass's Mother :** "When I can participate with them, I cannot. I have not enough even to eat, it depends on the doctor to manage… mostly, and one just relies on oneself. Whenever somebody is free, then that one will go. Sometimes we are free, but without money then cannot go. The first priority for poor is to make a living…"

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Conclusion

The chapter are noted that there are various meanings of Down syndrome defined by the mothers who experience on having Down syndrome's child. Those meanings are defined according to background of the mothers through encountering, perceiving and learning from society and culture which influencing their conceptual thinking. The meanings of Down syndrome are related to individual suffering in each period of life experience of having Down syndrome's child as well as different suffering management. On the other hand, religion and culture partly influence on the perception and meanings of Down syndrome of Down syndrome child's mothers which reflect the disease, health and illness of mothers' perspective and the cause of Down syndrome. Additionally, they also reflect to the treatment procedure and suffering management according to the symptoms and meanings. Those managements include the controllable suffering by the mothers, while several managements are beyond the controlling capability of the mother which base on the religious belief and culture namely the belief on the end of Karma, shifting the negative meaning to positive meaning and asking from the sacred objects, etc.

Furthermore, it was also found that the meanings of Down syndrome defined by each mother are not limited to only one particular meaning, but there are mostly many meanings. Similarly, the suffering management of the mothers also combines various means for each of them. The means of suffering managements are both implemented together and separately, depend on situation, symptom and the perception of symptom. In addition, the study revealed that the management of the disease which is the cause of suffering is not absolutely emerged as expectation or desire due to the constrain on economic and the limitation of health care service system. According to that, the Down syndrome's children lacks of accessibility to treatment procedure which result to recovering from the disease, especially in the children whose symptom rely on doctor.

However, it was observed in the study that the mothers and Thai family still discover the means of management the suffering from Down syndrome on the basis of eastern concept, which rather rely on religious belief and culture. Although the concept of sickness in the present day is influenced by western medical, but by the reason of the chromic disease of Down syndrome which doctor cannot notify the obvious cause nor be recovered through the modern medical treatment. This leads to exploration of the treatment alternatives base on belief and local culture of ones concept which totally distinct from medical explanation. To manage the suffering in different level, there are the means to

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manage each level of suffering individually. Those include to escape for relief and to defeat the suffering in order to live with the Down syndrome's child harmoniously which can be summarized as the following figure 9.

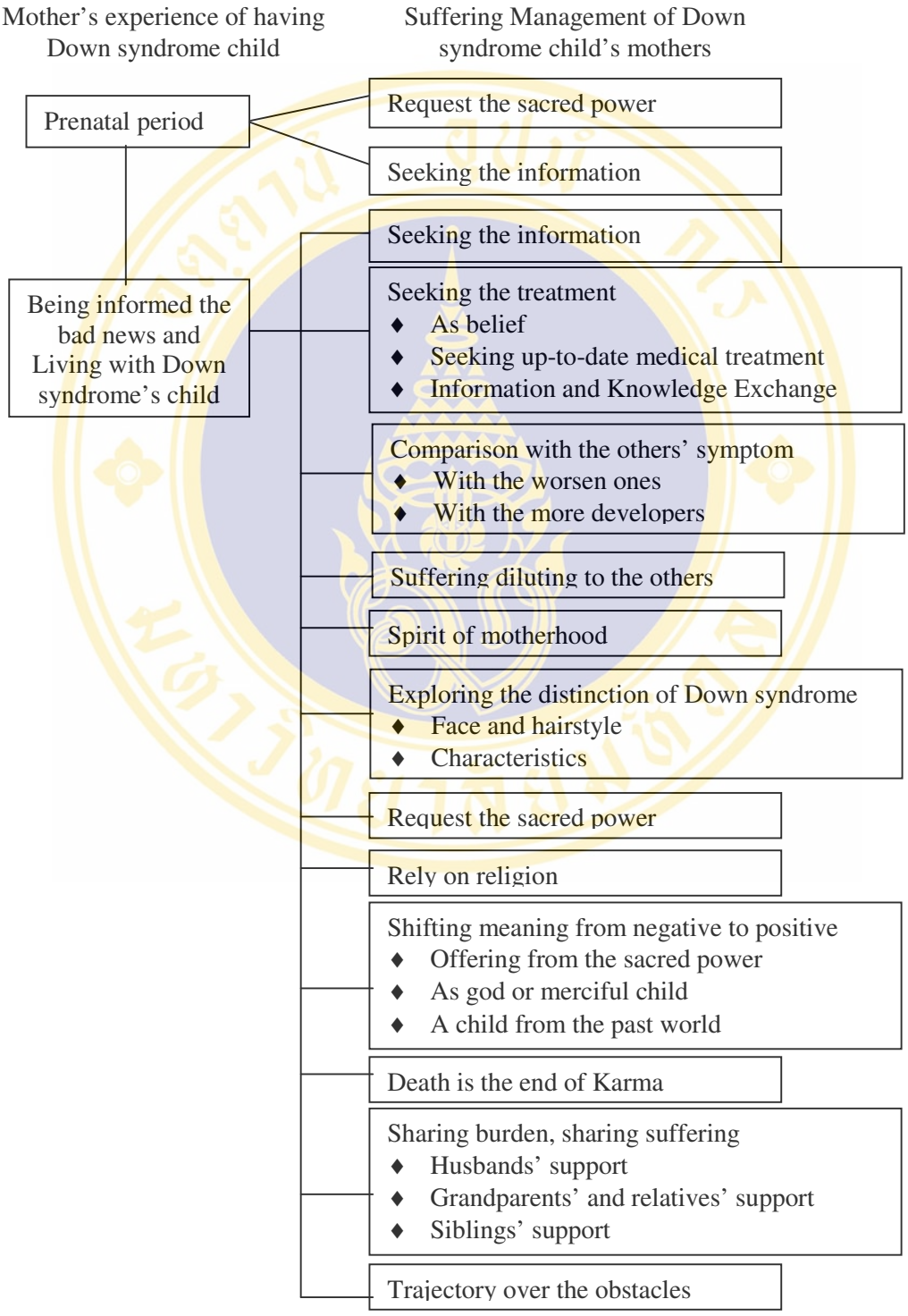

Figure 9 : Suffering Management of Down syndrome child's mother as the meanings of Down syndrome

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CHAPTER 8
CONCLUSIONS AND DISCUSSIONS

8.1 Conclusions

Social suffering of the poor mothers who have Down syndrome's Child has been studied under the Critical Medical Anthropology Framework which emphasize on political-economical factors, relationship of health care service system that reflects to individual suffering as well as defining and managing the suffering under this particular framework. The target group with poverty characteristics is targeted in the study area of slum and snowball technique is used for sampling. Finally, 22 mothers who have a Down syndrome's child are selected. 18 of them are poor while the rest are rich. It can be compared between these two groups to comprehend the difference of each context, defining and managing the suffering. The key informants are selected according to the characteristics as defined in the contextual framework. Those characteristics are poverty and social disparity of the key informants. Moreover, age of the key informants is varied according to clinical principle which defines the risk and non-risk group of women to have a Down syndrome's child. The critical age point is 35 years old, therefore, the key informants are covered the mothers who are younger than 35 years old and older. In addition, the age of Down syndrome's child is also considered to be distributed according to schooling age.

It can be summarized into 5 aspects base on the results of this studies namely; 1) Political ecology: Life cycle of the poor and social disparity, 2) Medicine, Its power and Suffering Experience, 3) Suffering under social and cultural structure, 4) Defining Down syndrome, and 5) Suffering management.

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8.1.1 Political Ecology: Life Cycle of the Poor and Social Disparity

According to population and sociopolitical ecological characteristics of the key informants, it has been indicated the characteristics of poor person or indigent and life that living in poverty cycle which is the root of experiences and suffering in everyday life of the Down syndrome's mothers. Two period of life of the key informants are presented as follows.

Lived Period I: Born and Grown Up in Poverty

This lived period is the childhood period since they were born, grown up and lived with their parent in the poor families until they grown up as teenager before married life or having their own families. The studies indicate that there are 9 common characteristics of these poor mothers which are; 1) they are grown up in *the agricultural family or relied mainly on agriculture*. Some of them are the farmer who has their own agricultural land who mostly realizes that that agriculture is unprofitable but they still continue working as a farmer since it is in their spirit. Some of the key informants are in a leaseholder farmer or agricultural labor family. They are poor and low payment. Uncertainty of the weather and production price has effected to the unreliable of their incomes from agricultural sector., 2) *Low economical status* is due mainly to lacking of budget and productive factors. They have to rely on the low income generation and uncertain occupation, therefore, most of them is poor., 3) Most of the mothers are *less education*. They complete only the primary school and then they have to leave the school to be a child labor since they are young. *Less education* is the result of poverty, separated family, being womanhood and the limitation of both the geographical and social environment. These conditions obstruct them to access the higher education., 4) *Rural-urban migration*, as a result of failure in occupation in an agricultural sector, influence on the mothers' migration to the city for more job opportunities and sufficient income for making the living of their families. There are two types of migrations namely, the whole family migration and individual migration., 5) Mother's death, parents' death and separated parents are the forms of *Separated family* which are found from this studies. These separated families have influenced on having new spouse of the parents. The fact that some fathers have many wives which result to the happiness of family life and family members., 6) *domestic*

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violence is violation in family which are the results of family failure which include physical action violence namely child labor and physical abuse, verbal violence such as scolding, and mental violence such as not allow for schooling and abandoned child., 7) *Sexual abuse* is done by the stepfather to the stepdaughter without any protection from their own mother. This force the woman left away form their house., 8) *Limitation of working opportunity,* it has been recognized that most of the key informants headed to the city for working right after graduating primary school. The works that they engage are mainly an informal labor such as a servant and labor in many types of enterprise. Those jobs are a low paid job and unprotected job under a labor law which results in lacking of rights and welfare., and 9) Living in *unstable and insecure residence* , because of poverty is the factor that brought them into the limitation in selecting the accommodations. Most of them are living in the unstable, dense, bad ventilation shanty which insecure to their property, health and life. According to these 9 characteristics, it has been found that most of the key informants meet some characteristics while some compile all characteristics together. These characteristics lead to uncertainty and trouble in many aspects of life, therefore, their life are uncertain, no choice, insecure and lacking of opportunity to improve quality of life which are the suffering that they encounter in everyday life.

Lived Period II: Addition poverty with political ecology of husband

From lived period I, the characteristics of poverty limit the women life and lead them to the second period of having husband. The result of the studies indicate that the key informants are confined in the poor environment since their childhood until adolescence, which fixed them in the society of the poor. They, therefore, meet and live in the environment of people who engage in the same political ecology. Finally, they can't avoid to marry with the husband who had the same characteristics of poverty and social disparity. This lived period is presented into 4 aspects which are; 1) *The same background*, namely their husbands are also from the poor agricultural family in rural areas, less education, low paid occupation and the same life style. Thus, these are seen as synergy of poverty and are repeated in the new families' life., 2) *Troubled life* was due to their married life with the poor husbands who are the same political ecology of key informants. So it is very difficult to have

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the better life. Consequently, most of them still exist in an unsanitary, health risk and insecure environment., 3) *Inequitable relationship* between spouse has been revealed that women are taken advantage in term of sexual relationship before marriage which effect to the problem of unplanned pregnancy and are existed without responsibility taken by men. Although in some culture like as *Isan* culture, there is an apologetic rite to express the responsibility for the unacceptable pregnancy before marriage, however, there is the social punishment for women and their relatives to feel embarrassed namely gossip. Additionally, women are also taken advantage after marriage in term of abandonment and disloyalty of husband. Furthermore, there are the disadvantage in an expected role of husband since many of husbands take advantage on their wives as forcing them to work in both outside and inside house., 4) *Domestic violence* are found that there were 3 types of violence which men reacted to women namely; (i) mental violence through forcing women to do cruel behavior and action which threaten family reputation such as forcing for drug abuse, (ii) physical violence; and (iii) rape or forced sexual intercourse which threaten women physically and mentally. Therefore, women encounter suffering from poverty and troubled life in the lived period II similar to the lived period I. However, it seems like their suffering even in the increasing trend.

8.1.2 Medicine, Its Power and Suffering Experience

Experiences of Down syndrome mothers are studied under medical relationship and it has been discovered that there are the gaps in the relationship of healthcare service system which are the gaps between this system and service receiver (the key informants) as well as between medical personal and the key informants. The first concrete problem in these relationship is communication gaps between medical personal and Down syndrome child's mother. It can be classified into 4 aspects which are; 1) The gap between the *medical and popular knowledge* which this study find that the medical knowledge is too difficult and inedible knowledge for the poor. This has been noted that information and knowledge given by medical personals are an abstract which are invisible as well as difficult to perceive and understand. Moreover, the medical personnel ignore the mothers' background and their concern mainly on the reason of economic as the cost of testing and these ignorance influence on the

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rejection of the testing during prenatal period., 2) *Moral problem*: *medical knowledge and motherhood*, according to medical knowledge which pay attention on normality, therefore, medical conception, reaction and advice are base on the perception that define the life which deviate from normality as an destructive abnormal object or illness. On the contrary of the mother perception, life is considered as their child who is the off-spring, beloved one and strong connection. It is a moral perception of mother which stands on the opposite ends of medical knowledge. Therefore, this leads to suffering of mothers as human dignity of their children is threaten., 3) *Bad news of unexpected baby*, it is the problem of improper communication system and unsystematic notification without concerning the background of Down syndrome child's mothers. The medical service lacks the consulting system to deal with the problem on having Down syndrome 's child. Thus, most of the mothers are frightened, shocked, gravely upset and deniable the sudden unexpected event., and 4) The perception that Down syndrome's child is as valuable life or worthless object, this makes the most mothers unhappily. This study indicates that the medical treatment process overlooks socio-economic aspects of them. Moreover, the Down syndrome's child always be treated as worthless object by medical treatment and this effects to their mother's feeling which are recognized the blemish and stigma in stead of their Down syndrome's child. Some mothers feel guilty and embarrass for giving birth of Down syndrome's child as they are the producer of an abnormality or deviance in the normal society.

The second problem is Medicine, Power and Suffering, which includes; 1) *Medical procedures as burden and source of suffering* has been revealed that medical procedures have been operated complicatedly in order to serve medical system itself more than considering on suitability and necessity to the patients. Moreover, the doctor is as the most knowledgeable expert in hospital, the system is, therefore, unsatisfied with regard to the clients (Down syndrome child's mothers) as they have lost in economic, social, emotional and mental aspects. Ultimately, the rejection of the medical procedures has been made base on their own perception., 2) The poor Down syndrome's child is the one who has either *poverty or abnormality* is as *marginal client. The poverty plus abnormality is as marginality* and it reflects the evaluation problem which treats Down syndrome child's treatment as unprofitable monetary value. That limits and obstructs those children's rights to access to the

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medical service. Moreover, the clients and their relatives have less participation in the making decision process. While the failure of the treatment is regarded as ordinary in medical system. For mothers, conversely, it is painful and a heavy burden for taking care of the child eternally., and 3) *No money, no treatment* is the problem of economic power for buying healthcare services. This reflects the disparity of accessibility to medical service of the poor Down syndrome's child. In case of Kwan, it indicates the long time waiting to access to the services as the long procedures and the cueing system. However, the high economic status makes her family to have more choices and the long procedures can be lessened only if money leads their way.

