YANGON UNIVERSITY OF ECONOMICS
MASTER OF PUBLIC ADMINISTRATION PROGRAMME

A STUDY ON SOCIO-ECONOMIC BURDEN TO FAMILIES OF DOWN'S SYNDROME CHILDREN IN YANGON

NAN SU YI MYO
MPA - 12 (18th BATCH)

JULY, 2019

YANGON UNIVERSITY OF ECONOMICS
MASTER OF PUBLIC ADMINISTRATION PROGRAMME

A STUDY ON SOCIO-ECONOMIC BURDEN TO FAMILIES OF DOWN'S SYNDROME CHILDREN IN YANGON

A thesis submitted as a partial fulfillment of the requirement for the degree of Master of Public Administration

Supervised by:	**Submitted by:**
Daw Malar Thant	Nan Su Yi Myo
Lecturer	Roll No.12
Department of Applied Economics	MPA (18th Batch)
Yangon University of Economics	(2017-2019)

July, 2019

YANGON UNIVERSITY OF ECONOMICS
MASTER OF PUBLIC ADMINISTRATION PROGRAMME

This is to certify that this thesis entitled "**A STUDY ON SOCIO-ECONOMIC BURDEN TO FAMILIES OF DOWN'S SYNDROME CHILDREN IN YANGON**" submitted as a partial fulfillment towards the requirement for the degree of Master of Public Administration has been accepted by the Board of Examiners.

BOARD OF EXAMINERS

1. Professor Dr. Tin Win Rector Yangon University of Economics	(Chief Examiner)
2. Professor Dr. Ni Lar Myint Htoo Pro-Rector Yangon University of Economics	(Examiner)
3. Professor Dr. Phyu Phyu Ei Programme Director and Head of Department Department of Applied Economics Yangon University of Economics	(Examiner)
4. Professor Dr. Tin Tin Wai Department of Applied Economics Yangon University of Economics	(Examiner)
5. Daw Aye Aye Moe Lecturer Department of Applied Economics Yangon University of Economics	(Examiner)

JULY, 2019

ABSTRACT

The study aims to assess the socio-economic burden of families of Down's syndrome children in Yangon. Data obtained from Department of Social Welfare and Myanmar Down's syndrome Association (MDSA). Descriptive method is used in this study. The quantitative research is conducted by distribution of questionnaires to respondents. The respondent in this survey was members of MDSA with the total respondent of 120. The respondents are caregivers, persons must responsible for day to day decision making and care of Down's syndrome children. This study shows caregivers perceived responsibility and associated limitation on self and family that is a burden in taking care of Down's syndrome children. The study shows, more than 70 percent of families know about why causes Down's syndrome. Almost all of the caregivers have problems for taking care of Down's syndrome children. Also taking care of Down's syndrome children results highest means score of 4.5. According to the result of the study, the families of Down's syndrome children have significantly higher difficulties and burden within the households and in social environment. There is also significantly financial burden associated with caring for a child with Down's syndrome.

ACKNOWLEDGEMENTS

First of all, I would like to express my gratitude to Professor Dr. Tin Win, Rector of Yangon University of Economics and Professor Dr. Ni Lar MyintHtoo, Pro-Rector of Yangon University of Economics for their permission and giving me the opportunity to undertake this study.

I would like to express my gratitude to professor Dr. Kyaw Min Htun, Pro-Rector (Retired) of Yangon University of Economics for their excellent teaching, coaching and guidance during my studies.

My special thanks are extended to Professor Dr. PhyuPhyuEi, ProgrammeDirector and Head of Department of Applied Economics and Professor Dr. Tin TinWai, Department of Applied Economics for perspicacious guidance and sharing knowledge and experiences during my studies.

I would like to express my deepest appreciation to my supervisor Daw Malar Thant, Lecturer, Department of Applied Economics, Yangon University of Economics, for her moral support, invaluable help, guidance, consistent supervision and sharing valuable knowledge for completion of this thesis.

In addition, I would like to thank all of the teachers of MPA Programme for their perspicacious guidance and sharing knowledge and experiences during my studies.

I am deeply grateful to Myanmar Down's syndrome Association which have to provide their valuable data and information and Ma HtetHtet Aung and Ma NweNweHtun from MPA18th Batch for their valuable support and kindly contribution, without their contribution, this paper could not have been completed.

Last but not least, I wish to acknowledge the kindness, friendliness, unselfishness of my family and colleagues of MPA 18th Batch and extend my deepest gratitude to them.

TABLE CONTENTS

LIST OF TABLES

LIST OF ABBREVIATIONS

APDSF	Asia-Pacific Down’s syndrome Federation
CRPD	Convention on the Rights of Persons with Disabilities
DPO	Disable People Organizations
DS	Down’s syndrome
DSA	Down’s syndrome Association
DSI	Down’s syndrome International
DSW	Department of Social Welfare
EDSA	European Down’s syndrome Association
FASTER	First and Second Trimester Evaluation of Risk trial
ID	Intellectual Disabilities
IQ	Intelligence Quotient
MDSA	Myanmar Down’s syndrome Association
MFPD	Myanmar Federation of Persons with Disabilities
NDIS	National Disability Insurance Scheme
NDSS	National Down’s syndrome Society
NEILS	National Early Intervention Longitude Longitudinal Study
NGO	Non Government Organization
NICHD	National Institute of Child Health and Human Development
SSI	Supplemental Security Income
UN	United Nation
WDSD	World Down’s syndrome Day
WHO	World Health Organization

CHAPTER I

INTRODUCTION

1.1 Rationale of the Study

To have a happy and healthy child is the most expected thing for every pregnant mother. When they were born, the expectation from the parents was highest and also the country welcome the future generation with many hopes. In spite of having the greatest hope, all of them are destroying at the time of diagnose as Down's syndrome.

Down's syndrome is a genetic condition that typically causes some level of learning disability and characteristic physical features. A child with Down's syndrome also varies in personality and ability. Everyone born with Down's syndrome will have a degree of learning disability, but the level of disability will be different for each individual. A baby born with Down's syndrome will have learning disability. It is impossible to know what level of learning disability a baby with Down's syndrome will have. It can vary from mild to severe. Some health problems are more common in people with Down's syndrome, for example, heart condition and problems with the digestive system, hearing and vision. Sometimes these problems can be serious but many can be treated.

With good healthcare, someone with Down's syndrome can live to around 60 years. Down's syndrome is a developmental issue, because of its bi-directional link with poverty: Down' syndrome may increase the risk of poverty, and poverty may increase the risk of poverty, and poverty may increase the risk of disability. Down's syndrome may lead to the worsening of social and economic well-being and poverty through multitude of channels including the adverse impact on education, employment, earnings, and increased expenditures related to disability.

Children with Down's syndrome are less likely to attend school, thus experiencing limited opportunities for human capital formation and facing reduced employment opportunities and decreased productivity in adulthood. People with Down's syndrome are more likely to be unemployed and generally earn less even when employed. Both employment and income outcomes appear to worsen with the severity of the disability. It is harder for Down's syndrome to benefit from development and escape from poverty due to discrimination in employment, limited access to transport, and lack to access to resources to promote self-employment and livelihood activities.

Down's syndrome may have extra costs resulting from disabilities such as cost associated with medical care or assistive devices, or the need for personal support and assistance and thus often require more resources to achieve the same outcomes as non-disabled people. People with disabilities and their households are likely to be poorer than non-disabled people with similar incomes.

1.2 Objectives of the Study

The objective of this study is to access the social and economic burden to families with Down's syndrome children.

1.3 Method of Study

The method used in this study is descriptive, based on primary and secondary data. For primary data, a survey is conducted on caregivers of Down's syndrome children. Most of the respondents are the member of Myanmar Down's syndrome association. Secondary data is obtained from Department of Social Welfare, Myanmar Down's syndrome Association and other facts downloaded from internet websites, paper and publication.

1.4 Scope and Limitation of the Study

The scope of the study is mainly concerned with the Socio-Economic burden to families of Down's syndrome children in Yangon Region. The respondents are caregivers who are members of Myanmar Down's syndrome**.** The scope of the study was conducted with 120 caregivers who look after Down's syndrome children age range from under 1 year to over 12 years of Down's syndrome who attend the ceremony of World Down's syndrome day which is held in Kandawgyi Park in Yangon. This study did not represent the Caregivers of Down's syndrome children in the community.

1.5 Organization of the Study

This study is organized into five chapters. Chapter I, introduces the rationale of the study, objective of the study, method of study, scope and limitation of the study and organization of the study. Chapter II illustrates of the literature review. It is also based on definition of Down's syndrome, cause of Down's syndrome and associated with Down's syndrome. Chapter III reviews in current rehabilitation in programmes of the disabilities in Myanmar including Down's syndrome. In Chapter IV, illustrate the case study on Family Socio-economic Burden of Children with Down's syndrome. Lastly, Chapter V is the conclusion of the study and recommendation for better improvement for caring of Down's syndrome children.

CHAPTER II

LITERATURE REVIEW

2.1 Down’s syndrome

Down’s syndrome is a condition in which a child is born with an extra copy of chromosome. This cause physical and mental developmental delays and disabilities. The symptons of Down’s syndrome from person to person and people with Down’s syndrome may have different problems at different times of their lives. Many of disabilities can shorten life. However, people with Down’s syndrome can live healthy and fulfilling lives. Recent medical advance, as well as cultural and institutional support for people with Down’s syndrome and their families, provides many opportunities to help overcome the challenges of these conditions.

In all cases of reproduction, both parents pass their genes on to their children. These genes are carried in chromosomes. When cell of baby develops, each cell is supposed to receive 46 chromosomes total. Half of the chromosomes are from mother and half are from father. In children with Down’s syndrome, one of the chromosomes does not separate properly. The baby ends up with three copies, or an extra problems as brain and physical features develop.