8.1.3 Suffering under Social and Cultural Structure

Besides medicalization, this study indicates that social and cultural context leads to the social suffering which divides into 2 aspects. The first aspect is Structural Violence and Suffering which includes 4 characteristics namely; *1) Sexual violence and feminine Down syndrome's child,* it is the social problem which emerged by men to women in both inside family such as rape and in society such as obscenity. Hence, families in recent day are anxious with nurturing and bringing up the children, especially daughters. As the results, the families which have the Down syndrome's daughters are extremely anxious. Double anxieties are emerged in those families which combine the anxiety as femininity and disability., *2) Religious rules, social rules and perpetual sin*, is the association of the social regulation and the perpetual suffering of spirituality. The religious rule about the giving birth prohibit women to get the birth control and abortion. Moreover, the social rule limits the maximum number of having child, is 2 to 3 children. The result of this study indicate the suffering of many mothers who have children more than the maximum limit or pregnant after having 2 or 3 children and then the more suffering of the mothers who do the sterilization without consulting their husband. The sterilization is mostly operated by women because women always think that the unwanted pregnancy is result of their mistake for improper contraception more than blemish her husband. Moreover, women perceive their burden of duty to take care of children as well as only them who have uterus and can be pregnant so it's better to sterilize to protect the pregnancy.

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Sterilization is not only impact to women physically but also mentally, especially in the Muslim mothers. The sterilization of some mothers is permanent contraception which has been prohibited in their religion due to the women surrender to social rule on limitation in number of children and a heavy burden in taking care of children. However, this violation of the religious rule leads to guilty or sinful feeling which remains perpetually with women alone. It has to be hidden among their closed relatives as it is a sin and embarrassment that needs to be kept as a secret; *3) Social rule of family planning* which shows the contraception that mostly does on women body. While women operates any method of birth control, they have to face suffering between the two ends of religious and social rule. Especially the poor mothers, they feel anxious for being blamed by medical personal and people in society about having children exceed the limited number as set in social rule. They will have more embarrassment if the Down Syndrome's child is the one who exceed the social rule of children's maximum number; and *4) Having Down syndrome's child among normalized society* is an unforgettable experience of mother. This study find that the Down syndrome child's mothers are suffered from disappointment and anxiousness of delivery the Down syndrome's children who are abnormal with the disease, physical and mental disorder and deviation from the common people. Although, presently, the mothers can adapt themselves and accept on having Down syndrome's child as well as manage the suffering at certain level. But when mothers are offered the choices and turned back time to the pregnancy period, they mostly accept to do prenatal test. And in case of diagnosis an abnormal sign, they mostly agree to stop the pregnancy in order to cut off the troubles and suffering on both the children and family.

The second aspect is Poverty and unequal accessibility to social services. This shows that poverty is the obstacle and limitation on social opportunity and accessibility to services and social welfare which ones deserve to as the country citizen or social member. It is noted that being Down syndrome in the poor family result in lacking of opportunities which are ; *1) Uncoverage of health insurance* is the reflection of limited opportunity of Down syndrome child's mother to access to resources, even the basic welfare and health service which deserved as Thai citizens. The limitations also include lacking of health care card and having the card but cannot be able to benefit. The social structure of an inequity depresses on Down syndrome

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child's mother and makes them more suffer., *2) Poverty* is the obstacle of *an accessibility of health services.* Although the development training is basically provided for every Down syndrome's child equally, however, it is actually engaged the difference on accessibility as a result of poverty. The poors are requisite to live their everyday life on the basis of struggle for existence, live from hand to mouth, so that absence at work means missing earning. Therefore working is a crucial obstacle which impact to the accessibility to the development training service of the poor Down syndrome child's mothers., *3) Mainstream education is not for Down syndrome's child* because it mainly aims to provide the curriculum and organizes for common children. The emergence of obstruction and denying the Down syndrome's child to entry the formal education make the mothers stress. Though the public policy proclaimed that the educational institutes commit to accept the disabled children to study, however, the institutes mostly refer to the reason on lacking of capability in order to refuse admission of the children. But in the practical, Down syndrome's children are denied and these are rooted the suffering into the parents. Moreover, it indicated that though the poor Down syndrome's children are in schooling age but they are limited the educational alternatives and lack of opportunity to study unlike common children. That is base on the two conditions namely being Down syndrome and being poor., and *4) Life insurance system and discrimination Down syndrome's child,* it is a social system problem as social activities normally create the standard according to the majority, especially for the majority who are healthy. Obviously, in the profit making business life insurance system is an instance of the system to secure the risk on sickness and accident for common people. For them, healthy of people is their profit. Therefore, being Down syndrome is the condition which risks to lose the more profit that obstructs the Down syndrome's child to access to the secure system.

8.1.4 Meaning of "Down syndrome"

Down syndrome in medical meaning is base on the particular knowledge which is the disorder of the 21st pair of chromosome. However, Down syndrome child's mothers define various meaning of "Down syndrome" depending on the different period of life experience. Moreover, it is referred to individual suffering which are the meanings defining in the period of pregnancy by the over-35-years-old

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mother who are the risk group. Those meaning are; 1) Mental retardation or "*Punya-on*", 2) Physical disorder or disability, and 3) Incarnated disease. While, the meanings define by the non-risk group mothers, it is found that the meanings are defined similarly to the risk group which those meanings are mostly emphasized on mental retardation. The meanings in the period of giving birth are varied according to the individual emotion. Certain mothers are shocked, upset, scare, sad, anger, tension, disappointed, and denial with the unexpected babies, while some are able to accept. Nevertheless, some mothers reacted in defense mechanism, denial and angry with themselves and other people. However, there are the various meaning of Down syndrome according to the mothers definitions namely; 1) mental retardation, 2) *"Sayan"* Syndrome, it is the name called by the same symptom of the joker actor, 3) Physical disorder, and 4) Abnormal symptoms. Mostly, the meanings are defined on the basis of physical emerging symptom and the experiences from perception or visualization.

The period of checking and confirming Down syndrome is the duration after being informed the bad news of Down syndrome's child, which the mothers need to adapt physically and emotionally. In this period, the mothers define the meanings similarly to the period of pregnancy and giving birth. They are mostly upset as they can't escape from having Down syndrome which acknowledge as *mental retardation*. While coming to the period of living with Down syndrome's child, the mothers define various meanings namely; *1) Down syndrome* is a disease that mothers and ther relatives perceive according to medical explanation., *2) Slow development disease* which is the symptom that the children are developed the physical, psychological, and social dimenson less than the capability of their age., *3) Physical and intellectual disorder* which is the recognized meaning base on experiences, social system, poverty and illiteracy, and failure of treatment. This reflects to nurturing or abandonment the children according to their fate., *4) 'Oer'* (iodine deficiency) or dullard which is the meaning defined base on social perception of physical appearance of the children, . At present, they still call *'Oer'* that confused with the iodine deficiency., *5) Mental retardation* which combines all the symptoms of brain, organism and neurotic disorder. This meaning has been recognized and defined for the long time without the distinction of different causes as medical concept., *6) Down as declining disease* is the meaning

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defines according to the meaning of English language when translation to Thai., *7) "Karma" or Incarnated disease* is the meaning which defines base on religious influence which is the "*Karma"* concept. That includes the past Karma in the past life and the present life Karma which are both impact to the recent life and can't avoid this occurance. , and *8) Hereditable disease* is the mother's belief that mental retardation and Down syndrome can transfer through the ancestor to the same lineage. The transference is also implied to transferring the sin from mothers to their children. So it is the problem on courtesy stigma which results in the questioning of society to the abnormal blood relationship and something wrong of the ancestor and their mothers.

8.1.5 Managing suffering as the meaning of Down syndrome

In the study' result, It is noted that mothers mostly manage the emotional tension and suffering from having Down syndrome's child with many means. The suffering management partly relates to the meaning of Down syndrome, which differs according to the related period as follows. During prenatal period, majority of mother manages their anxiousness and sufferings through relying on religious belief in order to comfort themselves namely; *1) Request the sacred power* for the healthy children as well as the gratification with the unseen objects is one means that bases on the religious belief., *2) Seeking the information* is the way for more knowing and understanding about Down syndrome. This action is not notified in the poor while only indicates in the educated and rich mothers. In the period of disclosure of the confirmation test result, mothers are experienced with the hardly acceptable feeling which lead to the various means of suffering management namely; *1) Seeking the information* which appears in the rich mothers for better understanding of Down syndrome., *2) Seeking the treatment*, most of the poor mothers find out the best treatment and the alternative treatment which contain the treatment on the basis of religious belief and magic art, the modern medical treatment, and an information and knowledge exchange among Down syndrome mothers; *3) Comparing with the others' symptom* is the means which comforts the mothers and feels encouraged because they never feel isolated as there are others people who also encounters the same situation. This comparison is classified into 2 types which are the comparison with the worsen ones. This leads to the better feeling that they are better off and

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containing less trouble than the others. Another type is the comparison with the more developers which bring mothers hope and encouragement to practice their children to be developed like the model., *4) Suffering diluting to the others* is the means used to lessen the stifled feeling or suffering of oneself through telling to the others. There are the dilutions to the medical officials and to the Down syndrome child's mothers. The mothers encounter the more comfortable feeling since there are other people who understand and listen to them., *5) Spirit of motherhood* is the reason of strong connection between mother and children which is full of love, pity and care. This connection reflects the resistance on the suffering and mothers' trouble which only for their beloved children., *6) Exploring the distinction of Down syndrome* with the general child is the means to escape or reduce the suffering of being Down syndrome. Mostly, the mothers attempt to identify the unique and good characteristics of the Down syndrome's child which is similar to general children or even better namely physical appearance such as face, hairstyle, intellectual and habit., 7) *Request the sacred power* relies on the supernatural and sacred power beyond nature. It is base on belief as expecting the miracle for recovering the children from Down syndrome., *8) Rely on religion,* including the merit, religious rite and praying, this is the means for tense management and living adaptation of being with Down syndrome's child through performing religious activities. This leads to comfortable feeling and expectation of the goodness power which influences to the improvement of sickness in both this present world and the next world., *9) Shifting meaning from negative to positive* and from suffering to happiness is the exploration of meaning base on the idea that Down syndrome's children are special children who are offering from the sacred power, as god , angel or merciful children, or the children from the past world. This is the recognition of Down syndrome's cause which markedly reflects to the way of taking care of the special Down syndrome's children and please them greater than general children., *10) The death is the end of Karma*, is the explanation according to Buddhism belief on death which refers to the end of suffering and terminates the so called 'Karma' as it has been perceived that Karma is belongs to the Down syndrome's child and all related people. The explanation with this belief comforts the mothers from the death of children., *11) Sharing burden, sharing suffering* is the situation of the practical, mental and emotional supports from the surrounding people to take care the Down syndrome's

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children. Those supports gain from husband, relatives, grandparents and sibling which benefit to the reduction of the mothers' tension., *12) Trajectory over the obstacles* is the means to move toward the dream. It is the challenging thinking to conquer the understanding of Down syndrome's child who has less alternatives in living. This phenomenon is emerged in some mother who are engaged in high economic and social status. They can access to the more information from aboard and aim to improve their children to duplicate the model., 13) Group empowerment is the idea and an attempt of only one family which is high educational and economic status. In case of Kwan's parents, they desire to form the group and network of Down syndrome child's families as intention to communication, information exchange and support each others. Moreover, they also aim to establish the database in order to generate understanding and knowledge of people in society and the negotiable power for the benefit of Down syndrome's child.

Additionally, the study indicate that the most mothers extremely suffer on having Down syndrome's child. The suffering in each period are rooted from individual condition such as the age of pregnancy and accessibility to healthcare services. Moreover, the service system and information notification strongly have impact to the mothers' emotion. While the study also reveal that the mothers define differently the meaning and feel suffering on having Down syndrome's child in different period as well as they employ the distinctive suffering management individually. However, the interesting aspect on the CMA conceptual framework is the structural relationship in healthcare service system between patient and client or provider which reflect to the disparity in service accessibility, especially in the poor mothers of Down syndrome's child. Finally, the analysis with the theoretical framework will be presented in the next part.

8.2 Discussions

With the concept of CMA to analysis and synthesis the results of this study , it indicates the linkage between capitalism in macro level and individual level, the poorer whose lives in the ordinary suffering of life. The studies have analyzed the health providing service regarding to the unequal between the providers and the

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patients that it therefore has the influence upon way of livings and way of thinking and its limitations and constraints to those Down syndrome's children to access such services. The individuals' depressions can be gradually increased by both medically and socially in the capitalism. This study is to analyze the political and economic power of the state that can be seen through the health providing services for those Down syndrome's children i.e. population , heath , education, and other social policy.

8.2.1 The poverty cycle of the poor and social suffering

Most of women who bear Down syndrome's child have experienced their lives to the poverty since they were young and even more so when they were growing up until they have their own families. The findings indicated that there are 9 characteristics of poverty such as living in rural areas, especially from North-Eastern part (Isarn) of Thailand. This is in accordance with the study of Pranee Tinnakorn (2002 : 1-4,70) about income disparity and the poverty of the rural people. The results indicated the poverty of North-Eastern people and they are poorer than in the other parts of Thailand. Most of them are farmers, and their education backgrounds are lower. Besides, those people are moving into the cities because of the failure of their careers in the agricultural part. The mothers of Down syndrome's children do not receive any good chance for education so that they also loose the chance to get better jobs as well as to level up their social class. This evidence is supported by Mathee Krongkaew and Pranee Tinnakorn's study (1985) that indicated that the poverty is the cause of loosing the opportunities in all aspects. Moreover, they also have to face with the disunity, violation, and the persecution which are the complex problems and bring them depressed. From the studies, those mothers have been in the cycle of poverty from generation to generation until it turns to be an image of Thai society as corresponded by World Bank (2001). It becomes more complex and is partly a real life of the poor because it limited social space of the poor and also the loosing of their opportunities in their lives from past to present. This is including the limitation of the getting married opportunities because they limit the physical and social circumstance. So the poor always meet the poor merely in the same class and get married with the same class and that means to the lesser chance for changing their

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social class. In cases of Boss's , Nuey's , and Phing's mother, their husbands and themselves work for general hiring with low rate of payment or low income. Whereas Rung's , Taen's , June's , Bengi's , and Linda's mother who are housewives while their husbands work for the companies with low average salary. Consequently, they are all struggling in the cycle of poverty and they sometimes can not feed themselves three times a day. Most of them accept this such situation as their normal lives and this corresponded with the study of Kleinman et. al. (1997). The study indicate that the suffering from poverty somehow is accepted by poor as their daily lives, and they sometimes express or not express about it but keep it in silence. The poverty of people also limits their rights in the society and sometimes causes those people mental sickness and depression than other groups.

This study clearly show that those Down syndrome child's mothers always confront to many complex problems including physical, mental and environmental health problems from the past to the present. Most of them live in Slum areas in the cities but in fact, the background of them have been moved from North - Eastern area of Thailand to the cities because in the rural area they can't find better jobs with better payment there. The poverty has the most effect upon the members of the families. On the other hand, it can be said that children in poor families are more likely to have less mature than other children. Besides, they also have less opportunities to get better social service as supported by the study of Pual Farmer and Bawker (as cited in Kleinman, et. Al., 1997) and Bruder (2002) whose their studies confirms that the poverty and social status are main factors that related to health problems, and depressions of those poor. In the survey research of Ladda Mahsuwan and her team (2000), it indicates that people from North-Eastern area seem to have more problems than other parts of Thailand and they must endure with the scarcity and the sickness even the solutions to those problems are yet found according to the situations of sickness as happened to Boss's and Bass's mother. To live in the cycle of poverty means to live with less chance for lives as repeatedly supported by Kawachi's study (1999) that explains about the relationship between the income disparity and mortality rate of infant, violation's and the crime's rate, and other involved conditions. Moreover, the research of Mellor & Milyo (2002) repeats the relationship between income disparity and their health. Such studies indicate that the more income disparity , the poor will suffer the poorer health. It is

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shown the same result in Kleinman 's study (1997) which indicate that in every social class , social depression can cause people health problems , but it is more likely happen in lower class, and the hopeless and powerless area.

Most of Down syndrome 's children mothers accustom themselves to depression and suffering as the part of their lives even they are very tired with the struggle to the scarcity. Nevertheless, the results show that some mothers accept these unavoidable facts. For example, Taen's and Bass's mother and their relatives have been forced out of the housing in the Slum area by the government. The government needs to use space to build up the International Conference Center to support national economic growth with the reason to improve the country economic. The government offers those poor no solution except being further away from the big cities. Contrarily, the government reason to the propelling the poor is very good impression for developing the whole economic of the country. Finally, those poor have to accept such propelling without any resistance because they are powerless to do any negotiation. Accordance with Navarro (1987 : 61-79), he commented that the capitalism ideology is shown in forms of the interference of the government in every spheres i.e. political, economic and social life. As a result, those mothers of Down syndrome's children have to live among avoidable pollution and unsaved environment. With the horrible fact of aforementioned, they still accept that their lives will be as it is forever, and that is the fact that they will not be able to change. Kleinman (1997) commented about this social depression that it has been placed into the groups of people in lower class that caused by country's rules has yet been discovered since that fact has been hidden and blurred the unequal relationship by the cultural, political, and economic power(Paul Farmer, as cited in Kleinman, et.al., 1997). The study corresponds by Veena Das (cited in Didur, 2000) that indicates the poor sufferer endure to the loosing without any words and would rather stay silence. Such toleration to suffering of those mothers are the result of the combination among their minds, bodies, cultures, and social interactions that are caused by government rules. The suffering experience has been reproduced and categorized with the social interpretation and influence of political and economic power of macro structure for transforming the underdeveloped circumstances i.e. politic, economic, society and culture with westernization (Nattapol

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Kantachai, 1994). These provide the context of daily life and the life cycle of the poor especially in the agricultural sector.

8.2.2 Population Policy and Patriarchal Ideology

"Daughter or son are fine, but just two"

"More children, More poor"

For more than three decades, these two statements have been using by the government to persuade people to have less child and to commit birth control. It seems to show more concern of government toward their people livings and economic status. But the hidden behind that people can't understand is that the population policy of government is as tool for improving country economic under the concept of modernization. In addition to the economic factor, it emphasizes on other factors which are important for social transformation under the belief that social transformation is the foundation of country development especially for economic growth. So, the government provides the policy to change the obstacle factors that relates to social institution. Family is the prior institution which must be controlled to have fewer family members, by family planning program and human resource development plan (Dubois, 1991 cited in Chairat Charoensinolarn, 2000). The population policy is in fact of governmental politic because it had changed on the way of political economic direction. Recall the past memory before Thailand economic policy had been interfered by the United State, the promoting policy of reproduction of the General P. Piboonsongkram had promoted and supported women to have more children. Besides, it had contested of the best mother and gave award to the mother who had the most number of children. The reason of such policy is to encourage human resource production since it id held as the most important factor for country development especially after the war crisis. His belief in that time is that increasing of population has meant to increase the power of production too. As stated by General P. Piboonsongkram in the day of establishment the Ministry of Public Health in 1943.

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> "Now, we have 18 million people all over the country. That means 36 million arms, and those 36 million arms will bring country the power of production that will lead us to be a great power country"
>
> Gen. P. Piboonsongkram

That policy showed the relationship between people and the nation security. Besides, to support the government policy, the Ministry of Public Health had set up the office of married makers to encourage the increasing of country population number. There were many propaganda to encourage the marriage. For instance, the statements of "To establish the country is everyone's duty", "To marry is to establish the country", or "Marry when you are young bring country the development" were published to persuade people to marry.

However, after Thailand accepted the concept of economic development, World Bank had suggested the National plan to develop economic and its society. This is including the policy about Thailand populations that emphasized on controlling the birth rate of Thai people. Under the reason that the increasing of country population will bring the nation to the crisis of consumption shortage that will effect people cost of living. Therefore, the project to provide the birth-controlled to volunteers had been set up (Manasawee Uunhanun, N/A). It was also announced to be the nation policy on March, 1970 stated that "It is the policy of the Thai Government to support voluntary family planning in order to help to resolve various problems related to the very high rate of growth, which constitutes and important obstacle to the economic and social development of Thailand". In 1974, the statement had been added "The state is to formulate population policy to suit the natural resource of the nation, social and economic conditions and technical progress for the interest of economic and social development and security of the state". The policy was to decrease the birth rate of nation as well as the number of individual family members. Such policy had been applied until the year of 1997 (Somchai Suksiriserikul, 2002). The project was supported by the United States who allocated the huge budget for Thailand. As a result, it was bearing a great fruit that can be seen from the population census in 1980. Such survey showed the percentage of 44.4 of the family that submitted family planning. The percentage was increasing to 71.4 in the year 2000. However, the real reason on this policy is that the number of country population has

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very close relationship with the nation revenue. As such, with the fewer number of efficient manpower, the government has less obligation, then the country economic will be expanded. (Aruree Jintakanon, 1965) The government has repeated people such fact by issuing the first, second, and third nation development plan. After those plans, country economic has been increasing for 7-8 percent each year or 50% comparing to country economic in the past. (Nation Economic Development Bureau, 1967). The nation economic development campaign, with the purpose to increase Gross-National Product (GNP), it is one of the other policies that the government used to decrease the population growth rate, and to reduce economic problems (Supap Wisethsurakarn, 1968) and people poverty. (Estava, 1992 : 7)

This policy was successful, as its campaign to having only 2 children in a family has been widely accepted by most of the people. Consequently, women who bear children more than two became less comfortable with their third and forth child. In case of Linda's mother, she would not dare to go to the hospital for her pregnancy-care because she was afraid that the doctor would blame her on not protecting herself from pregnancy after having 3 children. Likewise, Nuey's mother tried to abort the forth child on her own. In case of Afifa's mother, she decided to accept the sterilization which it is not only held as being against the rule of their religion, but also makes her suffering from the depression of being guilty for the rest of her life. Consequently, the social rule regarding the number of children in the family does have an effect upon the depression of those poor mothers.

Moreover, the findings of the study indicate that only the women have been forced to go through the sterilization program. Taking pills, or other way of such program are set for the women because those women do not have enough courage to negotiate with their husbands to get sterilization program instead of them. As what happened to Kong's mother, Afifa's mother, and Nuey's mother who decided to go through the process themselves. The study's results are accordance with the survey research of Boonlert Laewprapai and Vorachai Thongthai (1989 as cited in Phenprapa Kreeyindee and Orathai Roeyarchin, 2003 : 82) and the survey research of the population change (1995 as cited in Phenprapa Kreeyindee and Orathai Roeyarchin, 2003 : 83). Their studies indicated the portion of the gap between men and women regarding the receiving of sterilization program. In 1978, the portion between men and women who

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committed the sterilization program was one to five and changed to one to nineteen in 1995 (Phenprapra Kreeyindee, and Orathai Ruayarchin, 2003 : 82)

This phenomena somehow reflects social treatment upon female gender as they are used as the tools to force the economic growth of the country. The circumstance is associated closely by to human right problems and the inequitable relationship between male and female. (MOHFW, GOI, 1997; Measham and Heaver, 1996 ; Pachauri, 1998 ; World Bank, 1995 ; Bagchi, 1999). David Floyd (1996 : 150) The above studies had a comment on the sterilization for female gender that women are treated as the objects. Thailand population policy has reflected its thought towards female population who are the passives to any actions that sometimes their mentalities have been ignored. When we look back through Thailand history, we would see the same situation happened to female population. For example, in the era of General Por Piboonsongkram, women have to bear many children for the reason to increase nation manpower. But in the era of General Sarit Thanarat, population policy had been changed to focus on decreasing the population growth rate. As a result, female population need to commit the sterilization program to decrease the number of children in the family. It is obviously seen that women in every era have been treated as body politics, or as the public properties (Kaufert, 1996). Moreover, most of the time, government has used women body as the tools or means to develop the country economy through controlling the population growth rate.

To follow the government policy, woman bodies are used as samples to try on the new product of medicalization (Davis Floyed, 1996 : 150). Woman bodies have been invaded by the management of doctors such as to certain the menstruated cycle, also to used as part of country economic development and profitability process (Doyal, 1979 : 22-27). The government used the policy for country economic growth through the medical modern technology to cover the fact that every technology has either advantages and disadvantages. As such, women need to put up with the circumstance to be passive of the society through the country policy and medical technology. This fact reflects the belief that the women are ruled by the men.

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8.2.3 Medical Hegemony and Social Depression

Thai society has been dominated by the concern of ones' healthy and normality through medical technology and public health propaganda. It made people expected to be healthy, especially, those women who expect to deliver normal children with strong and perfect health. As Thai motto says that "To be no sick is to be most lucky", that reflects people belief in their healthiness. Besides, they also expect to see their children with completed body parts which is the extreme virtue. Medicalization has a great deal influence upon people lives and being used as the standard to define the boundary of "being healthy". Down syndrome is held as one of abnormality that mothers never desired for their children. Kaufert (1996) commented that medical information can bring the mothers' fear to such abnormality because the society has already set the standard for physical normality to judge people in the society whether that particular contain normal quality or abnormal quality. People are exposed to the ideas of "being healthy" as same as "being normal". It eventually discriminates people into two opposite ends, being healthy, and being unhealthy. Being healthy is the same as being normal, where as being unhealthy is the same as being abnormal. Such standards are used to judge people including the liminalities and abnormalities. Therefore, women would rather commit abortion than deliver Down syndrome's children as what happened to Ping's mother, June's mother, and Bengi's mother. The medical science is used to explain about 2 abnormalities of Down syndrome, that are empiricism and objectivity. The explanation emphasizes on representing and controlling bias that appear in the information about such disease that the government provides for the people through the definition of "normality". Statistics have been used on this matter such as mean, median, mode, and standard deviation (S.D.) to differentiate normal children from abnormal children. In this case, children who have IQ level lower than 80 are judged as being abnormal. This judgment causes a lot of depression to women. Herrustein and Murray (1994), and Harraway (1999 : 186, as cited in Chairat Charoensinoran, 2000) stated that such suffering is caused by the information of science analysis that contain bias. It is the base to level people who are not in the curve of standard deviation as the outsiders whose rights have been limited by society.

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Health, life quality, and normality are use to strengthen the power of medical knowledge and to divert it to be the protection that government provide for people health. Pregnant women who age more than 35 years have been suggested to check the abnormality of their fetuses because that age is the risk group. However, most of them did not follow the suggestions not because they were not listening to doctors. But it depends to many factors for them to receive pregnancy check-up such as less education, poverty, and miscommunication. From the study, it shows the inequitable relationship between the mothers and doctors that the doctors are knowledgeable and have the rights to manage the information and service for them including making decision to stop the pregnancy when the abnormality has been found. Women have to face with the suffering when their babies were found to contain abnormality status, even more so when they have already delivered abnormal babies. In Thai society the power of medicalization and sickness control has been run for a period of time under the government policies regarding the developed direction of country economic and public health. Therefore, the institution of public health has been set up similar to western country. Moreover, in university level, the curriculums have been added wider range of medical fields to produce more medical personnel. The Ministry of Public Health has finally been set up in 1942, whereas the medical knowledge has been spread out through the whole country along with the development of medical system and heath service (Methee Krongkaew and Praipol Kumsab, 1993 : 277-278). As a result, the government has launched the project to build hospital in every province of Thailand and the project has to be implemented within 1955. This project has been supported from the foreign fund, especially the United States. USOM offered the assistance on the project about mothering and childhood sanitation, environment, and personnel arrangement. AID gave the assistance on public health improvement, and providing a huge fund for medication and public health studies. In the meantime, the government also supported the business of private sector regarding people health in 1988. BIBF has issued the loan for those non-productivity businesses. Therefore, there were many of them use the loan for establishing the hospitals. So, 8,210 hospitals have been built by such loan which 3,449 hospital or 42% have been built in Bangkok. Besides, there was high rate of competition in this business in terms of medical technology. However, the

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expansion of such technology was not balanced in the cities and rural areas (Tassnee Em-orn and et.al, 1991 : 3-4) because about 30% of the population do not have health insurance (Sa-nguan Nittayaramphong and et.al, 2000: 5-12).

The process of medical personnel production gave them more power to manage people health and moreover, it became the most honorable profession in the society (Freidson, 1970). In Thai society, they are placed in the top status and be able to make the decision for people lives. This is because the process of production for those experts has already specifically formulated (Flexner, 1915 as cited in Suvajee Chanthanom, 1999). The process is consisted of all 4 steps that are composed of; Firstly, to select only those intelligence, and those who have a great deal of scientific knowledge., The second is to give a chance to those particular persons to have more authorize in managing people lives and arrange them more opportunities to become leaders in communities., The third is to let them free from being supervised by others., and The forth is to allow them to use high technology in providing treatments for people. So they finally become the knowledgeable experts in particular fields as well as become the leaders in their communities (Good, 1961). As such, in treatment process, doctors have absolute authority to make people comply. Parsons (as cited in Suvajee Chanthanom-Good, 1999) stated that medicalization power have been applied from, 1) the professional prestige that the doctors are more knowledgeable 2) Situation authority that the doctors are supervisors of patients through the treatment process, and 3) Situation dependency, those patients who become deforming will need to be taken care by doctors, and more likely to comply the doctors' instruction as they have high authority by their knowledgeable power to explain what happen to the patients.(Alvares, 1992b : 230)

To posses the authority for providing health service of medicalization regarding Down syndrome passives has created new knowledge that dominates those mothers with the depression caused by the uncertainty of getting pregnant. They feel uncertain about the mental retardation, perfection and normality, standard development of their babies. Somehow the mothers are creating homogenized group by the concerning about routinization since they have been nomalized to the necessity of pregnancy-care. It became a routine for mothers to go through the pregnancy-care process because they concern about their babies' normality (Rowland, 1992 : 133). For the amniotic fluid checking is held as the special treatment that those mothers

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request to have because they are too concern about the abnormality of their babies, as well as being more certain about the normality of their own babies. Evan (1985 : 119 – 120) has a comment of this matter that the amniotic fluid checking has much effect upon mothers' mentalities, the situation then turn to be more stress that those mothers were put in the circle of uncertainty about their pregnancy. Doctors may give the information about babies as one of the objectives that can level their normality or "being normal human" (Dyer, 1993 : 72 as cited in Seremetakis, 2001). That information has been used to judge imperfect babies as one of the damage products (Hadd, 1996 : 220) Those babies were compared to the products that their qualities can be controlled, on the other hand, that purchasers can change if the damage (abnormality) has been found by disregarding human moral or rights of those disabilities. The thought of pregnant termination rather than allowing to have abnormal babies has been projected to those mothers who agreed upon such matter. From this study, the interviewers are Down syndromes' mothers whose ages are less than the risk age (35 years), they also agree to terminate their pregnancy if they are found the abnormal fetuses and the delivery of the consequent abnormal babies. As Bengi's mother, she said that "to abort them when they are just the fetus better to bear them. Because they will suffer, and we will suffer too." And the same in the commendation of Sor's mother, she said that "to see her like this, I feel sorry for her. Better for her not born at all but we can't change anything. What we can do is to accept it and try to raise him as much as we can because we are the parents." In case of Kong's mother, she strongly said that "every risk pregnant mother should check - up if your baby is O.K. right after getting pregnant. If waiting until they are born, it is too difficult to accept." Nevertheless, those mothers think that it is better to terminate the pregnancy as soon as the abnormality is found. Such thought can reflect the medicalization authority upon the poor mothers in terms of their health and lives which is the hidden behind their thought and push them feel troubled.