Physical development in children with Down’s syndrome is often slower than development of children without Down’s syndrome. For example, because of poor muscle tone, a child with Down’s syndrome may be slow to learn to turn over, sit, stand and walk. But some will grow up to live almost entirely on their own, while other will need more help taking care of themselves. Despite these delays, children with Down’s syndrome can learn to participate in physical exercise activities like other children. (Down’s syndrome.org.uk, 2018)

People with Down’s syndrome are at increased risk for a range of other health conditions including autism spectrum disorder, problems with hormones and glands, hearing loss, vision problems, and heart abnormalities. Doctor are not sure why this happen. There is no link to anything in the environment or anything the parents did or did not do. They do know women 35 and older have a higher chance of having a baby with Down’s syndrome. Parents do not have Down’s syndrome because they have the right number of genes, but their child may have what called translocated Down's syndrome. According to National Down's syndrome Society (NDSS) about 1 in 1000 babies is born with Down's syndrome. (NDSS, 2018)

Down's syndrome is the commonest identifiable cause of intellectual disability, accounting for around 15-20% of the intellectually disabled population.(Wikipedia,2019)

2.1.1 Characteristics of Down's syndrome

Down's syndrome is usually made soon after the birth of the baby because of the appearance of baby. There are many physical characteristics associated with the condition, which may lead a parent or midwife or other medical professional to suspect that the baby has Down's syndrome. There are three types of Down's syndrome: (1) Trisomy 21, (2)Translocation and (3) Mosaicism (NEILS, 2018).

Trisomy 21, the most common type of Down's syndrome, occurs when there are three, rather than two, number 21 chromosomes present in every cell of the body. Instead of the usual 46 chromosomes, a person with Down' syndrome has 47. It is this additional genetic material that alters the course of development and causes the characteristics associated with the syndrome. Trisomy 21 accounts for 95% of cases.

Translocation accounts for 4% of all cases of Down' syndrome. In translocation, part of chromosome 21 breaks off during cell division and attaches to another chromosome, typically chromosome 14. While the total number of chromosomes in the cells remains 46, the presence of the extra part of chromosome 21 causes the characteristics of Down's syndrome.

Mosaicism occurs when no disjunction of chromosome 21 takes place in one- but not all- of the initial cell divisions after fertilization. When this occurs, there is a mixture of two types of cells, some containing the usual 46 chromosomes and others containing 47. Mosaicism accounts for about 1% of all cases of Down's syndrome.

All 3 types of Down's syndrome are genetic conditions, but only 1% of all cases of Down's syndrome have a hereditary component. However, in one-third of cases of Down's syndrome resulting from translocation there is hereditary component-accounting for about 1% of all cases of Down's syndrome.

The symptons of Down's syndrome vary from person to person, and people with Down's syndrome may have different problems at different times of their lives. Most babies born with Down's syndrome are diagnosed soon after birth and may have floppiness, eyes that slant upward and outward, a small mouth with a tongue that may stick out, a flat back of the head, below-average weight and length at birth, their palm may have one crease across it, abnormal ears, intestinal blockage and enlarged colon,

Common physical signs of Down’s syndrome include:decreased or poor muscle tone, growth failure mental retardation, short neck, with excess skin at the back of the neck, flattened facial profile and nose, small head, ears, and mouth, upward slanting eyes, often with a skin fold that comes out from the upper eyelid and covers the inner corner of the eye, small and arched palate, big, wrinkled tongue, dental anomalies, white spots on the colored part of the eye, wild short hand with short fingers and many loops on finger tips, a single, deep, crease across the palm of the hand, a deep groove between the first and second toes and special skin ridge patterns.

In addition, physical developmental in children with Down’s syndrome is often slower than development of children without Down’s syndrome. For example, because of poor muscle tone, a child with Down’s syndrome may have slow to learn to participate in physical exercise activities like other children. It may take children with Down’s syndrome longer than other children to reach developmental milestone, but they will eventually meet many of these milestone. Although children with Down’s syndrome share some common physical characteristics, they do not all look the same. A child with Down’s syndrome will look more like other family members than other children who have the syndrome. Down syndrome also affects the ability of person to think, reason, understand, and be social. The effects range from mild to moderate. Children with Down syndrome often take longer to reach important goals like crawling, walking, and talking. As they get older, it may take more time before they get dressed and use the toilet on their own.

And in school, they may need extra help with things like learning to read and write. Some also have problems with behavior – they may not pay attention well, or they can be obsessive about some things. That’s because it’s harder for them to control their impulses, relate to others, and manage their feelings when they get frustrated. As adults, people with Down’s syndrome may learn to decide many things on their own, but will likely need help with more complex issues like birth control or managing money. Some may go to college, while others will need more day-to-day care.

People with Down's syndrome will also have different personalities and abilities. Everyone born with Down's syndrome will have some degree of learning disability, but this will be different for each person (NDSS, 2018).

2.1.2 Causes of Down's syndrome

Down's syndrome is usually caused by extra chromosomes in cells of baby. In most cases, this is not inherited- it is simply the result of a one-off genetic change in the sperm or egg. There is a small chance of having a child with Down's syndrome with any pregnancy, but the likelihood increases with the age of the mother. For example, a woman who is 20 has about a 1 in 1500 chance of having a baby with Down's syndrome while a woman is 40 has a 1 in 100 chance. There is no evidence that anything done before or during pregnancy increases or decreases the chance of having a child with Down's syndrome.

Babies with Down's syndrome are born to mothers of all ages. The main factor that increases the chance of having a baby with Down's syndrome is the age of the woman when she becomes pregnant. The chance of having a child with Down's syndrome is also increased if you have previously had an affected pregnancy. There is around one in two chance of a child having Down's syndrome if one of his or her parents has the condition. Before Birth- It is possible to test pregnant women for Down's syndrome but this is not routinely done in Myanmar.(NDSS,2018)

After Birth- the diagnosis can often be suspected based on the physical appearance of child at birth. Medical diagnosis usually takes place through chromosome analysis. This happens when there is suspected Down's syndrome based on the presence of typical physical characteristics.

The reason for offering parental testing to all expectant mothers was the assertion that most children with Down's syndrome are born to women under the age of 35. Indeed, this is exactly what the Centers for Disease Control states: the age of the mother is the only factor that has been shown to increase the risk of having a baby with Down's syndrome. This risk increases with every year, especially after the mother is 35 years of age. However, because younger women are more likely to have babies than older women, 80 percent of babies with Down's syndrome are born to women younger than 35 years of age.

Dr. Resta's indicate that this statement is incorrect in stating that the increasing number of pregnancies occurring in women who are 35 years of age and older has recently resulted in that cohort accounting for slightly more than half of the number of Down's syndrome fetuses conceived in the United States. In the FASTER trial, where 21.6 percent of the screened population was aged 35 or older, compared with 14 percent for the US population, 69 percent of the Down's syndrome cases occurred among those older women. The FASTER trial was the First and Second Trimester Evaluation of Risk trial.(FASTER, 2017)

2.1.3 Medical Problem of Down's syndrome

Certain health problems are more common in people with Down's syndrome than in the rest of the population. These include:

a. 40-50% of babies with Down's syndrome are born with heart problems, many of which require heart surgery,
b. A significant number of people with Down's syndrome will have hearing and vision problem
c. Thyroid disorder
d. Poor immune system
e. Respiratory problem, coughs and cold
f. Obstructed gastrointestinal tract

None of these problems are unique to people with Down's syndrome, they also occur in the rest of the population.

2.2 Intellectual and Developmental Delay

Cognitive impairment, problems with thinking, and learning is common in people with Down's syndrome and usually range to mild to moderate. Only rarely is Down's syndrome associated with severe cognitive impairment.

Other common cognitive and behavioral problems may include:

a. Short attention span
b. Poor judgment
c. Impulsive behavior
d. Slow learning
e. Delayed language and speech development

Most children with Down's syndrome develop the communications skills they need, although it might take longer for them to do so compare with other children. Early, ongoing speech and language interventions to encourage expressive language and improve speech are particularly helpful. Parents and families of children with Down's syndrome can connect with other families and people with Down's syndrome from around the world to learn more and share information. The NICHD-led- DS-connect is a safe and secure registry to help differences in the physical and developmental symptons and milestones of people with Down's syndrome and guide future research.

All people with Down's syndrome will have some degree of intellectual disability. Children with Down's syndrome do learn to walk, talk and be toilet trained but in general will meet these peers. There is wide variation in ability in people with Down's syndrome just as there is in the rest of the population. Early intervention programs which help in all areas of child development are now wide spread. This program can include speech and physical therapy as well as home teaching programs for the child and the family.

While each child is a unique individual with his or her own combination of strengths and difficulties, some common thread has been observed in the development of children with Down's syndrome.

Lorenz identified some of these as:

a. Development is delayed and takes place in slower pace
b. The children require prolonged experience to acquire a particular skill or to use that skill spontaneously
c. Stubbornness and pretending behaviors are common. However these qualities suggest that the child is under-motivated, rather than being not capable of participating in tasks.
d. Associated impairments may be present-hearing impairment, and epilepsy is the most common.

At the time of starting nursery or school the self-care skills of children with Down's syndrome are commonly under-developed. In comparison with other areas of development, toileting, dressing, feeding are under-developed.

e. Chewing and swallowing may also be at an early stage.
f. Children may have not been learnt how to indicate their needs.
g. Dressing can be made easier by using simple garments rather than complicated on.

2.3 Society Impact of Down’s syndrome Children

Individuals with Down’s syndrome are becoming increasingly integrated into society and community organizations, such as school, health care systems, work forces, and social and recreational activities. Most people with Down’s syndrome have cognitive delays that are mild to moderate.

Due to advances in medical technology, individuals with Down’s syndrome are living longer than ever before. In 1910, children with Down’s syndrome were expected to survive to age nine. With the discovery of antibiotics, the average survival age increased to 19 or 20. Now with recent advancements in clinical treatment, most particularly corrective heart, surgeries, as many as 80% of adults with Down’s syndrome reach age 60, and many live even longer. More and more Americans are interacting with individuals with Down’s syndrome, increasing the need for widespread public education and acceptance.

Although there is no cure for Down’s syndrome, there is support available to help children with the condition lead healthy, fulfilling lives. These include:

a. Access to good health care including a range of different specialists
b. Support for your child’s development-this may include speech and language therapy, physiotherapy, and home teaching
c. Support groups- such as the Down’s syndrome Association, who can put you in touch with other families who have a child with Down’s syndrome.

Lots of people with Down’s syndrome are able to leave home, have relationships, work, and lead largely independent lives. Children who were identified with development disabilities, Down’s syndrome, are suitable and eligible to receive early intervention service. There are various definitions for early intervention: Bowe defines early intervention as a service or a special program for children from newborn to age of three years old with a development problem or at risk.

Meanwhile, the term early intervention according to Watts refers to the provision of therapy or early treatment before the age of four years old and usually begins as early as in the first 36 months of age. There are various family outcomes experienced by the family who received early intervention. There are five family outcomes identified which understand the strength, abilities and special needs of children, knowing the rights and talk on children behalf, assisting the child to grow and learn, having a support system and be involved in the community.