Moreover, the authority of the communication of medic and the depression of Down syndromes' mothers. It can be said that doctors ignore the properties of human-being and motherhood. From this study, it indicates that there are problems regarding the communication between doctors and patients' mothers from the beginning. The communication pattern between them is called "linear

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approach" or "Activity passivity model". It can be explained that this pattern is giving the most authority to doctors. On the other hand, the relationship between them is carried on unequally (Szasz and Marc Hollender, 1956). For the instance of Bee's , Fluke's , Bengi's and Kong's mother, they are caused to the unsatisfactory and suspect after the conversation with doctors have taken place. Sometimes, doctors can't clearly explain about the circumstance that they were facing so that they can't make better decision and prepare themselves for its results (Schott, 1998 ; Weitz, 1990). Besides, the inadequate information consequently bring them a lot more uncertainty and anxiety (Tailor and Mayberry, 1995).

Moreover, the doctors always talk about people bodies regardless to their mentalities, diagnosing them as only the body parts without lives. Although, doctors can diagnose people sickness, and provide them the proper treatment but they are dehumanizing the patients by doing so (Parsons and Fox, 1952 as cited in Mallika Mattigo, 2003 : 7) It is corresponded with the study of Norris (1986) about the depression that those mothers need to get through when they are waiting for the abortion process. They were tense, scared, and anxious, while they were feeling as they were in the animal sty. Kwan's mother gave a comment about the recommendation of the doctor to commit abortion. It seems to her that she was receiving a kind of advice about the treatment to their sickness not to kill one's life. At that moment, she can feel to the unexplainable pain and depression for that advice. Likewise, in David-Floyd & Sargent's study (1997) which was accordance with the study of Wiroj Tangcharoensatien, et.al. (1997), and Mason and Benesch (1996). These studies indicated that the medical process dominated people decision and life and it was suffering them by their acceptance to the authoritative knowledge of medicalization.

From the study of Rayna Rapp (1985 : 320-1) in North America, it explained about the medical process that has been done regardless to the patients' mentality. Doctors make an arrangement for every process which sometimes were done when mothers already feel to their babies' development in the womb. Once the abnormality has been found, those mothers have suffering by their decision to commit abortion even if their babies were in mid-trimester termination stages (babies start kicking and moving). Rayna Rapp (1997) indicated to the gaps in the communication channel between doctors and patients in the context of prenatal diagnostic test. She

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found that those mothers received the information that brought them more depression. Because such information are universal and abstract language, and are individualized narratives. Kwan's mother told about the feeling she received when she was told to check amniotic fluid while she can feel to her baby's movement. She said that the doctor talked about her baby as one piece of her body which without lives and suggested her to take out that abnormal piece. She then chose not to get prenatal test when she felt that her baby was completely developed.

Moreover, the medical personnel never consider to the time to inform the bad news of giving birth Down syndrome to mothers. In case of Down syndrome child's mothers, they commented that the bad news' information of the doctors were always out of place and time. Kong's mother said that she was unexpectedly told that her baby was Down syndrome, while she was alone and still suffering from the delivery pain. She felt as if she was walking lonely in the cemetery. Meaw's mother explained about her feeling when she received the bad news that it was similar to falling down into the deep abyss. It is accordance with the study of Murphy (2001) that mothers would get severe shock when they were told about the abnormality of their children. Clements et.al.' s study (1990) also explained that about 70 percent of parents felt to the difficulties when they were about to be told. It is overwhelming event that parents should acknowledge to their obligations, failures, that led them to the feeling of despair and tragedy (Kearney, 2001). Whereas, the study of Ney et.al. (1994 : 1193-1200) indicated that doctors always assume that this suffering of pregnancy ceasing bear merely little consequence, so they never prepared for such matter in proper way.

However, the communication about abortion of abnormal babies would have different effects to mothers' feeling for different stages of pregnancy. It is said that the more development babies in the womb are, the more difficulty those mother have upon the decision to commit abortion. As a result, the communication between doctors and those mothers regarding abortion in disregarding other factors especially the psychological factors, brought the depression to them. Some of those mothers agreed that doctors were looking their babies as some of integral part by omitting the relationship between the fetuses and their mothers, and ignoring mothers' emotional body (Rothman, 1982 : 48). In Fetologist, the fetuses are held as autonomous and the mothers are held as fetal container who lack of the right to make decision about those

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fetuses (Petchesky, 1987 : 228). Doctors make decision by using their authoritative knowledge for those fetuses' lives after the abnormality has been found. (Bonevski and Adams, 2001). It reflects the thought of body owners that doctors have on their patients' bodies (Seremetakis, 2001). Eschen & Whittaker (1993) stated that women have been dominated with 2 standards. First, the government treats the woman body as the tools to improve country economic, and second, those women are always ruled by the men. Kwan's , and Bee's mother feel to the dehumanization of the society has towards them.

The variable of the communication between those two parties are the education background (Machanic, 1958). It indicates that most of the doctors come from middle to high social class whose conversations are always based on logic but such behavior rarely happens among people in low class. Those Down syndrome child's mothers who came from the middle class of society rather speak out more to the doctors, and seemed to understand the situations better. They also tried to find more information from other sources about such disease so that they can handle the situations. Whereas, mothers who came from lower class society, realized to their uneducated background, as such, they chose to listen to their doctors without questions. Moreover, Ebert et. Al. (1976 : 825-827) explained to the gaps between known doctors and unknown patients which reflected unequal authority of both parties. The situation than created the alienation in the treatment process which brought those patients unnecessary depression (David Floyd & Sargent, 1997)

8.2.4 Courtesy Stigma and having Down syndrome's child

Most of Down syndrome child's mothers are suffering from the situations they have been facing and desire not to see the same situation happens to others. Kong's mother said that " if I knew that my friend or anyone got pregnant, I would tell them right away to get check amniotic fluid and do everything that the doctors told. I mean do as the doctors' order, so it will never happen to other like what happened to me." She added that if she can turn back the time, she would never hesitate to get prenatal test, and decided to stop her pregnancy if it was found abnormal. However, those Down syndrome's children do have a kind of lucky when

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their reception senses about what reaction their society have toward them are zero. Goffman (1963) named that reaction as the social sin to those abnormal people to be worthless subjects in the society. Taleporos and Macabe's study (2002) about body image and physical disability indicated that the disabled body will effect to one's psychological status, deposition, and negative attitude towards one's body image due to the standard of ideal body. This influenced on the expectation of ones' appearance, and normality so that the abnormality has been held as the symbol of terror and amusement (Murphy, 1995 : 143). As a result, those abnormalities find themselves difficulties to face with the situations that societies present bodies as the positive image, physical fitness, and beautiful image (Lawrence, 1991 : 140). Besides, their mentalities somehow are also ignored during the medical processes that its main purpose of the processes is to get rid of all undesirable factors.

Although the mission of mental health work is progressive under the World Health Organization (WHO) support. As the mental health and psychosis courses are included in the medical school in accordance with the western international standard (Fon Seangsinghkeaw, NA : 672-685) and the medical science of mental health are advanced. And the history and experience of Down syndrome are recognized as continuous problems. The possible reasons are the unawareness of people, the problem in public relation of responsible unit and limitation of mass communication. The studies found the parents were uneducated about Down syndrome and recognized it as mental retardation. However, many mothers knew and understood Down syndrome from their experiences to the joker star names "Sayan". They mostly haven't known Down syndrome, therefore, the explanation by doctor to the parents of Down children was rather difficult. "Sayan" was given as an example by doctors and nurses to make parents easily understood Down syndrome. Nevertheless, Down syndrome was perceptual as disgusting as appeared in medical service and in society. Down syndrome implied a symbol of sin because it was known as a dangerous life or short life and the mysterious disease that was a superstition, and inexplicit assumption of disease. This explanation was very complicated which physician hadn't been able to diagnose or discover a protection plan and efficient treatment. The disease perception and death led the patient stayed

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close to the fright and sense of insecurity and the symptom was severely perceived and attempted to control and quit from the community. (Williams, 1987 : 149-150)

As mentioned above, the sin was created, it was not influent only on the perception and affliction of Down syndrome's children but it extensively affected directly to the mothers and associated community where the Down syndrome's children were living in. Goffman (1963 : 2-5) called this situation as "Courtesy Stigma". The study found that mothers and others in the family of Down syndrome children were subjects to be stigmatized because the mothers were normalized to give birth a child who would be perfect and be a future of nation. So the abnormal child was the dilemma of motherhood because it made mothers missed the woman role, and felt tense, guilty, awareness of sin. It resulted in the sense of guilty, the failure life, the imperfect and inability of woman and wife. As the case of Bengi's mother, she was upset and unpleasant when others looked at her and her child. Moreover, she was afraid of her neighbors who might gossip her and her abnormal child that implied to her bad behaviors. Giving birth the normal child was the cultural and societal value in every age, class, religion and race (Griel, 1991).

Courtesy Stigma in Thai society partly resulted from the history that Down syndrome was defined as in the group of psychosis, neurosis and mental patient. The treatments, in the past, were to impound, chain, and control like animals. Evidence disclosed the place where to impound psychos was not a kind of hospital but the place for chaining them when they were raving mad. The interesting and solving the mental problem of government was objectified with the hospital construction for psychosis at Pak Klong San in 1910. The report of foreign physicians in that period reported the treatment manipulated with separate captivity or merged captivity depending on the symptom and many were treated like cruel animals by chaining with a piece of hardboard (Fon Seangsinghkaew, 2525 : 672-685). The understanding of mental health was presented negatively in the past. The belief in reason and treatment of mental health of Thai society have despite been modified from captivity to human care. The principal of psychiatrist has been further used, and Down syndrome perception has been developed with modern medical service so that the stigma still appears continuously. The names given to a hospital conveyed the meaning of discrimination such as, Hospital of Mental Retardation (Rajanukul Institute of Mental

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Health Department, Public Health Ministry) and Hospital of Psychosis. Their aspects are used to abuse, insult or be figurative the person in negative way which the mothers of Down syndrome's child also have the same conception as others that Down syndrome's child has been an idiot or a psychosis who was disgusting to socialize.

The stigmatization the Down syndrome's child has effected to their mothers and relatives, so called Courtesy Stigma which partly is understanding and knowledge of genes, and partly is cultural construction about the fateful belief of the relatives. As shown in the case of Kaew, her mother and grandparents believed that Kaew had been Down syndrome because of one's fate in the family and as a result, her mother suffered from guilty and hurt. The study shows that Down syndrome children's mothers can perceive the reactions of other people towards them which built the sense of stigma of their relationship. In accordance with the study of Gray (1993) found that the most parents of Autistic children were stigmatized. Goffman (1963 : 102) suggested the covering stigma was held back or widely unknown by parents and Blum also supported that the care giver tried to reduce or delete the image of stigma which relied on the circumstance. The care giver often stands with the patient who is stigmatized for saving their societal status as same as their face (Blum, 1991 : 281-2).

The expansion of courtesy stigma to Down syndrome child's mother is related to the study of courtesy stigma of Childs (1985 : 13-15) which found that mothers had many characteristics of courtesy stigma such as guilt, denial, inferiority, shame, confusion, anger, loneliness, unloved, and infanticide. These emotions happened to Down syndrome child's mothers which accorded to this study. The most mothers perceived the abnormality and were worried about the future and health of their children. They also were stressful in the role of wives and mothers. Moreover, some mothers kept these feelings in mind of themselves and appeared in form of pain and headache. As in case of Bas's mother, she had migraine and happened when she was tense and upset. Kwan's mother was so stress that she needed a psychologist to treat her tension. The study of Darghouth (2002) coherently found that headache and pain showed the affliction acted out by physical illness. Linda's mother shows the other form of expression the stress and hate of having Down syndrome's daughter, she tried to kill her daughter by crushing the pillow over her child's nose. This was partly

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explained by genes which Down syndrome's child represented their parents. Likewise, Land (1998 : 78) studied in the Israel mothers, it found the cruel behavior like animals of their children and the parents tried to kill their children without criminal feeling that they were inversely certain what they had done was correct. Kleinman and Kleinman (1996 : 1-23) found these murders were influenced by social interrelation.

The stigma represented in physical and mind, as well as, the viewpoint of Down syndrome child's mothers toward the religious belief and causality. The afflictions were managed by mothers who were discovering the good things to avoid Down syndrome of their children and changed the meaning of being negative to positive. In case of Bengi's mother, she believed that Bengi was a blessed gift from Kuan-im Bodhisattva, so she had endurance and hope to continue bringing up her Down syndrome's child as special gift. As same as Kong's mother who was suffering with delivery Down syndrome's son and her son finally died. However, she discovered an exit of affliction told by a monk in a temple located near her house. After the meditation of the monk, he explained the arrival and the death of her Down syndrome's son that was a story of god who wanted to purify thy soul. The new belief explained by the monk could release Kong's mother which related to Goffman that there are 3 catagories of covering and discovering stigma; 1) the concealment of sin with deviation and accusation., 2) Destigmatization by discovering information for sin reduction and keeping the positive characteristics as found in the study that mothers tried to present that their Down syndrome's children were as capable as normal children and sometime better. Like the study of Ablon (1984) which studied the Dwarf children who tried to have normal lives., and 3) To confront and deny the stigma by collecting the self-help group, responding the societal and mental requirement of members, creating the positive characteristics, flight and experience the painful in a positive unity. The first and second categories happened among the these Down syndrome child's mothers, however, there were less for the third category in Thai society, particularly in the poor mothers.

8.2.5 Poverty and the right limitation

The disabilities were the group that the government has arranged the welfare continuously since the past up to present. Department of Population Welfare

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has been responsible for registration so the disabilities have rights to use the public health service for free of charge. According to the Thailand Constitute A.E. 2540, the disabilities were assured and protected the right to the primary service from governmental sector. There are 3 sections concerned about the disabilities (Chairat Pattanachareon, 2542 : 13, 17, 25, 36). Section 52 of the equality states the equality of people in receiving the minimum standard of public health services and the evidence is shown in form of 30 baht project and other health insurance card that must cover the whole population. Section 55 of the disabled right states that handicapped and disabled children have rights to be generally facilitated and supported by government regarding laws. Section 80 of the government role to the childhood states that the government must administer child's health and support the handicapped, disabled, and minor people to have a better life and finally self-dependence. As seen in case of Down syndrome's child who registered as a disability would be serviced without any charge and also included in the 30 baht health insurance system.

Though, laws identify that disabled child has rights to access the health service without any charge but this study indicated that many mothers didn't give attention to the disabled card and be unaware of the privilege. As the political ecology of the poor mothers, the poverty and migration were conditioned. And moreover the limitation of service accessibility, therefore, the poor couldn't access those privileges. In addition, most mothers were favorably rendered services by clinics and out-system hospitals. With the case of Bas's mother who was a worker depending on only 200 baht daily wage and all of her income were also all her expense. She had to rely on her grandmother who was a rubbish collector. While her son frequently purged all day, she couldn't bring her son to see the doctor to treat the sickness. She should reach the health service according to the 30 baht project that loosen the expenditure's burden. Her son should be treated according to the Down syndrome's right, instead, he was taken to the nearest clinic with the reason of time difference between her work time and the health service hour. Moreover, the transportation cost, uncertainty of service quality, and unpleasant referral health system decided by physician were the obstacles of health service accessibility.