Data from the National Early Intervention Longitudinal Study which assess the family outcome for children whose early intervention was terminated at the age of three years old shown that many parents feel competent in providing care of their children, advocacy in service and have support system. Other than that, the characteristics of the Down's syndrome children family would also affect the family outcome.

Based on several researches, there are relationship between various demographic factors of parents, children, process and the staff with services and early intervention. The abecedarian Project, a supplier of early intervention services for children found children at risk for factor such as single parents, low parental educational levels and poverty will have the impact on the intervention result. Indirectly, the result of early intervention which is influenced by various factors, including parental socio-demography factor will also affect the family outcomes.

In respect of the families children with disabilities participating in early intervention, education level of mother and family income also have significant relations with the family outcomes. Parents with higher education levels have a more positive result in the family outcomes. For example, the analysis performed in NEILS study found parents who take care of their children special needs positively comes from families with higher educated mothers.(NEILS, 2018)

Most parents complained on their increasingly limited financial resources due to additional necessities of their special child compared to need of other children. This reason of their inability to fork out expenses neither to go on holiday, nor do any recreational or educational activities.

Hence, the family would not have the opportunity to engage in community support systems and caused their support system to become increasingly weak. There is a parent who complained taking care of their Down's syndrome children has caused their families to feel less in terms of standard of living and limited opportunities to participate in various activities.

Raising children requires a lot of financial scarifies especially for the families of children with special needs, which caused greater economic burden to the families. There are many studies which agreed that families who have children with disabilities need financial support from the others. Cunningham found that economic burden will affect family ties and increase family stress.

More efforts should be done to improve the families with disabled child upgrading the level of their education and knowledge and to improve their economic resources. The government has also approved the establishment of local training and service centre for these families.

Through this, parents who have children with disabilities can gain more knowledge about their special child and how to handle their family through participation in programs and workshops. Indirectly, these efforts have been able to alleviate some of the economic burden of families with disabled children.

The study in Turkey on the family experience of having Down's syndrome children and its social impact on family members, there is a mother who said her neighbors did not know his son has Down's syndrome and he never told them so for fear of stigma against their family. Parents tried very hard to provide care, comfort and joy as good as possible to their special children, hence, they less time for themselves, less leisure and fun than other normal families.

In other study found that mothers of Down's syndrome children have no time for themselves, where groups of children aged one to three years old always require intensive care, while children in the age group of four to six years and seven to twelve years were very active.

2.3.1 Working With Children of Down's syndrome

Here are some guidelines which consider in order beginning supporting a development of child and learning. Every child is an individual: despite having the same diagnosis and having some shared characteristics, learning of every child will be different and their physical, social, emotional, cognitive and linguistic development will have a unique path. (Hanson, 1987)

All children can learn and continue to learn throughout their childhood and in their adulthood: learning may occur at a slower pace or will be delayed; sequence may differ from the average but as long as the child is given motivation, opportunities and adequate support for learning, they will learn.

Adult make a difference (parents and professionals): interactions and targeted support are vital in enhancing developmental of children and learning. Early intervention is paramount in supporting early progression of children: while it is never too late to start to do targeted work with children with Down's syndrome, it is commonly accepted that early intervention is essential to prevent further difficulties in various areas of development and learning. Teaching targets are both developmental and functional: aim to achieve with children can be a combination of child-development stages and also functional skills- for instance, achieving steady walking is a particular developmental stage, but also a skill which is required in order to move about at home or in school.

The time to teach children is during every day, age and context-specific activities: daily activities and interactions carry many natural opportunities to work on physical, social, and language skills. Work with parents and other professionals to know more about the child, to develop own understanding of the need of children and to increase confidence in supporting the child through different activities.

2.3.2 Difficulties With Parents

Each child for care is unique: disability can be visible or invisible and may include low vision, blindness, hearing impairments, learning disabilities, attention deficits, mobility impairments, health impairments, and psychosocial impairment. The children in care all come from a range of backgrounds and experiences and represent many types of learning styles, including both visual and auditory learners.

Inclusive pedagogy is about designing instructional materials and actives that allow the learning goals to be achievable by individuals with wide differences in abilities to see, to see, hear, speak, move, read, write, understand language, attend, organize, engage, and remember. This is achieved by means of flexible materials and activities that provide alternatives for children with disparities in abilities and backgrounds. Working in this way makes content and activities inclusive and accessible to children with a wide range of physical and intellectual abilities, disabilities, ethnic backgrounds, language skills, and learning styles.

Children with impairments are not a homogeneous group. They have diverse physical, sensory, medical, intellectual and social needs and difficulties. Despite these differences, parents often face similar experiences while parenting these children. They come to terms with their unexpected disability of child, adjust their family life to accommodate the needs of the child and develop experience which is unique to the context of their own family. This experience is often shaped by how others support families and in particular how parents nurture development of child and learning is emotional, social and practical terms. Disabled children make additional demands on a family than other families.

Parents of disabled children tend to have lower income. This is because employment of parent is often affected. For example, one parent cannot to work so that someone can look after the child. Extra financial costs are involved with bringing up a disabled child, for example medication, extra laundry, equipment. As the disabled child grows many families find inadequate housing. This is because of the additional needs of the child, for instance space needed for mobility aids of child or personal equipment.

At a practical level parents develop a range of new skills while bringing up disabled child. These may range from handling skills to administering medication, preparing food, and helping children with exercises given by professionals etc. over time they try many new strategies with their children and become knowledgeable about what works for their own child.

Down syndrome is the most common chromosomal cause of intellectual disabilities (ID). An estimated prevalence of Down’s syndrome was 1 per 848 live births in Taiwan. Most children with Down’s syndrome are classified as having either a mild or moderate level of disability. Down’s syndrome poses multiple challenges to families, which leads parents to seek resources to cope with the birth and rearing of the affected child.

The passage of the physically and Mentally Disabled Citizens Protection Act in 1997 by Taiwan resulted in relevant legislative policies and welfare programs for individuals with disables and their families. The healthcare policies and services are affected by political power broking and social attitudes. Currently, social welfare and healthcare services for children with Down’s syndrome are underdeveloped in Taiwan. The traditional Chinese belief is that disables-particularly the hereditary ones-are regarded as a result of misfortune and/or retribution for sins or evil deeds committed by parents or ancestors. Families of children with disabilities face criticism, ostracism, prejudice and stigmatization in Taiwanese society.

Most Taiwanese parents often suffer from embarrassment, withdrawal and helpless and also worry about the effects of social stigma on their affected children. Because of the fear of being labeled as Down’s syndrome family and public humiliation, parents may hide the affected child, avoid participating in social activities, and be reluctant to openly disclose their concerns or seek help outside of the family. These fears of exposure of disgrace create conflicts and barriers to accessing support and services.

Families of children with Down's syndrome are likely to encounter unexpected demands more frequently and experience greater negative care giving consequences than families with typically developing children. Rearing children with Down's syndrome is not only subject to the same demands faced by families of typically developing children, but involves additional demands relevant to behavioral challenges, extra care giving responsibilities and restrictions to social life. Additionally, older-aged children with Down-syndrome and lower socio-economic status were found to be associated with family maladaptation.

Given the health, developmental and educational concerns associated with Down's syndrome, increased parental stress, high rates of divorce or poor marital relationships and decreased family functioning have been reported.

Parents with Down's syndrome require personalized follow-up and the health care services. They present multiple co morbidities including congenital heart disease and other gastrointestinal disorder, often requiring surgery during the first few years of life that can result in medical costs. As a result of the variety of possible medical conditions, children with Down's syndrome co morbidities such as congenital heart disease require specialized medical attention, with these children requiring at least three times as many medical appointments and hospitalization than children without Down's syndrome.

In addition, children with Down's syndrome require non-medical services and support associated with their emotional and psychomotor development. These requirements can generate a greater need for health services and therefore more expenses for their respective families. An additional burden for families of children with disabilities is the considerable investment of time required to care for them, which can affect their available economic resources. The income of affected families is often insufficient to pay for medical care in the medium and long run. For example, survey report form United States estimated that 52% of a sample of 78,771 families caring for children with disabilities had difficulty paying medical bills compared with only 32% of families of children without disabilities. According to another analysis, up to 40% of families having children with special health needs experienced a financial burden related to medical care.

2.3.3 Burden of Family With Down’s syndrome

A child with Down’s syndrome has effects on the family. Some effects relate to the likelihood that a child will display the cognitive and behavioral phenotypes considered to be typical of children with Down’s syndrome. These include specific patterns of strengths and weakness in information process, social interaction, expressive language, respective skills, motor skills, and motivation.

Such patterns may influence the behavior of caregivers of in dyadic interaction with the child. Other effects may be due to increased difficulties or diminished satisfaction in the parental role and to reduce opportunities of parents in other sphere of life such as career success. Positive effects are possible through the identification of parents of a particular purpose in life, or the development of particular talents that may not have been called upon in other circumstances. Parental adaption to a child with Down’s syndrome has also been studied extensively in relation to parental well-being, especially the psychological reactions of parents. However, parenting responsibilities, child demand s and psychological outcomes are related.

Parents of children with Down’s syndrome have more stress and psychological distress than the parents of healthy children. In the recent Greek study, it was observed that mothers of children with Down’s syndrome experienced more stress, as a result of greater total time demands, than mothers of nondisabled children. The parenting experience does not seem to be similar in mothers and fathers and cultural and social assumptions as well as role modifications affect the way in which they cope with it.

Traditionally, mothers in general have for various reasons stayed at home and have taken greater responsibility for the overall child care. In the past, mothers also took on more child care than did fathers when a child had special needs. Mothers of children with Down’s syndrome reduced their time in paid work by about 7 hours per week and increased their child care time by 9 hours per week. The mothers of children with Down’s syndrome experienced more psychological stress and had lower self-esteem compared with the fathers, mothers have also been reported to have poor self-perceived health in comparison with their spouses and with reference mothers of healthy children. Parents might use behavior management techniques that unintentionally evoke or reinforce child behavior problem and set the future child behavior problem. Poor health outcomes, due to their association with parental stress, are social support and child behaviors.(Barnett and Boyce, 1995)

The research explores another social factors that has received less attention in predicting psychological distress for parents, stigma. Stigma is associated with burden, marital satisfaction and social exclusion in parents of children with Down's syndrome. Stigma refers to the impact of negative attitudes and behaviors from the general public on individuals and often results in negative psychological and physical health for the stigmatized individual.

In addition to the emotional burden of caring for a child with Down's syndrome families typically face a multitude of practical demands. These demands include continuous time pressure, significant financial burden, the need to provide support and accommodations for their child's education and fewer opportunities to work. The inability to work increases financial stressors on families and may also diminish parents' resources for both social and emotional support.

Family quality of life is a commonly used measure of the negative impact of physical or mental illness and/or disability on the family system. Families of children diagnosed with Down's syndrome were found to have greater overall negative quality of life effects than those of children with healthy children. (Lord and Bishop 2016).

2.3.4 Parenting Children With Down's syndrome

Parental stress, several aspects of the syndrome suggest that these experiences of parents differ from that of parents which children who have other disabilities. First, as the most common genetic cause of intellectual disabilities, Down's syndrome is well known to professionals and parents alike, and boasts many active parent support and advocacy groups.

Perhaps these features of the syndrome may lead parents to greater sense of familiarity, control, and support than is available for parents of children with less known, more infrequent, and vaguer diagnoses. Second, even with the increased availability of screening procedures, the positive correlation between increasing age and higher rates of mother of Down's syndrome in her fetus continues. The stronger likelihood that Down's syndrome babies will be born to older and more mature mothers may explain these group predominant maternal characteristics, such as greater experience as a parent and higher level of socioeconomic status. Third, Down's syndrome advantage might stem from these characteristic of children behavioral functioning. For example, the trajectory of symptons among children with

Down's syndrome is quite distinct and quite stable over the life course, which may possibly promote sense of predictability of parents, control, and manageability.

Thus, during childhood and adolescence, parents of a child with Down's syndrome generally sense a warm exchange of emotion with their child and can realistically expect this type of relationship to continue into the future. Similarly, mothers of adults with Down's syndrome reported better relationship with their son or daughter than did mothers of adults with autism or mothers of adults with schizophrenia.

Children with Down's syndrome tend to have fewer and less sever behavior problems, which may constitute an advantage considering that level of child of maladaptive behavior. For example, parents of children with Down's syndrome reported more child-related rewards than did parents of children with other disabilities, with rates similar to parents of same-age typically developing children.

Rewardingness refers to the feelings of gratification and reinforcement brought about by parenting a child, and involves feeling love and appreciated by the child as well as feeling that the child returns the parents' love and attention. The relatively high capacity of children for socially oriented behaviors may also contribute to the Down's syndrome advantage.

Although debates are raised about the Down's syndrome personality, these children have a relatively less pronounced impairment in social development aspects. Compared to typically developing children of the same mental ages, toddlers with Down's syndrome, as a group, spent more time looking at an interesting adult than at surrounding toys.

During the school years, these children continue to look more at adults during problem-solving tasks than do their peers with other types of ID. Thus, it is not surprising that parents tend to describe their children with Down's syndrome as manifesting a high level of sociable and cheerful behavior, using terminology such as affectionate, lovable, nice, and gets on well with problems.

Similar descriptions were given by fathers of 7 to 14 years old children with Down's syndrome, such as sociable, friendly, lovable, and cheerful. Moreover, view of parents of their children with Down's syndrome as highly sociable appears to contradict with studies indicating that such children tend to have difficulties in high-level social skills, as manifested on hypothetical empathy tasks and on assignments requiring emotion labeling or under-standing.

Parents experience strong feelings of depression at the time of the birth of baby and diagnosis with Down's syndrome. After the initial period of depression, parents often do better until the baby reaches approximately 4 months of the age. At this point, a second wave of depression occurs when mothers realize the developmental implications of Down's syndrome, as their infant shows more dampened affect and less consistent social smiles than typically developing children.

Several waves of depression may also occur in the preschool period, when mothers are concerned about developmental milestones of children, such as walking, talking, and toilet training, and also through puberty and the onset of adulthood. Maternal emotions may be most intense directly after the birth of the child, but later milestones may also elicit strong reactions.

2.4 Down's syndrome day and Association

World Down's syndrome Day (WDSD) is on March 21. On this day, people with Down's syndrome and those who live and work with them throughout the world organize and participate in activities and events to raise public awareness and create a single global voice for advocating for the rights, inclusion and well being of people with Down's syndrome.

AFRT, the French Association for Research on Trisomy 21, was created in 1990 for supporting research and informing on medical and scientific advances in the field of Down's syndrome. In 2005, AFRT decided to select the date of March 21 as a symbolic date for the Day of Trisomy 21. The first meeting was organized by AFRT on March 21, 2005, in Paris.(AFRT, 2015)

In June of 2005, Dr. Juan Pereira organized an international meeting in Palma of Majorca on Behalf of EDSA (European Down's syndrome Association), AFRT proposed them to choose the date of March 21 as a symbolic date by both the EDSA and Down's syndrome International (DSI) boards.

On this day, let realfirm that persons with Down's syndrome are entitled to the full and effective enjoyment of all human rights and fundamental freedoms. Let do enable children and persons with Down's syndrome to participate fully in the development and life of their societies on an equal basis with others. Let build an inclusive society for all. (Ban-Ki-moon, The Secretary-General of United Nations, 21 March, 2012)

The Down's syndrome Association (DSA) is a British charity organization which describes itself as being the only organization in the United Kingdom that focuses solely on all aspects of living successfully with Down's syndrome.

The association was founded in 1970 by Rex Brinkworth as a local group and now has 20,000 members and about 126 local groups. Its headquarters is at the London down Centre, formerly Normansfield Hospital, built as a private hospital by John Langdon Down, the father of Down's syndrome.

The Langdon Centre includes the Langdon down Museum of Learning Disability about the history of treating people with learning disabilities, and the Normansfield Theater. Former footballer Kelvin Killbane, whose elder daughter has Down's syndrome, is a patron of the charity.

2.5 Review on Previous Study

Advance maternal age and altered recombination are known risk factors for Down's syndrome cases due to maternal non-disjunction of chromosome 21, whereas the impact of other environmental and genetic factor is unclear.(Jessica, 2014 Aug 6).

The demographic and socioeconomic characteristic of families of children with Down's syndrome as well as how Down's syndrome and other disabilities impact the economic situation of families. Two consistent demographic patterns are found. First, parents of children with Down's syndrome on average are older than parents of other children. Second, families of children with Down's syndrome are more likely to have social advantage in terms of parental education, income, and race/ethnicity status relatives to families of children with other intellectual or developmental disabilities", consistent with a Down's syndrome advantage. In addition, most US studies find that live-born infants with Down's syndrome are more likely to be born to Hispanic parents and less likely to have a Black or African American parent than other infants. Financial impacts on families with a child with disabilities such as Down's syndrome can result from high out-of-pocket expenditures and reduced parental employment and earning. Employment effects of child disability are greater among two-parent or one-parent families and whether fewer mothers of child with disabilities are in the paid work force or part-time employment is substituted for full-time employment. Many families of children with disabilities experience financial stress, in part as a result of underinsurance. Public programs, notably Supplemental Security Income (SSI) benefits, can help to buffer the financial impact of caring for a child with a serious disability. (Scott D Grosse, December 2010).

CHAPTER III

CURRENT REHABILITATION PROGRAMMES FOR DISABILITIES IN MYANMAR

3.1 Definition of Disability

Myanmar has approved a national on the rights of the persons with disabilities; the definition of disability used in it is not explicit or widely understood. Other definitions of disability used by most stakeholders were also largely outdated and reflected a charity model not aligned with the Convention on the Rights of Persons with Disabilities (CRPD) of establishment of persons with disabilities as rights holders. In fact, disability is most often described as a physical impairment, a difficulty with communication, “mental or learning” “impairment, or as having a low IQ” and in some cases derogatory terms were used.

Parents and caregivers were able to identify 30 types of disabilities or limitation, and all were related to physical condition. None of these mentioned an environmental barrier (lack of accessible transportation or a lack of knowledge about sign language) as disabling.

Daily lives: Difficulties are there in areas such as self-help and hygiene, eating, and changing clothes. Although many children with Down’s syndrome can do things independently, many require assistance. Sixty-seven percent of the children with disabilities are out of the formal education system and do not attend school. This represents an exponentially higher percentage of children out of school than among children without disabilities, 11 percent of whom do not attend school, according to the most recent national census. A 93 percent of the 2 to 4 year olds with disabilities have no exposure to school readiness programmes, while attendance of children with disabilities at monastic schools, vocational training centers and special school was found to be negligible.

Community and social life: Perceptions regarding social interactions varied among stakeholders, with no difference for girls or boys with disabilities. Overall, 81 percent of the children with disabilities reported faced the same treatment by the community, good or bad, as all other children. Seventy-nine percent of the parents with children with disabilities felt that community members generally understood and supportive, a sentiment reflected in almost equal proportion by parent and caregivers of children without disabilities.

Notably, however, some of the children with disabilities were bullied by children, and 13 percent were bullied by adults. Community members largely agreed that all children, including children with disabilities, are entitled to have a happy life. According to the World Health Organization, Down's syndrome affects about one in every 1,000 births but the number of people in Myanmar with the disability is unknown. Life can be challenging in Myanmar for those with Down's syndrome or any other disability, because of a lack of government healthcare support and stigmatization in the community.

In recent years, Myanmar has made progress towards providing improved care for members of its disabled community, starting with the first national disability survey in 2010 to compile much needed data. The government adopted a National Plan of Action for people with disabilities in 2010, ratified the UN Convention on the Rights of Persons with Disabilities in 2011, and enacted the Disability Rights Act in June, 2015.

However, the feedback from families with disabled loved ones is that while there has been an increase in rules and regulation, little has change in reality. While waiting for meaningful change at government level, the volunteering mothers of the Myanmar Down's syndrome Association dedicate to improve the quality of life of loved ones. As well as organizing the swimming classes, hold monthly meetings to discuss plan for the future. Member of MDSA want to start a dental clinic for people with Down's syndrome, join the Special Olympics and arrange some vocational training. The empowerment that came from forming MDSA group is generating lots of ideas.

3.1.1 Governmental Organizations for Disabilities

The government organizations for disabilities include Department of Social Welfare, Ministry of social welfare, Relief and Resettlement, The Department of Health, and Ministry of Health and sport.

Department of Social Welfare (DSW), Ministry of Social Welfare, Relief and Resettlement is taking social and vocational rehabilitation by running special schools for the rehabilitation of persons with disabilities. Besides, the organizations of people with disabilities and welfare organizations are also making such efforts. Rehabilitation processes of the DSW are categorized into two ways which as follow: Institution Based Rehabilitation and Community Based Rehabilitation.