Nevertheless, the study still found that many mothers had experienced the unpleasant health service under the health insurance system, for instance, lower

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limit of service's right regardless the patient's health that poor mothers didn't know it was the hospital policy such as rejection of higher reference by doctor which a child deserved to receive and uncertain medical appointments. This can be explained by the case of Bengi's mother, she tried to control the transportation costs to the special hospital where experienced to Down syndrome, by switching to the near clinic and used the right of disabled person. She found the extreme difference with the special hospital because the near clinic was not ready for service both the personnel and developed program for Down syndrome's child.

The health care reform with health insurance, financial policy and budget allocation all are the frames to the guidelines of hospitals and medical human resources who concerned only the cost of operation. Consequently, there was a reversion of different quality between service expectation and lower base of service privilege, and this incongruity of policy influenced the service given to chronic Down syndrome's patients who needed longitudinal remedies and high expenditure. If the principle of medical economics based on a breakeven, the medical service for Down syndrome's child would be limited as found in case of Kong's mother. She was awared of the limitation and less importance in Down syndrome treatment. Likewise, Kwan's parents felt the disadvantage of her daughter because they had to wait for a long queue and time. Health service system for poor Down syndrome's child could be called "Triple Standard" which referred to the limitation of service caused by type of disease, poverty, abnormality or disability and kept the Down syndrome child's mothers away from basic and qualitative services . Therefore, the poor mothers always suffered from difficulty in taking care, developing and curing their children.

8.2.6. Education Policy and discrimination Down syndrome's child

The government announced that all the disabled children can study as possible as they desire. (National Education Act and the announcement of Ministry of Education in 2542 A.E.) In fact, the mainstream school refused to admit Down syndrome's child to study with the normal student as June's mother said "I nevertheless asked the school director, he insisted the school was not ready for disabled child. Some had achievement test that also used for normal children, so how

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Down syndrome's children passed the test. I just felt hurt because my child was treated as inhuman. No one accepted her."

The study still found that most Down syndrome's children in the poor families were in trouble to enter the mainstream school. They were refused by either in-the-list schools or out-of-list school which was declared by government to manage both the mainstream and the special system for disabled child. The reasons of refusing were the inexperienced administration of special education, and the afraid of burden that was from the unable learning of Down syndrome's child in the normal instruction. Those were related to the global education based on modern science that believed in cause and effect principle, rule of progress, universality, regularity which all have affected to the belief of education management and quality of life since the 17th century. The universal concept aimed to create modern children regardless human difference like physical disabled and intelligence limitation. The abnormality was placed outside the area of normal child, so education theory ignored the children who were not included in normal criterion (Freud, 1938, Froebel, 1904; Piaget 1950). Up until now Fugu (1973) criticized the concept of Universal Child Nature, the primary of education management and mentioned the child difference who needed special requirement. Therefore, educational theorists and practitioners had seriously reviewed the instruction of given standard deviation (Elkind, 1998). However, the new concept of education has been accepted that the special needs differentiated from norm.

The midst of 19th century the school of disabled person was established in Europe, but most people were against and rejected the school since the society didn't accept the abnormality which caused the unavailability of facilities for disabled person. After WWII, the physical disabled and mental disabled person as well as normal person had to work and study at the same time. The contradiction was accepted by a special course and special needs instruction for disabled person, however, the attitude toward them still remained. The family with physical disabled or mental disabled person inevitably confronted the emotional critic. Many parents blamed themselves and abandoned their children. In 1940, a group of disabled people was set up in the U.S.A. and the Individuals with Disabilities in Education Act (IDEA) was carried in 1975 which was about education right for special need children contributed by government. It was a sign of requisition for disabled person's

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acceptance without discrimination. In 1994, the Salamanga Bulletin was announced in the world conference of Spanish government and UNESCO held in Salamanga. The bulletin covered the principle, policy and practice for special need education, particularly, the standard regulations of equality for minority in accordance with interaction declaration of human rights and world declaration of multitude's education (Office of the National Education Commission, 2000).

In the beginning period of special need education, the schools for disabled child were set up because of rule and regulation, this was also adopted in Thailand, but a separation of disabled child instruction still appeared. In the postmodern era, which accepted the child distinction, there was a mainstreaming education (Elkind, 1998). Thailand absorbed this influential idea and then declared the education rights for disabled children as policy in Thailand constitution A.E. 2540 and in Nationa Education Act A.E. 2542. They were also concretely appeared in government policy and Ministry of Education's policy with the statement "Every disabled child has a chance to go to school", the policy has been implemented up to present. Nevertheless, in reality the disabled children aren't practically accepted by most schools. In 2542, there was an increasing in school admission for disabled children, however, decreasing later as June's case , that period she could study in pre-school level but the management refused to further her study in primary level. Her parents concluded that it seemed to be just a policy but not a real awareness to the disabled person.

Moreover, the instruction was a kind of separation between normal children and abnormal children, a test was created to select the children. The psychologist used a criterion of IQ 80 to identify retardation regardless their family background. The different background affected the cultivation and chance of children development. Most Down syndrome's children who were from poor family were lace of opportunity to participate the same class as normal children did. Linda and June were averaged when they applied in school, her parents couldn't find any school for them because of the poverty and barriers of some school. The opportunity were less for Down syndrome's children with regards to the studies found that in 2537, there were 34.6% or 1.2 million people were not been prepared for pre-elementary education which were the group of poor children in urban, poor children in rural,

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minority, children impaired in physical and in intelligence. Although primary education was the national curriculum, there were many children couldn't reach as found that 6.2% or 400,000 children were uneducated for national curriculum. Most children didn't have a chance to study because they were poor and lived in distance, some were wandering, some were refugee, some were stateless, some had physical problem or intelligent problem, for instance. The 7-14 years old disabled children were approximately 100,000 and only 5% of them were educated either in special school or attendance in normal classes, therefore, there was a conflict of polity and its practice for disabled children.

Consequently, the family of disabled child confronted the complexity of problem caused by illness and the expectation made up by society. The public announcement about disabled education's right constructed hopes and perception to the family but they were finally upset with the untruth of policy. They were suspended among the conflict, pain, and anger because their children were unsatisfactory to the society. Some of Down syndrome's children, thus, were looked after according to the family condition and environment which failed in development and learning. Linda, for example, couldn't go to school as her age was due, she learnt slowly and wasn't taught to live with society, in addition, she was left alone as her mother didn't have time and she often was physically abused. Therefore, Linda was an aggressive Down syndrome's child, dirtiness, unable to communicate to others. In corresponding with the studies, in Thai society that low educated and poor mothers would have children less developed in linguistics, social relationship, and self-minister (Nittaya Kochapakdi, 2541).

8.2.7 Religion and normalizing suffering to be reality of life

The results found that the Buddhist beliefs and other belief in society have had influenced to way of life of Down syndrome's child family for example, the explanation the cause of poverty, the cause of having Down syndrome's child and suffering management of living with Down syndrome's child. The most relates to religious belief that the suffering is ordinary of life and has always occurred to everyone. Moreover, the belief of "karma" which human can't avoid and must

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compensate for the new or the better life as in belief of June's, Kong's, Bengi's, Bass's, and Kaew's mother. This belief fixed the suffering of having Down syndrome's child to be the reality of life and lived experience. As in the Buddhist belief that "Thukka" is the undesirable condition (Phrarajchaworamuni, 1985 : 99) and all form of unhappiness. (Phrathampidhok, 1995) Thukka exists and appears in the principle of truth (Ariyasajsi) that the first truth believes that the life surrounds with twelve kinds of suffering. And none has never had suffering. (Fisher, 1997) This truth is taught and repeated to make the people belief that the suffering is an ordinary. So confronting the scarcity, and the burden of living with Down syndrome's child are the ordinary suffering.

For belief of "karma" of the result of practice, it includes both good and bad practice. However, in general belief of Down syndrome's mother always describes "karma" in the meaning of bad practices or undesired practices. So the suffering and the scarcity of having Down syndrome's child, discrimination and inaccessibility to health services and social welfare are accepted that they are ordinary life of the poor. This is the effect of religious belief, karma, that continuously has constructed and impressed in the way of thinking till the present time. Under this belief, the poor mothers of Down syndrome's children have not questioned to the disadvantage of political and economic structure which made them suffer. They were fixed with the poverty and the suffering that blinded the reason why they were disadvantaged so that they had yielded to the oppression, avoidance and struggle for another alternative even though they could not access to the public health care service according to their rights.

8.2.8 Suffering on the sexual exploitation

The phenomena of sexual disadvantage in Down syndrome's family clearly points the sexual dominance with patriarchal ideology. As the lived experience of women from the childhood till having own families and having Down syndrome's children, they were in the amidst of the unequal relationships between male and female. The explanation of the sexual differences comprise of these follows; Firstly, the biological and physical differences are the division between male and female i.e.

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womb, skeleton, nerve system and brainy size. Secondly, the psychological differences are emotion and feeling and judge the women by the nature of perception , emotional support and being the artist better than men while men have had more the rational nature than women. (Tigers and Fox,1971) Women endure to do the order and platitudinous work and they have had the passive characteristics and the instinct of giving happiness to other, because of the motherhood instinct. (Jacklin, 1989) In other words, Mead (1963) remarked that the different characteristics related to the culture that made either the similarity or difference. Thirdly, the primary socialization or the cultural reproduction produces the sexual difference. It has been accepted by the social institutions i.e. family, educational, social, economic, political, regular and social control, religious, health and mass communication institutes.

In case of Afifa's and Sor's mother, they are in Muslim family that limits and discriminates the daughters to have higher education like the sons. They must learn how to do homework and earn money to support the education of the sons. The different division of status and sexual role reveals the distinct discrimination as the appearance in the past law. It reflects the basic assumption that women are as an object which depend on men who are as the owner. (Sawang Boonchalermwipass, 1999 : 55) Thai society is one of the Asian country that has highly had the sexual difference and the unequality**.** (Passorn Limanont, 2001 : 25) In case of Nuey's mother, she suffers with high responsibility in many ways i.e. pregnancy, giving birth, working both in and out of home, and look after her children. Her husband didn't help or lighten her burden and nothing support. But her husband has disadvantaged her by threatening and squeezing her money for drinking alcohol with his friends without any responsibility. Bass's Mother is the same case who confronts the hard responsibility to the amount of debt of her husband. She has worked hard to earn money for paying back the debt. She can endure to the hardship life except the unfaithful husband who has had the other women. Similarly, in case of Afifa's mother, she works and looks after her children alone because her husband has the another woman which was assured by the religious rule. Moreover, she decided to do sterilization even though it has violated the religious rule and stigmatized her for ever and ever. These results clearly show the sexual difference. Simon de Beuvior (1989, cited in Varunee Purisinsith, 2002 : 47) mentioned to the inferior and being the other

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of women which was not because of the biological difference but the social condition made them to be the other as these followings.

1) Different life and opportunity in childhood

The educational opportunity of boy is higher than girl. It's because of the womanhood that provides the different role so that women mostly has finished the primary level, working in home and get married when they were young. Afifa's and Sor's mother has finished only in the compulsory education and help their parents to earn money and promote the higher education of their brothers. Feminist reacts to this unequal issue that the intelligence or brainy size of women is not different from men so women can study in the high level too. (Parichart Valaisathien et.al., 1998 : 87) Starving the educational opportunity of women is the divisible ideology which provides the women way of thinking that they are as "the back foot of elephant" and domestic ideology. And their labor and work are devalued in different value. According to the educational data of Thailand, it reported that the educational regulation had effected to the educational proportion nearly one hundred percent in the compulsory level and its rate decreased in the secondary and higher level. Moreover, the proportion of men had education higher than women. (Passorn Limanont, 2001 : 77, National Statistical Office, 1994)

2) Virgin Ideology

Thai women were socialized to conserve their virgin or brahmacharya. So women must conserve their brahmacharya till the time of marriage. To infringe this rule or behave out of social norm, women will be condemned and stigmatized to be promiscuity and vileness as in case of Boss's and June's mother. They had been felt guilty for prematurely pregnancy before get marriage. They had lived with unsecured life , hopeless and unhappiness. Similarly for Nuey's mother, she was pregnant without the responsibilty of her boy friend. Though the premature pregnancy has not the tradition of strict punishment as in many countries i.e. Bangladesh, Pakistan and Turki which has the belief and tradition of "killing in the name of honour" for the adultery who has sexual relationships before marriage. (Watcharint Patjakevinyusakul et.al. 2003 :40) But in Thai society, the punishment always stigmatizes by gossip about her behavior that suppresses women to keep in guilty. On

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the contrary, men has had several sexual partners without guilty but they feels that this strengthen their masculinity.

3) Sexual exploitation and Violence

The biological disadvantage of women whose have womb and pregnancy, is the inferiority which make them easy to control by the social rule. In general, the promiscuity of men was more accepted than women and according to the some religious rule that let men have many wives without condemnation. Contrarily, it became the advantage of men and also conserve their power in the patriarchal society. This is unfair for women who must confront to the physical and mental suffering and sexual disadvantage as in case of Afifa's, Linda's, and Bass's mother. Accordance with the study of Nichter (1997) and Pensri (1997) found that the problem of reproductive health and unequal relationship in family were from the sexual behavior of male, and using power of male to control his spouse and including the irresponsibility of male which had impacts to the quality of children life. (Chanpen Chuprapawan, 2000 : 108-109)

Moreover, the results found the problem of double standard that appeared in the birth control which women were the target. This result is consistent to the country situation that 95 percent of using family planning services are women (Passorn Limanont, 2001 : 138) and the most of them response to their pregnancy though it's undesirable. The results found that at least three mothers, Namwan's, Nuey's and Linda's mother, attempted to abort by themselves with the pills and anyway without consulting to their husbands or anyone else because they had accepted their missing on controlling birth. Otherwise, women perceived about the attention to the sexual relationship more than further thinking to the pregnancy and giving birth. So women have submitted to the responsibility of pregnancy and pregnant termination. Women had confronted to many risks of pregnant termination by several dangerous method, such as scratching the fetus during being in fetus, getting pills and etc. Women have less concerned to the health impacts and the further consequences.

More than the above mentioned, the double standard ruthlessly treats women as if they and their Down syndrome's children are not human life. This can imply with the communication and the suggestions of the clients to mother to

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permit the sterilization to Down syndrome's children. The sterilization bases on the protective thought to the sexual violence. Most of mothers agree with the clients to do for protection the coming social problem. As in the narrative of Bengi's and Kaew's mother that "when her daughter is grown up, she will sterilize her or cut off the womb". These perceptions were the cruel operation to women and clearly showed the operation of patriarchal power.