Activities of daily living, social interaction, primary education, supports for studying higher education, basic vocational training, information and technology courses, art and sport education are providing based on the types of disabilities in special schools.

3.1.2 Department of Social Welfare (DSW)

Department of Social Welfare (DSW), Ministry of Social Welfare, Relief and Resettlement is taking social and vocational rehabilitation by running special schools for the rehabilitation of persons with disabilities. Besides, the organizations of people with disabilities and welfare organizations are also making such efforts.

Rehabilitation processes of the DSW are categorized into two ways which as follow:

1. Institution Based Rehabilitation
2. Community Based Rehabilitation

According to the types of disabilities, the department is running special schools for the rehabilitation of persons with disabilities. Besides the organizations of persons with disabilities and welfare organizations are also making such efforts. Activities of daily living, social interaction, primary education, supports for studying higher education, basic vocational training, information and technology courses, art and sport education are providing based on the types of disabilities in special schools.

3.1.3 Myanmar Down's syndrome Association (MDSA)

Myanmar Down's syndrome Association (MDSA) was initiated since 15th February, 2015 by a group of parents of the children with Down's syndrome. A working committee representing MDSA set off activities since then. Ministry of Home Affairs is issued a registering certificate to MDSA as a recognized local organization in Myanmar on 5th July, 2016.

The mission of MDSA shall be ensure that all individuals with Down's syndrome and families receive the support necessary to participate in, contribute to and achieve fulfillment of life in community. (a) Help parents and families adjust to the birth of a child with Down's syndrome about nurturing and up bringing; (b)

Through Down's syndrome and their families Association networks, disseminate all individuals with Down's syndrome and their families about educational, employment, medical, social support services and resources; (c) Provide social and educational events for individuals with Down's syndrome and their families to meet, interact and learn, and for community awareness raising; (d) Establish a Down's syndrome training school for part-time or full time therapeutic training and a Down's syndrome Vocational Training Centre for employment and income generation; (e) Assist to protect the people with Down's syndrome from violence, abuse, neglect and exploitation.

3.1.4 Capacity Building of Myanmar Down's syndrome Association

With an intention to building up the capacities of the members of the MDSA, some of the mothers attended the following workshops and training courses (mostly at their own expense) conducted by the experts (both nationals and internationals); then shared the knowledge and skill learnt to the rest of the members during the monthly meeting of the MDSA.

The workshops and training courses attended were as follow: Therapeutic trainings such as Speech therapy, Music Therapy Job Coach Training, Parenting Training, Basic Handicraft Training, Caregiver Training for Special Needs Children, Assistant Teacher Training for Special Need Children, Basic Counseling Skills and Counseling for Behavior Change, Psychology of Leadership, Family Therapy Workshop, Social Work Workshop.

The MDSA working committee organized an event in commemoration of World Down's syndrome Day on March 21, 2015 in coordination with the entertainment groups in order to raise Public awareness on Down's syndrome. In commemoration of Down's syndrome Awareness month, Oral and Dental Hygiene education talk, dental and oral health screening for persons with Down's syndrome was conducted on October 25, 2016. The education talk, dental and oral health screening was organized with the support of the University of Dental Medicine where 120 persons with Down's syndrome participated. Parents and public have improved their knowledge in dental hygiene and oral health education after this awareness raising event.

Moreover, mothers and families of persons with Down's syndrome have introduced to a dental clinic situated in the University of Dental Medicine compound, giving a chance to take oral care at low cost. The persons with Down's syndrome have also been exposed to the public, dental surgeons and nurses during the event upon giving voluntary services like distributing water bottles and participated in the event for blood testing as subjects for a research conducted by MDSA technical advisor and Associate Professor from Anatomy Department of University of Medicine 2, Yangon.

Hearing Test: The hearing test was conducted for the people with Down's syndrome at Yangon hospital at every Sunday of October, 2016 with the cooperation of Neuro-Oto Audiology Special Interest Group from Head & Neck Surgery Specialist Hospital.

Table: 3.1 Hearing Test for Down's syndrome

Description	**The quantity of persons with Down's syndrome**
Under 5 years	10
Non cooperation	9
Non-follow-up the further testing	21
Only Tympano	6
Test	81
Total	**127**

Source: Myanmar Down's syndrome Association

Myanmar Down's syndrome Association (MDSA), New Hope Association and Ear Hospital in Mandalay organized an education talk on Down's syndrome and health; a session on how to conduct a hearing assessment for persons with Down's syndrome for the families in October 2017.

Dental Cares: The dental cares was conducted for the people with Down's syndrome at 25th, October, 2015 at Mary Chapman School for the Deaf Children in Yangon Region, Myanmar. One hundred and twenty Down's syndrome individual 69 males and 51 females were participated in oral examination section. Age ranged from 4 years to 32 years. Dental cries status was recorded using WHO criteria for assessment of dental caries.

Eye Care Test: Down's syndrome awareness month in October 2018, MDSA collaborated with Yangon Eye Hospital to conduct eye screening test for persons with intellectual disability, (176) Numbers of persons with Down syndrome were tested, referred to put on eyeglasses and received treatments as required.

3.2 Representation and Coordination at the National Level

The executive members of Myanmar Down's syndrome Association (MDSA) were initiated to attend the voting process for the second term election of Myanmar Federation of Persons with Disabilities Executive Committee (MFPD). At the National level, MDSA executive members actively involved in various sub committees of MFPD and collaboration with the other Disable People Organizations (DPO) at the monthly coordination meetings. Myanmar Down's syndrome Association performed so that the ice-cream making can be learned by people with Down's syndrome by engaging with the ice-cream company in 2016.

By cooperating three associations such as Myanmar Down's syndrome Association, Myanmar Autism Association and Future Stars Self Advocacy Group, and supporting by Danish NGO working for and with people with intellectual disabilities, the team decided to do Bakery and the Bakery Process is now in progress. The aim of the team is to create job opportunities to generate income towards independent living and improving quality of life of the intellectually disabled persons.

Myanmar Down's syndrome Association has plans to conduct health screening and treatment of persons with Down's syndrome in relation to the problems with Eyes, ears, nose, throat, thyroid and cardiac in coordination with the concerned health professionals from the hospitals. MDSA has plans to disseminate knowledge on Nutrition, Physiotherapy, Art, Music, and Speech Therapy among parents, members and families of person with Down's syndrome with the technical support of professionals and experts, every quarter of a year. MDSA has plans to found Vocational Training Centre for the people witgh Down's syndrome to get job opportunities and to reduce the burden of family and also the Country.

Myanmar Down's syndrome Association is a non-profit, non-government association aiming to build capacities of care givers for persons with Down's syndrome through reachable and affordable trainings and referrals. Long term goal is to develop a "One Stop Service Centre" for all round development of persons with Down's syndrome in Myanmar.

Inclusive Education for the development of Intellectual disabled persons in Myanmar within the era of Education reform. MDSA can be an organization for advocacy at the National level in cooperation with the Department of Social Welfare. MDSA also link with Asia-Pacific Down's syndrome Federation (APDSF).

Regional Networking**:** MDSA members attended the Asia Pacific Regional Down's syndrome Federation in September 2017 in New Dehli for continuous information sharing, communication and regional linking. On 20th February, MDSA contributes information in response to the questionnaire related to the presentation for Asia Pacific Region Down's syndrome Federation at the UN on the occasion of the World Down's syndrome Day.

Education for Special Need: Special need teachers' training courses are conducted by University of Wolverhampton in coordination with Myanmar Special Education Association and the Charity with love all things are possible. The training course includes 8 levels of teaching, where the special need teachers from private schools in Myanmar have been trained up to course level 2. The special need teachers from government schools fail to join the level 1 and 2 courses.

Therefore, Myanmar Special Education Association launched pre level1 training to teachers from the Basic Education department, and Social Welfare Department, Civil Society Organization and parents in 13 different regions of Myanmar on management of children with special needs since 2017. A sharing workshop on UNCRPD conducted to the members of MDSA on 30 September 2017 for continuous learning. Schools for children with Special needs and our association are providing caregiver trainings to the parents and families.

Special Welfare Department in coordination with the Leoprosy Mission in Myanmar conducts Early Childhood Care and Development a 10 months Diploma course in 2018. Executive members from MDSA and teachers from schools for Special need children had a chance to attend five-week-training course of social education and leadership in Flinder University, Adelaide, Australia during February and March 2018.

On invitation of MDSA and three other special needs schools, the professor and students from Flinder University visited Yangon in July 2018 and conducted workshop to other members covering the topics of Positive Behavior Support, Sex Education for children with special need, Home based training with person with Down's syndrome, leisure play and Trust building management of teenagers etc.

3.3 Laws, Policies and Rights of Persons with Disabilities

Myanmar has a disability prevalence of 2.32 percent; translating to approximately 1.2 million persons living with disability The Republic of the Union of Myanmar is undertaking medical rehabilitation, social rehabilitation, and vocational rehabilitation for people with disability. (Census, 2014)

In 2008, Constitution Article 32: the Union shall care for mothers and children, orphans, fallen Defense Services personnel's children, the aged and the disabled. In 2011, Myanmar ratified CRPD. On 7 December 2011, Myanmar acceded to the Convention on the Rights of Persons with Disabilities (CRPD). The convention entered into force on 6 January 2012. In 2015, Law on Rights of Person with Disability-PWD by law on 2018 (Down's syndrome is under Intellectual Disability category). Article 16C: Parents/ caregivers may act for the best interest of an ID (Intellectual Disability) on behalf that ID. Article 19: An act of a person with ID, where may not know/ understand/ realize act is unlawful, shall not be regarded as a criminal act.

Intellectual disability means a significantly reduced ability to understand new or complex information and to learn and apply new skills (impaired intelligence). This results in a reduced ability to cope independently (impaired social functioning), and begins before adulthood, with a lasting effect on development. The use of the term intellectual disability in the context of the WHO initiative (better health, better lives) includes children with Down's syndrome who have intellectual impairments. There are no specific laws prohibiting discrimination against Down's syndrome with disabilities in employment, education, access to health care, or in the provision of other state services; the government does not provide ample protections for these people. (WHO, 2017)

The government did not actively discriminate against persons with disabilities in employment, access to health care, education, or the provision of other state services or other areas, but there were few official resources to assist persons with disabilities. There are no laws mandating accessibility to building, public transportation, or government facilities.