4) Domestic Violence

This study found both physical and sexual abuse. The physical abuse by the husband found in family of Linda and Nuey and the further event was the sexual abuse. These problems accord to the study about the domestic violence to the women in Thai society during 1999 to 2002 (Krittiya Archawanitakul, et.al. : 2002) found that 40 percent of the partnered women or the ever partnered women had ever been abused either physical or sexual in their life ,and 13 percent had only sexual abuse. In case of Nuey's mother, she told that it was not worthwhile to discuss the matter because it would not be any social interference. The domestic violence had always been perceived that it was the ordinary of family. So it was not surprising why the neighbor, policeman, and the people neglected to the domestic violence and marital rape. Even though the society has had law about marital rape but it could not effectively protect the marital rape. The married women of the most society have been accepted the status and role of wife which one role is the sexual relationship with their spouses. So many mothers who were raped and abused, they could endure in silence under the discourse of family, motherhood and the dominance of functionalism. One mother said that "her duty was for her children, she didn't want her children have any problem from divorce so she must endure". According to Mahoney & William 's study (www.nntr.org/research/pv/pv-ch5.html), they said that those women thinking are the illusion and the wrong belief about the role of married women and domestic violence without any social concern. To yield to the privacy of domestic violence of the people and the same thinking of policeman are the problem to the women disadvantage from past to present and may be the future. The status of women in Thai law and the real phenomena could confirm and clarify the patriarchy of Thai society. (Prissara Saekuay, 2001 : 25)

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5) Women Status and Role

The results showed that the most care givers are female such as mother i.e. Rung's, Nuey's and Linda's mother and grandmother i.e. Afifa's and Bass's grandmother. These results has accorded to the study of Wimolrat Puwarawutpanich (cited in Falida Ibrahim, 1996 : 21) which found that the most care givers were mother, grandmother, aunt and older sister of Down syndrome's children. This event has reflected the division of labor as the sociology of family. Ruth B.Dixon (1976), the American sociologist had repeatedly described the family function, especially the single family, that it composed of three functions; sexuality, giving birth, and nurture. However these functions always be of the women.

6) Woman is low waged labor

Rural women had moved to the city and transformed from peasant and farmer to labor in the industrial and service sector. Though they work as hard as men, but their wages were lower than men. Nuey's mother had ever worked in the construction cooperation and she was treated differently and got low wage if compared to the wage of men. The different wage between women and men are stipulated in labor law and in practice. The labor law has provided the minimum wage which men will gain more than women. It accords to the survey data in 1990 that 67 percents of women aged more than 13 years were participated in economic system (UN ESCAPb, 1996) but they had low income which was very different if compared to the higher wage of men. Moreover, women have hardly gotten the social welfare and labor insurance because the employment always be within the household. (Thanachak Yenbumrung, 1999)

8.2.9 Down syndrome and death without weeping

Pond's mother who her Down syndrome's child was dead, didn't present any sadness or weeping for the loss. It is unusual and can be noticeable as death is a major concern of human. For Pond's mother, she only feels nothing but also smile on her face when she talks about her life. Silence and non-weeping are the symbol of social affliction that is so embedded that it because insensible. Likewise,

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the study of Nancy Scheper-Huges (1987) stated that the pain was embedded in Brazilian women's daily life which were hunger, death, loss of notion, emotion, feeling and expression. They were in complicated structure such as industry, sugar cane farming, laborer, consumer in the vicious sugar cycle that caused famine, food scramble both in the family and community, madness of hunger, thirst, and deadly misery. As were in his speech, "No other calamity has quite the shattering effects on personality and behavior as the experience of acute hunger", and "my life would not be on of suffering and misery…He was like a mother to me." In a land of famine, there was a fairy tale of mother and her dead infant because of her abandonment which Nancy Scheper-Huges (1990) proved that actually political economics took advantages on the emotion presented by a poetry. Love of mother was absolutely determined by economic and cultural constraints, it wasn't supernatural but it was an output of social and cultural structure. Therefore, love was a puzzle and danger that led to murder and presented through a fairy tale.

The performing reflection of economic and political influence against a woman's conception changed a merit love to an insensible love. It was a pain embedded in emotion, feeling, and soul of womanlike and motherhood; a symbol that difficulty reflected or interrelated to structural domination which intervened mother's life and feeling. Pond's mother, a 26-year-old woman, had experienced all difficulty for getting education, family broke down, immigration with others, recognition of parents separation, recognition of stepparents, no rights to be citizenship, sexual harassment, self-earnings since young – these situations formed a difficult life. She was challenged the society by being pregnant since young, having many partners, doing abortions, bringing up her own child who was born without intention, living in desolate buildings and being a prostitute. Her life was risky and unsecured, she felt nothing to be more hurtful. An ID card and citizenship were not important for her so a Down syndrome's child and death were only simple in her life, besides, death was a way to terminate her suffers. A death of her Down syndrome's child set her free from pain, no sadness and weeping.

A facing with child abnormality and death of the poor (Pond's mother) challenged mother's love. The social pain happened by economic structure, politics and culture against womanlike and motherhood. These influences were unreachable

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for poor mothers to analysis and understand. The idea of CMA can clarify the influence of political economics and culture setting in code and conduction of passive poorer or called social affliction such as verbal development effect in agricultural failure, poverty and no opportunity in society, uneducated status, unprivileged Thai citizenship (no ID card) because of being lack of parent's attention, unavailability of career occupation, social life limitation, sexual harassment, sexual abuse, birth control done only by woman side.

8.2.10 CMA and Postmodernism : Spirits of Resistance and Medical Discipline

This part concludes the CMA concept under Marxist Tradition Model that are important to the influential political economic structure under capitalism affecting social policies and other system like health system, education and environment status, and culture which definitely dominate the lifestyle and thought, especially, the poor get poorer, they are disadvantage by society. Therefore, the concept certainly believes in social structure or political economics factors that exist the dominated power and disadvantages endlessly. The analysis of mentioned direction shows the certain concept as same as the frame of modernism analyzed primarily by structural functionalism, even if, culture are shaped and set up the social relations and identities (Gidden, 1984, cited in Kate Nash, 2001 : 77-92). The identities were formed under the hegemonic discourse that certainly remains unchanged.

Although the study found that capitalism power tried to dominate lifestyle and thought of community, there was a cultural reverse in agency or subjectivity pattern that appeared in the belief instead of pain and moved the passive action to powerful agency. They disclosed the rejection of deterministic model or structural determinism found in structural-functionalism according to the post-structural theorists. Structural- functionalism or postmodernism sights the social life with variety and flexibility that are not only compromise but also the movement of agency with symbolic value. As the structure of postmodern try to strongly dominate and create unquestioned tradition, but in opposite way, where are dominated would happen a condition and weak gap, conflict, and uncertainty for social activities

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(Bauman, 1992, cited in Kate Nash, 2001 : 77-92) and influential fight as well as a protest to normalized identities and social relationship of individual or subordinate.

Whilst the CMA concept detected the authority exercise that stopped the poor Down syndrome Child's mother until they didn't have any chance for complex binding. There were only the pictures of pain from power losing, loss of human dignity. We conversely found the power created by mothers that was chosen for cultural means as belief like a superstition which existed in the community without proving or critics. The explanation of Down syndrome's child meant to the precious gift from heaven that came from reliable source and understood by member in society. The new definition flow out from the authority of medicals and society to overcome the disadvantage of stigma that became a special power. Down syndrome child's mothers eliminated their pains with policy believable culture as same as the authority against woman and Down syndrome's children. Referring to Ahwa Ong's study (1987) in Malaysia, it found that the grouped incarnation of working women in the industrial factory, that resisted the capitalism power influencing women's lives both in workplace and in house. To protest and resist the undesirable authority, they used the process of grouped incarnation and this was the behavior which employers and society couldn't criticize but accept and then solve the problem. In Thai society, the explanation of Down syndrome's children with religious belief and new definition that was positive instead of negative, disadvantaged instead of advantaged – the authority movement gave an opportunity for mother's power, so Down syndrome and death weren't always meant to pain.

Conclusion

Women's suffering or Down syndrome's child's mother suffering with CMA concept, which emphasized on economics and social structure analyze, found that poverty was the major factor of the poor. Since the poverty narrowed down their lives and created the cycle of poverty together with disadvantages, for example, the difficulty in financial expectation and social relationship, illiteracy, health risk and less opportunity in society. The above reasons are the basic affliction of their lives resulted by the power of political economic structure of global capitalism in many

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actions and several plans were applied to underdeveloped countries or countries where were the followers of developed countries. So the action plans powerfully exercised through the development practices, health and normality. The criterion regulation - set up by developed and powerful countries which imposed and concealed some hidden economic and political benefits in other countries' policies were dominated by the power of capitalism and masculinity ideology such as economic policy, population policy, health policy, social and educational policy, including the social structure, culture, and health system. Therefore, the society was graded by the rich and the poor, medical personnel and patients, male and female, normal and abnormal child, moreover, the rule and regulation also forced individuals to think and live with standard. Mothers of Down syndrome's child, hence, suffered from the performance of structural power that affected the poor, womanhood, motherhood, abnormality and disability. It was an affliction caused by complex multiple standard that hindered mothers of Down syndrome's child from society and took advantage from them.

Whereas CMA concept considers the discursive practice of perfect powerful structure as a barrier to freely thought and performance for individuals who had homogeneity, the study shows the weak idea that unexpectedly flows from powerless person to self-empowerment. The more variety accepts, the more empowerment employs. For this reason, the disabled children and Down syndrome's children have chances to highly present their potentials, capabilities, and civic rights in public such as Poor Assembly, Health Assembly and Disabled Assembly.

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CHAPTER 9
RECOMMENDATIONS

9.1 Recommendations to practiced

9.1.1 Health Care System

1) Pre-caution System to elder-age mothers to be careful in pregnancy by Mental Health Department of Public Health Ministry and the related division including healthy service units on each level should publicize and provide data and knowledge to elder age mothers to prevent and precise pregnancy in a broad way by using mass media to people who are in the risk of having a Down's syndrome child.

2) Both nursing homes and homes' care of public and private at all level provide pregnancy handling system of risky group of age 35 year old. Also the other groups are in the precarious. The homes implement an abnormal condition system on each level per its potential. There are also providing continuation system to decrease processes and expenses. To assist the risky woman group who are poor status, inaccessible to secondary system. Community hospitals are able to supply in the case like an ultra-sound inspection. It may be less sensitive than a down's syndrome case inspection directly. At least it could guide to inspect at a risky condition state if it was found for preparing to a higher level.

3) All nursing homes should public and extend knowledge and comprehension widely It helps to support their decision making most especially for a risky group. Not less than three power of choice need to be given : 1) System to provide knowledge to inspect watery searching for an abnormal condition ; 2) System to provide some advice to abnormal groups to have decision to continue or break their pregnancy. System must be transferred all dimension of data to allocate their mind at encountering in a difficult state of making a decision and conflicting between culture and morality and 3) Readiness system to help parents in case they would continue to

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have a pregnancy even in the case has been found. In order to provide knowledge understanding and encouragement parent mind's condition to look after a down's syndrome child.

4) Department of mental health, Ministry of Public Health and the concerned division should systematize in modern, flexible and comfortable ways of consultation such as setting phone hotlines, web-page data and internet access services.

5) Nursing Home should provide ending pregnancy services for pregnancy women whom the abnormal cases were found. From the study discovered that majority of down's syndrome mothers agreed to be determined. Whenever the cases were found should terminate pregnancy earlier. So the system services should be designed to allocate mothers to gain freedom of choices in a decision making.

6) Public Health services in ANC(Anti-Natal Care) should gather unusual detection information. For the low-class level people in preventing more problems to come after could be sustained by a part of ANC basic services or 30 baht project for all disease treatment.

7) Both of public and private nursing homes should organize data and consultant to down's child mothers including other abnormal children to help them and families having correctly perception. The name of "slow rate development" would be better than "down's syndrome" or other names. In the comprehensible meaning to bring hope and love to mothers and families in living with a down's syndrome child. Simultaneously, to share more apprehend between a down's syndrome child and or a child as lacking of Iodine element.

8) Public nursing homes at all level should do medical care on the basis of human right deserving the right to be taken care of. As of down's syndrome and common factors need special doctor more than normal children. Therefore, the public need to mostly share the right of healthy services to them in the tertiary level including physiotherapy services from the beginning of life.

9) Nursing homes necessary to have in-house-visit system to follow child patients getting properly development to look after their own self as it should be.

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9.1.2 Developing potential of Nursing home services

1) Ministry of Public Health should aid resources of primary and secondary level more effectiveness to watch out seriously. Mostly, low-class level mothers firstly often access to primary level. So the public should distribute most instruments at secondary level to allow them for services effectively and equally.

2) Under 30 baht project , Ministry of Public Health need to develop potential of primary-and secondary level services in providing develop services. Responsible person would have a strong knowledge background to give an answer to poor mothers feeling confidence and decreasing their expenses in other services.

9.1.3 Information System

1) Mental Health Department, Ministry of Public Health and Department of Public Welfare should coordinate activities to update data basis and classify deformation and syndrome by using modern information technology system. It would be used as an easily-access research base for interest person. Also the concerned divisions could apply to alert condition, managing of welfare and benefits. Mental Health Department, Ministry of Public Health develops indicators linking with previous data information. The department needs working together with other public division to regularly bear national survey. Adding up indicators in a basis survey forms once a year survey form in a village survey level, every 2 years survey in a country development survey,, the survey of health by Office of the National Security Council, the registration of disable people of Department of Public Welfare, and services data of every nursing home at all level. Finally, it needs to update data continually.

2) Mental Health Department, Ministry of Public Health should unite data network to enhance a unity. To apply it more useful in planning of service managing deserved benefits effectively. Considering Thai society remains delivering problem in statistical data. From the data base of Office of the National in 1998 found disable people 13 percent or 1.7 million people. But the data of Public Health Association of Ministry of Public Health surveyed in 2003 found disable people 81 percent or 48 million people. There are significantly different. It caused to have

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difficulty in an operation planning. Equally, disable people registration of an act of retrieving disable people in 1994 found 296,376 people or 28.04 percent of National Statistical Office in 2004 and 6.17 percent of Thai Health Institute.

3) Health Institutes should afford quality information system. They offer to support various media in research and facilitate a service corporation as their necessary basis. For examples, the information area an inspect confirmation note, an inspection report note, a disability people registration form, developing practices in a nursing homes and caring for different symptoms

9.1.4 Mass Media and Community Corporation

1) Health Institute should develop to support system using to supply healthcare at home. As a down's syndrome child in long term need to learn on a mother or close relatives taking care of at home. For those poor people that have encountered some difficulty in services and discontinuity. Therefore, health institute and a medical provider ought to emphasis on knowledge and skills of a medical provider in getting more understanding. It would be created and implied surrounding. They are suitable for health development of a down's syndrome child higher potential. For instances, building simply instruction mediums, producing common equipments in low costs for developing practices and in-house visiting to provide a consult for environment improvement to the child are to be furnished.

2) Since a lot of number of children in services of any Nurse Homes should gather groups of down's syndrome families in one center division to meet ,exchange experiences and reinforce mothers and care taker including activities in parallel with perceiving condition of a down's syndrome child for both social and economical context.

3) Nurse Homes should acquire network between both direct and health divisions. For examples, division of Welfare department and Compulsory Educational Department create in between the proper basic need and the welfare suitably.

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4) Nurse Homes of down's syndrome children should originate network with nurse homes near a community and leader of the community to transfer information and follow up the cases.

9.1.5 Social Security System

1) Ministry of Public Health need to publicize how important to have a social security card. Organize issuing card system to the poor people whom are resettlement and no permanent houses. To have at least one type of a social card, either a 30 baht social card or a disable social security card.

2) All nursing homes need to organize the quality system to respond the basic need especially development practices to decrease for expenses of other services and unnecessary.

9.1.6 Human-resources Productive System of medical and public health

1) Education course reform in medical and public health institutes should stress on health as a whole not to separate physically mind and soul from each other. It will get some ideas explaining in the view of patients and relatives. It could stand for the basis of prestige and value of human being. The practices are as follow:

- Medical Institutes should add more units in sociology and anthropology subjects both in pre-clinic and clinical period. For instances, health behavior, sociology, medical anthropology, academic health communication and ethics subjects. At the present study about 12 units from the total of 245 units, too less. The said subjects are often studied in Pre-clinic or first year. It should continually study in higher years.

- Medical Institutes should nourish human resources of medical-general practice/family practice to adapt attitude and thinking method of a physician. The institutes allow to provide illness viewing as a whole unit.

- Organizing of medicine student education experience in a type of community base especially in less opportunity community. To shape understanding method of patients or ailment cases under patient's attitude and complex problem which related to illnesses.

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2) Human resource institute of Public Health Ministry like Boromarajachonnani Institute the College of Public Health. The institute should produce more clinical psychologists or psychiatric nurses, community nurses and public health personnel as the trend of problems are increasing. Oppositely, the amounts of medical providers are less. The ratio is 1 to 80,000 in Bangkok and 1 to 60,000 in provincial area.

3) The institutes of Public Health Ministry including higher education institute had better given priority to the contents of course with new vision to health and learning processes to a down's child and disable person sympathizing with respect of prestige of human being.

4) Mental Health Department of Public Health Ministry and higher education institutes should care short-and-long course training in clinical psychiatry to all level of human resources to create a new vision of health as whole, develop working techniques, establish good attitudes and conscious mind to work and listen to the need of patients whom are disable and uncompleted development of mind limiting in access to the services.

9.1.7 Social Welfare Development System

1) Social Welfare Department of Interior Ministry should corporate with Ministry of Public Health to set up data base and system to help disable people by assigning to public health unit in which is the basic unit for health services organize data base supply to welfare system of disable people. Trying to decrease steps to be most convenient for medical provider of a down's child.

2) Ministry of Education by special and compulsory education should prepare education of down's children in a type of helping and developing person and family level. By working with public health expert personnel help to manage suitable education.

3) School under Ministry of Education in each area should design learning courses. On account of the condition of environment relate to reformation policy of education in the goal of the constitution of Thai Kingdom in 1999 and law of national education in 1999. In this year, Ministry of Education clearly declared to be the year of education of disable people. It said "Every disable people who wish to study he

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will have the education for those wishes". The revised paper no.2 in 1999 of law of compulsory education and in 2001 of policy and practice in receiving disable and less opportunity children of school under Office of the basic Education Commission.

4) Ministry of Interior should agree and corporate with Ministry of Education strongly to support schools in guiding education by 2 types. First one, for special schools of disabled children who are not able to participate with other normal children obtaining numbers of 10-15 students per classroom. Second one who could study with normal children depends on school readiness. But if the school could not prepare studying in this case. It needs to act with special education division. Therefore, education policy of special children would have a goal intelligibly. To strictly maintain special or less opportunity children is done by taking in them to educate especially at the level of education basis.

5) All relevant division of public health, welfare and education should generate good welfares, advices and helps to bring a chance to select a way of life in society.

6) Readiness School for disable children should focus on "mainstream schooling" (down syndrome's child study with a normal child) and devise special education or alternative education. Most of experiences found that down syndrome's child living with normal child could have better growth than not living with them. The studies were attained an effective programmed of development since an early childhood helping them to have learned experiences being happily in society.

9.1.8 Creating social environment

1) All school are necessary to have responsible to put up knowledge to people understanding the syndrome not to bias a down's child but having sympathy, gentle kindness to respect human dignity.

2) Mass communication system should distribute in all types of communication entertainment, a life feature and information. The contents should to be considered to effect to comprehension and attitude adjustment in a path of acceptance without any prejudice.

3) Religious Institutes should play a role of responsibilities and do work with disable people. To reveal virtues offer the disable people a better

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opportunity in society. Creating helpful activities together with attitude adaptation pass to especially for the poor people. For instances, setting up organization and social welfare home apply to them. Act of aiding to be alms-give to the poor also conduct social atmosphere without any obstacle to a down's child.

4) Community public health division should train and developed potential of community leader in both knowledge and understanding about a down's child and other disability children. To take precaution, embody and give an advice to the families.

9.1.9 Grouping of down's child families

1) Public Health service division of Ministry of Public Health in which have down's child family association like Siriraj Hospital should provide data base system to help and follow down's child continually. Then it needs to educate and expand activities to be more known in public in order to a good attitude to down's syndrome children.

2) The effective public health services division. If there are many people encountering the services, the institute should set up down's child club. It will help gathering families to participate in activities, learning and helping each other in a kind of self-help group.

3) Rajanukul Institute under Mental Health Department of Ministry of Public Health should be host in corporate between clubs network or some division in regard to with down's child to be know I a society.

4) Rajanukul Institute under Mental Health Department of Ministry of Public Health and Club of down's child of Siriraj Hospital as it s a potential institute should organize National Down Syndrome community. Since last 20 years ago, in the world community collected medical providers as doctors, teachers, psychiatrist and developer to help down's child. Having world meeting about the content to develop the way of down's child care providing to live with normal people in society. So to organize community in national level to link with world level to push law and the right of down's child should be deserved from public and society.

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9.2 Research Suggestion

9.2.1 Regulation of research

1) To support research in practical of community level to find out common part of disabled people.

2) Study research in practical in clinic or nursing homes to have suitable services get along with the disabled people.

3) Compare the effectiveness of common study (disabled children study with normal child) to be base for public to expand proper education for down's children properly.

4) Study appropriately of quantity analysis expenditure of caring down's child.

5) Research document about direction and policy in acting upon disabled people from foreign countries and ours. It helps to compare alikeness and dissimilar use for suggesting direction and policy of Thai government working.

9.2.2 Targeted Group

1) To implant intent in filtration of abnormal cases to the high-risked women group (35years up) to confront the case and service for pregnant women of high-risked group to be use as data for the risked group.

2) Experienced women were found an abnormal case and made decision to pregnancy and having a down's child. It will imply the data to apprehend unhappiness for the risked group of pregnant women.

3) Good status to understand context, meaning, managing sadness of down's child to compare different in managing sad ness and use in directing of develop services exactly as the need of each group.

4) Group of concerned person- psychiatrist or practical teachers, regular teachers from special education institutes, managers of education institutes, doctors and nurses to study the problems and obstacle services to down's children.

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5) Family member-father, cousin by studying comprehension and effect to as being together with down's syndrome including support from member that effect to down's child and encouragement.

9.2.3 Theory

To study and analyze with the structural-functional theory is to understand structure and role of related division to services. To aid down's child and disabled children including other obstacles leading to improve systems responding to more problems.

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APPENDIX A

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APPENDIX A

Comparative epidemiology of Down Syndrome in each country

Authors	Area	Period	Results
Egan JF., et al. (2000)	United States	1974 to 1997	In 1974, the estimated second-trimester prevalence of Down syndrome was 1 in 740, but by 1997 that had increased to 1 in 504. The proportion of Down syndrome fetuses at 16 weeks´ gestation in women 35-49 years old increased from 28.5% in 1974 to 47.3% in 1997. However, live births to women 35-49 years old increased more rapidly from 4.7% in 1974 to 12.6% in 1997. Serum testing of all pregnant women would reduce the number of amniocenteses and decrease procedure-related losses.
Bishop J., Huether CA., Torfs C., et al. (1997)	California, USA	1989-1991	The observed prevalence was 1.13 per 1,000 live births, and the adjusted total prevalence, which including the termination of affected pregnancies following prenatal diagnosis, was 1.53 per 1,000 live births. The risk rates by race between Hispanics and whites differed significantly. Attribution to prenatal diagnosis and elective abortion of affected fetuses was 25.8%, with a 49.1% reduction being observed at maternal ages > or = 35 years. Hispanics had the lowest overall reduction (10.0%), while whites had the highest reduction (46.3%). The findings indicate that prenatal diagnosis and elective termination of affected pregnancies has had a substantial impact in reducing the number of live borns with Down syndrome and live births with Down syndrome should be considered minimal because of some under ascertainment of prenatally diagnosed cases.
Krivcheni a E. et.al. (1993)	southwest Ohio and metropolita n Atlanta, Georgia, USA.	1970-1989	The expected data of the Atlanta white data set was 1.27. If excluding aborted fetuses with Down syndrome diagnosed prenatally, the observed incidence of Down syndrome was equal to 0.98 and when adjusted to include aborted fetuses with Down syndrome , the total incidence was equal to 1.17. Over the decade, the prenatal diagnosis had effected to the selective abortion and increased the termination of fetuses, selective abortion with Down syndrome.
Freeman, S.B. et.al. (1998)	Atlanta, Georgia, USA	1998	Birth prevalence of down syndrome was 0.96/1,000. For diagnosing the cases, 44% had congenital heart defects (CHDs).

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Authors	Area	Period	Results
Forrester MB., Merz RD. (2002)	Hawaii, USA	1986-97	The total prevalence was 14.74 per 10,000 live births and fetal deaths. The unadjusted live birth prevalence was 8.67 per 10,000 live births. The adjusted live birth (effect of elective terminations) prevalence was 12.59 per 10,000 live births. The total prevalence per 10,000 live births was highest for Far East Asians (22.01), followed by whites (17.06), Filipinos (15.94), and Pacific Islanders (9.21). Prevalence per 10,000 births was higher in metropolitan Honolulu (18.57) than in the rest of Hawaii (14.15). After adjusting for maternal age, however, the differences within the demographic groups were not statistically significant. The live birth prevalence of Down syndrome was lower than reported in the literature and the differences were appeared to result from differences in maternal age distribution
Lai F.M., et.al. (2002)	Neonatal nurseries in Singapore	1993-1998	There were 295 Down Syndrome livebirths, four stillbirths and 197 Down Syndrome foetuses aborted. The increasing number of Down Syndrome foetuses diagnosed antenatally ending in termination and this is accompanied by a falling trend in the Down Syndrome livebirth rate in the same years from 1.17 in 1993 to 0.89 per 1000 total live births in 1998 which due to antenatal diagnosis and selective termination.
Sheu BC., Shyu MK, Lee CN., Et.al (1998)	Taiwan	1975-1995	The study was used as the age-specific distribution of women who had unaffected pregnancies. The total live births were 7,232,689 cases and 527 cases of Down syndrome live births were registered by Down Syndrome Association. A total of 466 cases (88.43 per cent) of Down syndrome live births occurred before age 35, which was higher than occidental reports. This study established the first sizeable database of maternal age-specific risk for Down syndrome in an Asian population.
Hoshi N., Hattori R., Hanatani K., et.al. (1999)	Japan	1980-1997	1,299 consecutive DS infants were born among a total of 2,232,694 births, a rate corresponding to approximately 10% of all births over the same period. The increasing risk of DS with advancing maternal age was confirmed. The overall prevalence was 5.82 DS births per 10,000 livebirths (8.3-9.7 per 10,000 after correction according to the estimated ascertainment ratio: 60-70%). The prevalence rate by year of child birth represents a statistically significant increase (P = 0.001) and in this period, recent trends of the prevalence of DS failed to show a consistent tendency to decrease, probably because of the concomitant increase in pregnancy in advanced maternal age.

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Authors	Area	Period	Results
Zhang SZ, Xie T, Tang YC., et.al. (1991)	Sichuan, China	na	the prevalence of chromosome diseases in Sichuan was 31.5 per 100,000. The prevalence of DS was 14.2 per 100,000 for the total population, and there should therefore be 154,000 cases of Down syndrome in the whole of China with its population of 1,100 million people.
Nazer J., Eaglin MA., Cifuentes L. (1998)	Latin America : University Hospital Maternity of Chile	1972-1997	Both the birth rate of Down syndrome and mean maternal age increased significantly with slopes of 0.13 years of age per year and 0.05/1000 born alive per year, respectively and comparing both rates, the prevalence rate increased in 0.31 per 1000 born alive per year of increment in maternal age. a higher prevalence rate of Down syndrome than in previous periods in the same maternity, was found. The influence of maternal age on this prevalence was clearly established.
Staples AJ., Sutherland GR., Haan EA., Clisby S. (1991)	South Australia	1960-1989	The incidence of Down syndrome at birth for the study period was estimated to be 1.186 Down syndrome births/1,000 live births and if current trends in the maternal age distribution of confinements continue, the population incidence of Down syndrome is predicted to exceed 1.5 Down syndrome births/1,000 live births during the 1990-94.
Cornel MC., et.al. (1993)	Northwest European countries : Netherlands	1992-2001	The predicted livebirth prevalence in 1992 is 1.36 per 1000. Demographic factors will cause an increase to 1.76 per 1000 in 2001 with present indications for prenatal diagnosis and a utilization ratio of 50%. An increase of the utilization ratio to 90% in 2001 will lead to a prevalence of 1.22 per 1000, a little less than the present prevalence. Alternative screening programs, including maternal serum screening, could lead to a further decrease of the livebirth prevalence.
Johnson Z., Lillis D., Delany V., et.al. (1996)	4 Irish counties : Dublin, Kildare, Wicklow and Galway Ireland	1981-1990	The crude birth prevalence for the four counties was 18.5/10 000 for all births and 18.3 for live births. There was a fall in the total number of DS births over the decade, but less change in the crude birth prevalence owing to an increase in the proportion of mothers aged 35+. Galway had the highest crude birth prevalence of DS, 23.5/10 000. The risk of having a DS child increased 70-fold from 1:1841 at age 15-19 to 1:26 at 45 years or older.

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Authors	Area	Period	Results
Fryers T., Mackay R.I. (1979)	industrial cities	1971-1975	The prevalence at birth is shown to have fallen from 1.70 per 1000 births in the period 1961-65 to 0.84 per 1000 births in 1971-75. An earlier increase in the number of Down Syndrome children is shown to reflect a greatly improved survival in the first 5 yrs of life. The policies of amniocentesis of older women and termination of affected pregnancies will have progressively less effect on the number of affected children if this demographic trend continues.
Steele J., Straford B., (1999)	United Kingdom	Before 1995	The overall prevalence of Down syndrome was 6.7 per 10,000 general population and prevalence was also presented in 5-year age bands. There was no indication of a sizable reduction in the future Down syndrome population. The recent reductions in prevalence among the youngest age bands may be explained by changes in the maternal population
Molteno C., et al. (1997)	Cape Town, South Africa	1974-1993	There were 784 Down syndrome pregnancies and 32 terminations. The overall prevalence rate was 1.49 per 1000 (white 1.88, coloured 1.54 and black 1.29 per 1000). Over the last 5-year period the prevalence rates in all three population groups were 1.3 per 1000. An increasing risk with advancing maternal age was confirmed, but no maternal age-specific differences in rates by race were demonstrated.
Kupperm ann M., Gates E., Washingt on A.E. (1996)	University of California at San Francisco	1993-1994	Latinas and African-American women were much less likely to undergo prenatal diagnosis than were whites and Asians. Trends persisted at diminished magnitude, after adjustment for socioeconomic characteristics. Non-white women age 35 and older were significantly more likely than white women to give birth to a Down syndrome-affected infant: risk ratios for Asians 1.81 (1.61-2.03), Latinas 3.00 (2.74-3.28), and African-Americans 1.86 (1.63-2.11). Racial-ethnic differences exist in prenatal diagnostic test use and associated outcomes in women aged 35 and older. Socioeconomic factors are partially responsible; patient education and preferences may play a role.