In National Health Plan, the state has laid down four social objective along with 12 national objectives and one of the social objectives is to uplifting health, fitness and education standard of the entire nation. In order to realize this social objective and the implement the National Health Policy, Ministry of Health has set two objectives- to enable every citizen to attain full life expectancy and enjoy longevity and to ensure that every citizen is free from disease. Three strategies have been identified to fulfill these objectives and those three strategies are: widespread dissemination of health information and education to reach rural areas, enhancing disease prevention activities and providing effective treatment of prevailing disease.

In implementing the objective of uplifting the health status of the entire nation, the Ministry of Health is taking the responsibility of providing comprehensive health care services covering activities for promoting health, preventing diseases, providing effective treatment and rehabilitation to raise the health status of the population. The main areas of service of delivery and support activities are: Health Service Delivery using Primary Health Care Strategy, Services for the Target Population Group, Promoting and Protecting Healthy Communities, Prevention, Control and Management of Communicable Disease and Non-communicable Disease.

Rehabilitation is implementing as one of the main objective under the prevention, control and management of communicable disease and non-communicable disease. The rehabilitation services are provided under the objective to prevent and reduce disease, disability and premature deaths from chronic non-communicable disease and conditions.

Myanmar Disability Rights law 2015 mentioned every person with disabilities can attend any mainstream government schools in their accessible area. Currently, the children with special needs can not readily attend the mainstream government schools because there is no readiness of the government school teachers who have been trained appropriately to nurture them in the classes. There are limited number of Government special need schools and private schools for persons with disabilities in Myanmar. At the present situation, persons with Down's syndrome are being invited just to entertain audience at some events for their performance as a tokenism with appreciation.

Vocational training and job creation are still limited for persons with Down's syndrome in Myanmar. There is a plan to develop national registry for persons with Down syndrome but still in the primitive stage and no special clinic for persons with Down syndrome.

3.4 Asia-Pacific Down's syndrome Federation (APDSF)

The APDSF is a federation of countries in the Asia Pacific region with representation from its various organizations formed for the betterment of persons with Down's syndrome. There are three committees which work on a focused agenda: Healthcare, Community Inclusion, and Education.

The decision to set up the APDSF was made by organizations and individuals interested in furthering links and support for each other in the Asia-Pacific region in 1992. The conference was hosted by the Australian Down's syndrome Association and the Chaired by founding President Penny Robertson. The meeting was attended by delegates from Australia, Malaysia, and Singapore. New Zealand, and India and the office of the Australian DSA acted as the office for APDSF until 1996.

In 1997 a meeting was held in the Philippines at which the Chair of the APDSF was handed over to Gerard Walmsley. Later in April 2004 along at Singapore it was re-structured and re-organized. It was attended by over 30 people and Dr. Balbir Singh was elected as the Chair. Side event was elected as the Chair. Side events were held at the World Down's syndrome Congress in Canada in 2006, Ireland in 2009 and South Africa in 2012.

Prior to the world Congress in Chennai, India it was decided to reactivate the local conferences and a meet was held in Singapore in 2013. At that meet Dr. Rhonda Faragher was elected as the Chair of APDSF and it was decided to set up a secretariat and that role was taken on by Japan. A meeting was held in February 2014 at Chennai and later in Bali, Indonesia in December 2014. The APDSF had a brief meeting in August 2015 along with at Chennai.

At the APDSF meet, it was decided to make APDSF as a registered body that would be able to address the needs of the Down's syndrome population in the Asia Pacific Region. Mr. N. Ramachandran was unanimously elected as the Chairperson for the APDSF. The idea was to have the registration done immediately so that the APDSF could start functioning. APDSF looks at itself as a voice that speaks for the rights of persons with Down's syndrome in the Asia Pacific region and a body who can provide support to them.

3.5 Special Training Schools for children with Down's syndrome

There are (28) Special training schools for children with Down's syndrome in Myanmar, (16) in Yangon, (6) in Mandalay, (3) in Shan state and (1) each in NayPyi Taw and Kachin state and is shown in the following table. Out of the total number of schools, the profile of the selected (3) schools are presented.

Table 3.2: Down's syndrome schools for Down's syndrome

No	Schools	Location
1	Eden	Yangon
2	Lighthouse Learning Center	Yangon
3	Flower Education Center	Yangon
4	Montessori Children's House	Yangon
5	New World Therapeutic Training Center	Yangon
6	Aye Myittar	Yangon
7	Moe Training Center for Special Needs	Yangon
8	Success Special Education Center	Yangon
9	Guiding Star Special Education Center	Yangon
10	Starfish Special Education	Yangon
11	Lumbini Academy	Yangon
12	Mandalay Special Education Center	Mandalay
13	Star Special Education Center	Mandalay
14	Smart Kids College	Mandalay
15	Thiri Thant Special Education Center	Mandalay
16	Lighthouse Learning Center	Mandalay
17	CLAT Center	Kachin
18	New Heaven Learning Center	Shan State
19	New Life Center	Shan State
20	CHIN CBR (Eden) Project	Shan State
21	Thazin Ni Special Training Center	Shan State
22	New Hope Association	Mandalay
23	Golden Hope Child Care & Physiotherapy Center	Yangon
24	Star Special Education	Nay Pyi Taw
25	Training School for the disable youth	Yangon
26	(IDDC) Hlaing Thar Yar	Yangon

27	Ingynn Learning Center	Yangon
28	Living Water	Yangon

Source: Myanmar Down's syndrome Association, 2019

Among these, (13) school in Yangon are link with Myanmar Down's syndrome Association and three of special need schools are described as follows.

Training School for the Disable Youth was founded on 6th October, 1971. Providing primary education to disabled children who are not retarded; providing special education to retarded children; providing training in handicraft to children who cannot cope with formal education; teaching children their daily routine. The school gave training to the age between 6 and 18. The capacity of the school is 100 pupils. Types of disabilities that the school gave training were amputee, cerebral palsy, autism, Down's syndrome, mentally retarded and osteoporosis. The school accepts the referral from parents or national rehabilitation hospital.

Lumbini Academy which was founded in 2006. School provided Inclusive Education Program to children with mental/physical handicaps, those being deficient in sight and hearing. The school gave training to the age between 3 and 21 and the total number of pupils is 50. The school also offers the vocational training for students who are limitation in academic education. The school has psychological department, art and craft department, music therapy department and play therapy for students.

New World Therapeutic Training Center which was opened in 2008. The school gave training to the age between 2 and 16. The school has the capacity of 100 pupils. The school has the following programs: Behavior modification, cognitive therapy, speech and language development exercises, play therapy, art activities, occupational therapy, physiotherapy, music activities, counseling, parents-child activities, personal-social-emotional skills, self-help skills, cognition/understanding skills, language and communication skills, fine motors skills and gross motor skills. The school curriculum based on Individualized Education Program.

CHAPTER (IV)

SURVEY ANALYSIS

4.1 Survey Profile

This survey profile is selected Myanmar Down's syndrome Association in Sanchaung Township, Yangon. Myanmar Down's syndrome Association (MDSA) was established on 15th February 2015 by a group of parents of the children with Down's syndrome. Ministry of Home Affairs issued a registration certificate to MDSA as a recognized local organization in Myanmar on 5th July 2016. Myanmar Down's syndrome Association is a non-profit, non-government association aiming to build capacities of care givers for persons with Down's syndrome through reachable and affordable trainings and referrals. The MDSA organized an event on every year of 21 March in coordination with entertainment group in order to raise Public Awareness on Down's syndrome. This survey was conducted on this event on the member who attended on this event in 2019. MDSA has 226 members in 2019. This survey conducted total number of 120 respondents who joined the MDSA event. The respondents are caregivers who look after Down's syndrome children age range from 1 to 15 years old.

4.2 Survey Design

The survey is designed to examine the social and economic burden of the families of Down's syndrome children. Regarding to the secondary from MDSA, there are 226 members in this association. To cover the whole members, 120 respondents were selected. Respondents were also selected who were attending the MDSA awareness event on March 21, 2019.

The survey design involves the use of quantitative data collection by conducting a survey collection. The survey was conducted from March to April in 2019.The questionnaire is constructed in three separate sections. For the first divided into two demographic factors. For the respondent demographic factors are to identify the age group of the respondents including questions relating to gender, education, age, marriage status, occupation, family members and family income. The Down's syndrome child demographic factors are to identify gender, age and education level. The second part is the problem of families of Down's syndrome children. The last section mainly focused on the difficulties and socio economic burden of the families of Down's syndrome children.

In the last section, questionnaire contained 12 questions which the results and responses were assessed based on Likert Scale, especially a multiple indicates- on a 5 point scale referring to numerous respondents and evaluation ranging from Strongly Disagree, Disagree, Neutral, Agree, Strongly Agree. The questionnaire constructed in Myanmar language first and then later translated it into English version.

4.3 Survey Results

This study concerns with research finding based on quantitative studies. This study aims to study socio economic burden to the families of Down's syndrome children. This section presents analysis and interpretation of the result of survey data collection and statistical techniques carried out from the answers of survey questionnaire.

4.3.1 Demographic Characteristics of Respondents

The total number of the respondents in this study is 120 randomly selected families of Down's syndrome children in Myanmar Down's Syndrome Association in Yangon Region.

(a) Demographic Characteristic of Respondents

In table (4.1), it expressed the demographic which include gender, age, family income, occupation, education level, marital status and number of family income.

Table (4.1) Demographic Characteristics of Respondent

Attitude	**Category**	**Number of Respondent**	**Percentage**
Gender	Male	28	23.22
	Female	92	76.67
	Total	**120**	**100**
Age	Under 30	13	10.83
	30-35	17	14.77
	36-40	22	18.33
	Over 40	68	56.67
	Total	**120**	**100**
Marital Status	Married	98	81.67
	Divorced	0	0
	Widow/widower	7	5.83
	Single	15	12.5
	Total	**120**	**100**
Occupation	Own business	18	15
	Private employee	37	30.83
	Government official	35	29.17
	Dependent	30	25
	Total	**120**	**100**
Family Member	Fewer than 5	95	79.17
	5-7	21	17.5
	8-12	3	2.5
	Over 12	1	0.83
	Total	**120**	**100**
Education Level	Middle school	4	3.35
	High school	31	25.85
	Graduate	82	68.3
	Master	3	2.5
	Total	**120**	**100**

Source: Survey data, 2019

According to the table (4.1), the demographic characteristic data expressed the background of the respondents in term of gender, age, education level, occupation, marital status, family income and family member in household. In term of gender, most of the respondents, 76.67%, 92 in number were female caregivers and the rest, 23.22% is male caregivers. Next, have a look to age group, most of the respondent caregivers' age range over 40 years old, 68 persons, 56.67% out of 100. 98 respondents are married and 12.5% of respondents are single caregivers. 35 respondents are government servant who were the second largest occupation group and which occupied 29.17% of the study and the rest 30% are dependent persons and 15%, 18 respondents have own business.

For the family members, 95 persons of respondents, over 70% of respondents have less than 5 family members. Only 1 of the respondent has over 12 family members. In the last row concerning Education nearly all of the respondents 68.3% are graduates, almost 29% are under graduates. There are only three persons holding master degree.

(b) Monthly Income of Families of Respondent

Table (4.2) describes the monthly income of families of respondent that divided into four categories.

Table (4.2) Monthly Income of Families

Income	**No of Respondent**	**Percentage**
Under 300,000	30	25
300,000-500,000	27	22.5
500,000-800,000	42	35
Over 800,000	21	17.5
Total	**120**	**100**

Source: survey data, 2019

According to table (4.2), 25% of families have income under 300,000. The highest income group is 35% respondent in the income range of between 500,000-

800,000. 22.5 percent of respondent have income between 300,000 to 500,000. Only 21 respondents, 17.5% have income over 800,000.

4.3.2 Demographic Characteristic of Down's syndrome Children

(a) Demographic Characteristic of Down's syndrome Children

This table described demographic characteristic of Down's syndrome children which includes gender, age of Down's syndrome children as shown in below.

Table (4.3) Demographic Characteristic of Down's syndrome Children

Attitude	**Category**	**Number of children**	**Percentage**
Gender	Male	74	61.67
	Female	46	38.33
	Total	**120**	**100**
Age	Less than 5 years	67	55.8
	6-8	24	20
	9-12	8	6.7
	More than 12	21	17.5
	Total	**120**	**100**

Source: survey data, 2019

Table (4.3) shows 61.67% of Down's syndrome children are males and the rest of respondents 38.33% are females. The highest population shows 55.8% in less than five years old. Between six to eight years old is 20% and nine to twelve years old is only 8 persons, 6.7%. More than twelve years is 17.5%

(b) Education of Down's syndrome Children

Table (4.4) describes the education condition of Down's syndrome children.

Table (4.4) Education of Down's syndrome Children

Education condition	No of Down's syndrome children	Percentage
Special need private school	44	36.7
Government training school for disable youth	38	31.7
Government primary school	4	3.3
No Education	34	28.3
Total	**120**	**100**

Source: survey data, 2019

According to table (4.4), there are 44 Down's syndrome children, who attend the special need private school. 38 Down's syndrome children, 31.7% are attending at government training school for disable youth which accept only one hundred intellectual disabilities in school. 28.3 percent of Down's syndrome children are not attending school or training for special need. Only 3.3% of Down's syndrome children are attending primary government officials who are between KG to Grade 4.

4.3.3 Education of Down's syndrome children related to Family income

Table (4.5) describes the education condition of Down's syndrome children which is related to family income.

Table (4.5) Education of Down's syndrome children related to Family Income

Income	Down's syndrome Education				Total
	Special school	Training school	Government primary	No education	
Under 300,000		5		25	30
300,000-500,000	2	19	1	5	27
500,000-800,000	21	14	3	4	42
Over 800,000	21				21
Total	**44**	**38**	**4**	**34**	**120**

Source: survey data, 2019

According to table (4.5), there are only 5 Down's syndrome children who are attending at Government training school for disable youth and 25 children of Down's syndrome are not have no education level. For family income between 300,000-500,000, there are 19 Down's syndrome who are attending at Government training school for disable youth and 1 child who have Government official primary education. For family income group between 500,000-800,000, nearly half of Down's syndrome is attending at special need private school. Income over 800,000 groups, all of the Down's syndrome children are attending at special private schools. All of the special need private schools have higher school fees which cost at least 150,000 per month. For lower income family group, school fees are very difficult and which can cause financial burden for family. Most of the Down's syndrome who have lower family income has no education because most of the families do not have enough knowledge about Down's syndrome children. Even families know about Government training school, this school has limit student number which can accept 100 pupils for all intellectual disabilities for all counties.

4.3.4 (a) Health Condition of Down's syndrome Children

In table (4.6), questions are designed to get Yes/No answer concerning the health situation of Down's syndrome children.

Table (4.6) Health Condition of Down's syndrome Children

Description	Yes	%	No	%	Total
Does Down's syndrome children suffer illness than other normal children	92	76.7	28	23.3	120
Does Down's syndrome children take more time to get recovery well than other children	78	65	42	35	120
Does Down's syndrome children have serious medical problems (heart problems, poor immune system, obstructed gastrointestinal tract)	63	52.5	57	47.5	120

Source: Survey data, 2019

According to table (4.6), more than 75% of Down's syndrome children suffer illness than other normal children because most of the Down's syndrome children have lower immune system than other normal children. Because of poorer immune system, Down's syndrome children take more time to recovery well. 79 children of Down's syndrome take more time to get recover from illness and the rest of 35% does not need to take more time to get recover. Some of the Down's syndrome has great immune system like normal children. More than 50% of Down's syndrome children have serious medical problems from birth (heart problems, poor immune system, and obstructed gastrointestinal tract), the rest of 47.5% does not have serious medical problems.

(b) Health condition of families of Down's syndrome children

In table (4.7), questions are designed to get Yes/No answer concerning the health situation of Down's syndrome children.

Table (4.7) Health Condition of Families of Down's syndrome children

Description	Yes	%	No	%	Total
Does family member suffer illness or injuries because of Down's syndrome children	31	25.8	89	74.2	120
Does existing disease of family members become worse because of Down's syndrome children	-	-	120	100	120
Does family member have mental illness because of Down's syndrome children	12	10	108	90	120
Does family member have more stress because of Down's syndrome children	34	28.3	86	71.7	120

Source: survey data, 2019

According to table (4.7), 74.2% of family member does not suffer illness or injuries because of caring Down's syndrome children and the rest of 25.8% suffers illness or injuries because of Down's syndrome children. All of respondent answered that there is no family member whose existing disease become worse because of Down's syndrome children. Nearly all of the respondents, 90% of respondents does not have mental illness because of Down’s syndrome children. 34 respondents, 28.3% have more stress because of Down’s syndrome children and 71.7% of respondents do not have more stress because of Down’s syndrome children.

(c) Medical Checkup of Down’s syndrome Children related to Family Income

Table (4.8) describes the medical checkup related to family income of Down’s syndrome children.

Table (4.8) Medical Checkup of Down’s syndrome Children related to Family Income

Income	Medical Checkup			
	Yes	%	No	%
Under 300,000	2	6.7	28	93.3
300,000-500,000	4	14.8	23	85.2
500,000-800,000	12	28.6	30	71.4
Over 800,000	18	85.7	3	14.3

Source: survey data, 2019

According to table (4.8), more than 90% of Down’s syndrome children cannot do medical checkup regularly that have income under 300,000. Nearly all of Down’s syndrome do medical checkup regularly that have income over 800,000. As the result of table (4.8) family income affect medical checkup and health care condition for Down’s syndrome children.

4.3.5 (a) Problems of Caregivers of Down’s syndrome Children

The statement in this section is to know the problems of caregivers of Down’s syndrome children. Questionnaires are designed to get Yes/No answer concerning the problems of caregivers.

Table (4.9) Problems of Caregivers of Down's syndrome Children

Descriptions	Yes	%	No	%	Total
Does Down's syndrome children more taking care than other children	109	90.8	11	0.2	120
Does family member delay on performance of daily routine because of taking care of Down's syndrome children	90	75	30	25	120
Does family member delay on performance of their respective responsibilities because of Down's syndrome	48	40	72	60	120
Does Down's train to rely on their own as independent children	90	75	30	25	120
Does Down's syndrome children involvement in household chores	96	80	24	20	120

Source: survey data, 2019

According to table (4.9), 90% of respondent are more taking care on Down's syndrome children than other children because Down's syndrome children are intellectual delay persons. Ninety respondents (75%) are delaying on performance of daily routine because of taking care of Down's syndrome. Moreover, 60% of family member are not delaying on performance of their respective responsibilities for taking care of Down's syndrome because higher income families rent caregivers to take care for Down's syndrome children. Furthermore, respondent of 75% are training Down's syndrome children to rely on their own as independent children. As Down's syndrome are intellectual delay person they do not have self-help skills. Even caregivers are train children to rely on their own as independent children 80% of Down's syndrome children can involvement in household chores. Because when Down's syndrome involve in household, they feel that they can do as a normal children by this way Down's syndrome children feel happiness.

(b) Knowledge of families of Down's syndrome Children

In table (4.10), questions are designed to get Yes/No answer concerning the knowledge of respondents about Down's syndrome.

Table (4.10) Knowledge of the families about Down's syndrome

Description	**Yes**	**%**	**No**	**%**	**Total**
Do you know why Down's syndrome causes	89	74.2	31	25.8	120
Is there medicine or treatment to recover from Down's syndrome	118	98.3	2	1.7	120
Can Down's syndrome symptom diagnose before birth	59	49.2	61	50.8	120
Do you know physical characteristic(physical appearance) of Down's syndrome	120	100	-	0	120

Source: survey data, 2019

According to table (4.10), knowledge of the families about Down's syndrome children, more than 70% of the families know why Down's syndrome causes. The rest of 25.8% do not know why Down's syndrome causes in children. Nearly all of respondents know that there is not medicine or treatment to recover from Down's syndrome. As Down's syndrome is genetic problems conditions but not a cure, there is not treatment for Down's syndrome. Nearly half of the respondents know that Down's syndrome genes can be test when the mother pregnant. All of the respondents know the physical characteristic (physical appearance) of Down's syndrome. As Down's syndrome is intellectual delay person and have the same look, all of the respondents can distinguish Down's syndrome children.

4.3.6 Difficulties Regarding Down's syndrome Children within Families

In this section, the difficulties of respondents having Down's syndrome children in families are described by the usage of likert scale questions format. Generally, the difficulties of respondents divided into 3 parts. These are difficulties concerning with taking care of Down's syndrome children, difficulties in respondent's social activities and difficulties in financial.

(a) Difficulties relating to take care of Down's syndrome children

The following table (4.11) briefly analyses survey data result of 120 respondents concerning with difficulties in taking care of Down's syndrome children.