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Authors	Area	Period	Results
Woreboer MJ., et.al. (2000)	Northern Netherlands	1987-96	The live birth prevalence, based on the maternal age distribution and the age specific risk of delivering a child with DS was expected to increase from 1.26 in 1987 to 1.62 in 1996. The live birth prevalence of Down syndrome (DS) and the impact of maternal serum screening (MSS) and prenatal cytogenetic diagnosis (PCD) were examined. The fact that despite utilization of PCD based on opting-in and a discouraging government policy regarding the offer of MSS. When MSS was available , the potential of reducing the birth prevalence of DS is limited by the low utilization of MSS and PCD by pregnant women.
Wilson MG., Chan LS., Herbert WS., (1992)	Latino population , Los Angeles County, U of Southern California Medical Center,	1974-1988	DS was ascertained primarily by clinical monitoring of newborn infants. The overall rate of DS was 1.60/1,000 live births and had minimal fluctuation throughout the 15 years. The rate of DS for Latino births was 1.69/1,000 live births, 1.67 when adjusted for maternal age, and 1.75 when corrected for prenatal diagnosis. The high rate of DS in the Latino population was associated with advanced maternal ages and increased maternal-age specific rates for DS, especially in the age ranges of 30 to 34 and 40 to 44 years, when compared with other studies.
Iliyasu Z., Gilmour WH., Stone DH. (2002)	Glasgow , Scotland	1980-96	All registered cases of DS were diagnosed at or after birth plus terminations following prenatal diagnosis. A total of 293 cases of DS were registered over the 17 year period, 198 (68%) were live births, 8 (3%) stillbirths and 84 (29%) induced abortions following prenatal diagnosis. The prevalence of DS was 1.36 per 1000 total births and after adjusted pregnancy prevalence was 1.24. The annual proportion of DS cases diagnosed prenatally slowly increased to around 60% towards the end of the period. The termination rate also increased, especially in younger (under35) women. The epidemiological impact of antenatal screening and subsequent prenatal diagnosis is clear with pregnancy and birth prevalence rates diverging steadily over time since the late 1980s. The rising termination rate in younger women suggests that the benefits of antenatal screening are now extending to the lower risk younger age groups.

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Authors	Area	Period	Results
Caruso TM., Westgate M.N., Holmes L.B. (2002)	urban hospital, Brigham and Women´s Hospital in Boston, MA.	1972-1994	From 1972 to 1974, Down syndrome was not diagnosed in any affected infants prenatally. In the early 1980s, amniocentesis was the primary method of diagnosis; later, maternal serum screening and ultrasonography were as likely to be the first method of detection. Most couples (86%) elected to terminate pregnancies with affected fetuses. The effect of prenatal detection and the choice of elective termination produced a significant decrease in the portion of fetuses with Down syndrome who were liveborn.
Davidov B., Goldman B., Akstein E., et.al. (1992)	Israel	1978-92	In the Jewish population, there was a slight increase in the DS live birth rate, from 1.05 in 1978, to 1.37 DS cases/1,000 live births in 1987, which corresponded to an increase in the prevalence of older pregnant women, from 8.0% in 1978 to 14.8% in 1987. Thereafter, there was a continuous decline, to 0.71 DS cases/1,000 live births in 1992, as a result of increased acceptance of prenatal testing by women > or = 37 years (67%) and, recently, also by younger women (from 5.6% in 1990 to 14% in 1992). While in the non-Jewish population, there has been a very low acceptance rate of prenatal testing so that it has been the high prevalence of DS live births (1.4 cases/1,000 live births).
Cuckle H., Nanchahal K., Wald N. (1991)	England and Wales	1974-1987	On average, the natural birth prevalence of DS was 12.6 per 10,000 births and increased slightly from 12.2 to 13.2 per 10,000 births over the 14-year period. When adjusting of induced abortions, 14 per cent of affected births were avoided by the induced abortion of affected pregnancies, so that the actual birth prevalence of Down´s syndrome was estimated at 10.8 per 10,000 births. And when using data on Down´s syndrome births reported to OPCS under the voluntary congenital malformation notification scheme, the prevalence was 7.2 per 10,000 births
Hahn JA., Shaw G.M. (1993)	California	1983-1988	Trends in the prevalence of Down´s syndrome in livebirths were examined when prenatal screening and subsequent termination of Down´s syndrome pregnancies among women under 35 years of age was increasing. In this period, the crude prevalence of DS was 1.03. The risk ratio for 1988 compared with 1983, after adjusting for maternal age and other confounders, was 0.98, showing that there was no change in livebirth prevalence over this period.

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Authors	Area	Period	Results
Corne. M.C., Breed A.S., Beekhuis J.R., et.al. (1993)	northwest European countries The Netherlands	1992 to 2001	The increasing of maternal age which lead to an increase of the prevalence of DS. Meanwhile, the increased use of prenatal cytogenetic diagnosis (PCD) will lead to a decrease in the prevalence of DS among livebirths. The predicted livebirth prevalence in 1992 is 1.36 per 1000 and will increase to 1.76 per 1000 in 2001. Alternative screening programs, including maternal serum screening, could lead to a further decrease of the livebirth prevalence.
Binkert F., Mutter M., Schinzel A. (2002)	eastern half of Switzerland	1980-1996	Despite increasing prenatal detection rates of trisomy 21 foetuses (an increase of 169% in the last 5 versus the first 5 years of the study period) and subsequent termination of pregnancies, the number of liveborn Down syndrome children remained constant. The reason is a shift towards a higher mean maternal age from 28 to 30 years between 1980 and 1996. If the tendency to have pregnancies at a more advanced age continues and if the use of prenatal diagnosis does not increase, an increase in incidence of Down syndrome liveborns may be expected in the first decades of the 21st century.
Vik T., Borthne K., Johansen OJ. (1999)	Norway	1978-97	Ultrasound examination offered to nearly all pregnant women in Norway may lead to the identification of fetuses with Down´s syndrome. This may lead to termination of pregnancies and to a reduction in the prevalence of live-borns with Down´s syndrome. In a retrospective study of hospital records, the prevalence of Down´s syndrome, associated malformations and diseases during the last 20 years, 1988-97, was 1.16 per 1,000 births and 1978-87 was 0.8 per 1,000 births. The prevalence of livebirths with Down´s syndrome was not reduced in 1988-97 compared to 1978-87 and children with Down´s syndrome have a wide range of somatic disorders and need close and systematic medical follow-up.

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Authors	Area	Period	Results
Raesch C., Steinbicker V., Kropf S. (2000)	eastern part of Germany	1980-1990	The average prevalence in the entire period is 1.0 per 1000 births. In 1997, a prevalence of 1.7 per 1000 births was already observed. After 1990, there is an increase in the prevalence of conceptions with trisomy 21 whereas the prevalence of live births with Down´s syndrome remained the same. The reasons for this are an increase in the age of the mothers and a broad acceptance of prenatal diagnostics. Ethical questions, that might reveal societal changes in the attitude to children with Down´s syndrome and require sociological investigations which cannot be carried out by the malformations register.
Stoll C., Alembik Y., Dott B., Roth M.P. (1990)		1979-1987	The epidemiology of DS was studied in the area which is covered by our registry of congenital malformations. The prevalence of DS was 1.17%;3.6% of the DS cases were stillbirths and 14.4% were induced abortions. . In our material the first-born infants were at lower risk of DS than the later born. The pregnancies of the DS children were often complicated by threatened abortions.
Stoll C., Alembik Y., Dott B., Roth MP. (1997)		1979-1996	The prevalence of DS was 1.66 per 1000; 2.2% of the DS cases were stillbirths and 29.4% were induced abortions.
Lopez PM., Stone D., Gilmour H. (1995)	Glasgow Register of Congenital Anomalies, Scottish city	1980-1990	Over the period 1980-90, 173 cases of DS were identified (1.2 per 1000 births), of which 135 (78.1%) were livebirths, five (2.9%) were stillbirths and 33 (19.1%) were terminations following prenatal diagnosis. The increasing risk of DS with advancing maternal age was confirmed. The proportion of all DS pregnancies terminated showed a statistically significant rise from 14% in 1980-87 to 31% in 1988-90.
Czeizel E., (1988)	Hungary	1973-1982	The true birth prevalence of Down´s syndrome was 1.2 +/- 0.1 per 1000 total births. The rate of undernotification and misdiagnosis was 25% and 5%, resp.

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Authors	Area	Period	Results
Sapek A., Gregor V., Horaicek J., Chudovai M., (1999)	Czech Republic	1961-1997	The mean incidence of DS in born children during the investigation period was 7.91 per 10,000 liveborn infants after prenatal diagnosis and these pregnancies were terminated. When the results of prenatal diagnosis of DS are added the mean incidence was 9.47 per 10,000 liveborn children. The success rate of prenatal diagnosis of DS increased to as much as 60% of detected cases. The age distribution of DS indicates a significantly increased risk for mothers already from the age of 34 years.
Stratford B., Steele J. (1985)	Sheffield and Buckingha mshire		Down´s populations have been critically examined along with factors effecting such populations; i.e. better health care , changes in maternal child-bearing age, under-diagnosis and prenatal diagnosis. Results from these surveys indicate a current overall incidence rate of 4.63 per 10 000 though there are differences between the two areas.
Julian Reynier C., Aurran Y., Dumaret A., et.al. (1997)			It shows that 43% of the 280 DS fetuses had died by the end of the first year of life, owing to termination of pregnancy (27%), late spontaneous abortion or stillbirth (4%), or death during the first year of life (12%). These results show that in some instances parents or professionals feel justified on one hand in not providing DS children with the necessary care and on the other hand to transfer their responsibilities to the public health system. The influence of prenatal diagnosis of chromosome disorders as a determining factor of the social acceptance of DS is still questionable.
Elwood JH., Darragh PM., (1981)	Northern Ireland	1960-1969	An estimate of prevalence at birth during 1960-1969, was of 2.23 per 1000 livebirths. Mortality among mongols born to older mothers was after one year almost fifty per cent whilst those born to younger mothers was twenty-three per cent.
De Vigan C., Vodovar V., VacritAc S., et.al. (1999)	Paris, France	1992-1997	For this period, data of DS from the Paris Registry were 670 cases and 71.0 per cent were terminations of pregnancy .The prenatal diagnosis rate among mothers 38 years and older, all of whom were offered amniocentesis, was 89.9 per cent. Nearly all affected births in this age class followed maternal decisions, either to refuse amniocentesis or continue the affected pregnancy. In younger mothers, the overall French prenatal screening policy led to increase an overall prenatal diagnosis rate from 67.3 per cent to 78.8 per cent in 1997. The birth prevalence, 8.7 per 10 000 births, diminished only slightly over the study period.

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Authors	Area	Period	Results
Op't Hof J., Venter PA., Louw M. (1991)	South Africa	1980-1984	An overall world mean rate for DS of 1,34/1,000 live births (mainly Caucasian) for single-year maternal ages was calculated. Accordingly, 58 cases of DS were expected in the 40-year and older maternal age group in South Africa. Only 34 cases (59%) were detected prenatally and another 24 DS cases in the maternal age group of 40 years and over could thus potentially have been detected prenatally and prevented.
Mikkelson M., (1990)	Denmark	1980-1985	In Denmark in the 1950s, 50% of Down´s syndrome cases were born to mothers over the age of 35. The percentage went down to 25% in the 1970s and was reduced by prenatal diagnosis to 8% in the 1980s. For the period 1980-85, The birth prevalence was lowered for the age group over 35, but there was a steady rise for the age groups below 35. To achieve a reduction in incidence, maternal alpha-fetoprotein serum screening for low values may be a possibility but not primary prevention, of Down´s syndrome is available.
Xavier AR., Carvalheiro CD., Ferrari I. (1978)	San Paulo, Brazil	1972	An incidence rate of 1.66 was determined for Down´s syndrome by a check of hospital birth records in the city of RibeirÃ£o Preto for the year 1972. . The prevalence rate was estimated as being 25.2.

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APPENDIX B

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In-depth interview guideline

1. Let mother narrate her life history and her family
   - Biography of mother, life history before marriage, from young to adolescent , eg. her background, siblings, kinship, family's occupation, religion, education, relationship, way of life etc.
   - emotion and feeling to life experience, Is there any suffering event? What are the factors which have influence to the suffering?
   - How about the life experience with Down syndrome's child and way of think about Down syndrome?
   - Family life : when does it start? How about her husband : background, relationship in family, division of labor, family planning and child expectation, How about the family experience with Down syndrome's child ? When does mother perceive about Down syndrome? How does mother perceive and how does she feel to perception about Down syndrome ? How and why does she worry for having Down syndrome's child?
   - General data of Down syndrome's child
2. Prenatal period
   - readiness to have child eg. co-dicision with spouse, maternal age, economical status, intention for having baby, any problem or any something wrong during pregnant,
   - Any checking and diagnosis the abnormal pregnant, and how and why? How does she feel and worry for having abnormal child and how does she manage that feeling?
   - How about the relationship between pregnant mother and medical personnel eg,. providing information, communication, etc.
3. Delivery period
   - Where is the delivery place? How does she know that her child is Down syndrome and how does she feel? How about the relationship between pregnant mother and medical personnel eg,. providing information, communication, etc.

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- What is the meaning of Down syndrome in mother's perspective? and how does she manage that feeling?

4. Checking and Confirming Down syndrome period
   - the process after know that mother has Down syndrome's child, checking and confirming information? How does mother feel? and how does she give the meaning of Down syndrome and how does she explain why this happen to her?. How does she manage the feeling of having Down syndrome's child?
   - How does society react to her Down syndrome's child and directly to her? How about health care delivery react and serve to her need ? How about the relationship in her family and is there any support, from whom and how?
5. Living with Down syndrome's child period
   - - How long does she accept that she has Down syndrome's child? How does mother feel? and how does she give the meaning of Down syndrome and how does she explain why this happen to her?. How does she manage the feeling of having Down syndrome's child?
   - How about the interaction of social system to her Down syndrome's child eg. Acceptance, health care delivery for Down syndrome's child, educational opportunity and educational system for Down syndrome's child . How are social welfare and social service suitable for Down syndrome's child and family?
   - How does living with Down syndrome's child make mother suffering and why? And How does she manage or project the suffer from living with Down syndrome's child?

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BIOGRAPHY

NAME	Mrs.Mondha Kengganpanich
DATE OF BIRTH	8 October 1964
PLACE OF BIRTH	Lopburi , Thailand
INSTITUTION ATTENDED	Mahidol University, 2004 Ph.D. (Health Social Science) National Institution for Development Administration (NIDA), 1989 Master of Arts (Social Development) Chiengmai University, 1984 Bachelor of Science (Sociology and Anthropology)
POSITION & OFFICE	1987-1992 Assistant Director of Diocesan Social Action Center of Ratchaburi (DISACR) , Thailand 1992-Present, Assistant Professor level 8 Department of Health Education and Behavioral Science, Faculty of Public Health, Mahidol University, Thailand.
HOME ADDRESS	62/376 Mu 5 Thakorn 2, Tumbon Watchalor, Amphor Bangkrauy, Nonthaburi 11130

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NO. 194/2003

Documentary Proof of Ethical Clearance
The Committee on Human Rights Related to
Human Experimentation
Mahidol University, Bangkok

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Title of Project: Mothers' Experience with Down Syndrome's Child: Social Suffering, Context, Meaning and Management

Principle Investigator: Mrs. Mondha Kengganpanich

Name of Institution: Faculty of Social Science and Humanities

Approved by the Committee on Human Rights Related to Human Experimentation

Signature of Chairman: _____
(Professor Dr. Srisin Khusmith)

Signature of Head of Institute: _____
(Professor Dr. Pornchai Matangkasombut)

Date of Approval: 23 NOV 2003

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