Table (4.11) Difficulties relating to take care of Down's syndrome Children

Description	1	2	3	4	5	Total	Mean score
Taking care of Down's syndrome children is more difficult than other normal children	-	-	7 6%	38 32%	74 62%	120	4.5
Down's syndrome child's behavior (fussy, aggressive, love to destroy, lack of sleep), family is difficult.	-	17 14%	28 23%	44 37%	31 26%	120	3.7
Family is difficult because Down's syndrome children are lacking consideration of other people (being noisy while other people are being rest).	8 6%	19 16%	42 35%	33 28%	18 15%	120	3.2
Family is difficult for Down's syndrome children inability to look after himself.	20 17%	22 18%	33 27%	38 32%	7 6%	120	3.2
Total Mean Score							**3.7**

Source: survey data, 2019

Table (4.11) shows difficulties level regarding Down's syndrome children within families. Taking care of Down's syndrome children results show highest among four statements with difficulty level according to mean result 4.5. So taking care of Down's syndrome children is the most difficult for families than taking care of other children. Among four categories, Down's syndrome child behavior (fussy, aggressive, love to destroy, lack of sleep) results average mean score of 3.7. This category result second highest among four categories. Because of lacking consideration of other people (being noisy while other people are taking rest), it results mean score is 3.2. Due to his or her inability to look after himself or herself (personal hygiene, eating, going to school), it result is 3.2. Overall total mean score is 3.7 and it is above the average point 2.5. All the statements were above 2.5 mean scores such that the respondent had high difficulties for taking care of Down's syndrome children.

(b) Difficulties in Social Issue

In this part, table (4.12) expressed the perception of caregivers' social problems regarding Down's syndrome children.

Table (4.12) Difficulties in social issue

Description	1	2	3	4	5	Total	Mean score
Because of the child with Down's syndrome, family suffer social isolation	15 12.5%	31 25.8%	40 33.4%	24 20%	10 8.3%	120	2.9
Activities (excursion trip) and plans of the family have to postpone because it is difficult to take him/her with or leave him/her at home.	10 8.3%	8 6.7%	30 25%	30 25%	42 35%	120	3.7
Problems and misunderstandings occur among family members because of the child with Down's syndrome, it makes family difficult	36 30%	18 15%	44 36.7%	22 18.3%	-	120	2.4
Because of the child with Down's syndrome, family feels embarrassment in society.	5 4.2%	24 20%	30 25%	28 23.3%	33 27.5%	120	3.5
Total mean score							**3.1**

Source: Survey data, 2019

Table (4.12) shows highest social problems were postponed plans or activities (excursion trip) because families have difficult to take Down's syndrome children with or leave him/ her at home with mean of 3.7. As Down's syndrome children are intellectual delay persons and most of the children are physically weak (cannot walk well, cannot stay alone, and cannot control his or her emotions). The second highest mean score is 3.5, because of the child with Down's syndrome, family feel embarrassment in society. Because of the child with Down's syndrome, family suffer social isolation, it result is 2.9. As Myanmar citizens are helpful and have lovely culture, families of Down's syndrome cannot feel social isolation too much. The lowest social problems were due to the problems and misunderstandings occur among family members with the mean score of 2.4. Overall total mean score is 3.1 and it is above average point of 2.5. Among four statements, three statements were above 2.5 mean score so the respondents had difficulties in social issue.

(c) Difficulties in financial

The statements in this section describe to know the perception of caregivers of financial problems regarding Down's syndrome children.

Table (4.13) Difficulties in Financial

Description	1	2	3	4	5	Total	Mean score
Give up job and consequently losing income problem for taking care of Down's syndrome is difficult	4 3.3%	43 35.8%	48 40%	23 19.2%	2 1.7%	120	2.8
Financial difficulty for health care cost due to Down's syndrome children is difficult for family	6 5%	20 16.7%	32 26.7%	56 46.6%	6 5%	120	3.3
Caring services fees and therapies for Down's syndrome children is difficult for family.	-	20 16.7%	60 50%	34 28.3%	6 5%	120	3.3
Total mean score							**3.1**

Source: survey data, 2019

Table (4.13) shows financial difficulties for families of Down's syndrome children. Financial difficulties for caring services fees and therapies for Down's syndrome children had mean of 3.3. The same with financial difficulty for health care cost due to Down's syndrome children had mean of 3.3. Give up job and consequently losing income problem for taking care of Down's syndrome children is with mean point of 2.8. All of the three statements are above 2.5 difficulty score and overall mean score is 3.1. So the respondents had financial difficulty.

4.3.7 Overall Difficulty level of Families of Down's syndrome Children

This section presented this overall difficulty of families of Down's syndrome children. Each category presented with its own total mean score.

Table (4.14) Overall Difficulty levels of Families of Down's syndrome Children

Description	Mean Score
Difficulties related to take care of Down's syndrome children	3.7
Difficulties in Social Issue	3.1
Difficulties in financial	3.1

Source: Survey data, 2019

Table (4.14) shows the comparison of mean score of difficulties within families of Down's syndrome children. The difficulties related to take care of Down's syndrome children is 3.7 mean score, whereas the mean score of difficulties in social is 3.1. The difficulty in financial mean score is 3.1. Comparing among these 3 difficulties, the difficulties related to take care of Down's syndrome children is highest mean score, means that it is the highest burden for families of Down's syndrome children.

CHAPTER V

CONCLUSION

5.1 Findings

The socio-demographic characteristics of respondents are as follow: more than half of caregivers are female over 76 percent while only 23.33 percent of caregivers are male. More than half of caregivers, 56.67 percent are over 40 years old. Two-third of the respondents is higher educated people. 20.83 percent of caregivers are private employees and 25 percent of respondents are dependent person. Respondent 17.5 percent have income over 800,000.

Regarding the socio demographic of Down’s syndrome children, 61.67 percent are males and 38.33 percent are females. Less than 5 years old children are 55.8 percent and age between 9 years to 12 years is 6.7 percent and 36.7 percent have special need private education.

Concerning the education of Down’s syndrome children related to family income, families which have over 800,000 kyats per a month can invest on special need private school for Down’s syndrome children. For the family with under 300,000 kyats per a month have difficult to invest education for Down’s syndrome children.

Regarding the health condition of Down’s syndrome children, more than 75 percent of children suffer illness than other normal children and 65 percent of children take more time to get recovery well. For health condition of family members, 74.2 percent does not suffer illness or injuries because of Down’s syndrome children.

According to medical checkup of Down’s syndrome children related to family income, families that have income over 800,000 can do medical checkup regularly.

Regarding the problems of caregivers of Down’s syndrome children, more than 90 percent have problems for taking care of Down’s syndrome children. Caregivers of 75 percent of caregivers delay on performance of daily routine because of caring Down’s syndrome children. Even spending a lot of time on caring Down’s syndrome children, 60 percent of families do not delay on performance of respective responsibilities.

Concerning the knowledge of families of Down’s syndrome children, 74.2 percent of families know about why Down’s syndrome causes. All of the respondents know physical characteristic (physical appearance) of Down’s syndrome.

According to the survey data, the difficulties regarding Down’s syndrome children within family, taking care of Down’s syndrome children, results highest among four statements with the mean score of 4.5. So taking care of Down’s syndrome children is the most difficult for caregivers. The mean of 3.2 shows in fact that lacking consideration of other people are being rest) and because of inability to look after himself makes the family difficult. It is the lowest mean score among four statements. Overall mean score is 3.7 and it is above the average 2.5.

Concerning with highest social problems was due to the family postponed plans or excursion trip because of difficult to take or leave Down’s syndrome children. The total mean score of social issue is 3.1.

Concerning with the highest financial burden was due to health care cost for Down’s syndrome and caring services fees and therapies for Down’s syndrome children.

Comparing total means score among taking care of Down’s syndrome child, social issue and financial, difficulties related to take care of Down’s syndrome children were the highest burden of 3.7.

Despite this study could not draw out significant predictors of both Down’s syndrome children and caregivers, which were associated with family burden, it was expected that the results of this study might be useful for interventions to reduce the sense of burden felt by family members who take care of Down’s syndrome children. In conclusion, it is found that caregivers of Down’s syndrome children had social and economic burden. The results and conclusions of the study are expected to be valuable in some extend for caring of Down’s syndrome children.

5.2 Recommendation

According to secondary data, there is only one public school for children with special need in Yangon. Therefore more public schools should open in Yangon under the guidance of Department of Social Welfare. There is no specific policy for person with Down’s syndrome. So there is a need to set up the policy and specific guideline for Down’s syndrome. Public policies are needed to implement the health care services for children with Down’s syndrome. According to education status of Down’s syndrome children, only 3.3 percent have formal education. More effective and efficient training program for Down’s syndrome is able to access to formal education. The highest percent of Down’s syndrome family member has difficulty for taking care of Down's syndrome children. Therefore awareness training program family members should be improved. All households should focus more on behavior therapy program both in private and public sectors. More open and friendly groups are needed for the family because the families suffer social and economic burden. Some families did abuse things to relief their stress related to Down's syndrome children. So creation for better environment for families is needed to abuse their stress. According to table (4.13), the main financial burdens for families were high cost of special education service fees and caring service fees. The government should give subsidy for the Down's syndrome child is needed.

This study revealed that caregivers of Down's syndrome have family burden. So caregivers of children with Down's syndrome may require services and care that extend beyond the current health care system. Raising community awareness in a culturally sensitive manner should be an important part of service development. This is particularly important for early detection and diagnosis of Down's syndrome disorder as early interventions are likely to be more effective in care giving for Down's syndrome children. School mental health programme should be promoted in raising awareness about mental disorder not just in the school children but also their non-school going, parents and neighbors. More generalized mass media campaigns will need to be implemented side by side with intervention delivery to increase awareness and reduce stigma about the Down's syndrome, ultimately leading to a greater acceptance of Down's syndrome children by the community.

REFFERENCES

1. A. A. Rahman, N. Mohamad, K. I. Musa, W. P. W. Ibrahim., A. Othman, A. A. Aziz, et al., A preliminary study on the reliability of the Malay version of PedsQL™ Family Impact Module among caregivers of children with disabilities in Kelantan, Malaysia, Malaysian Journal of Medical Sciences, vol. 18(4), pp. 62-67, 2011.
2. A. P. Corrice and L. M. Glidden, The Down syndrome advantage: Fact or fiction?,The American Journal on Intellectual and Developmental Disabilities, vol. 114(4), pp.
3. Bailey DB, Bruder MB, Hebbeler K (2006). Guidance for States in Documenting Family Outcomes for Early Intervention and Early Childhood Special Education. Menlo Park, CA: SRI International
4. Bailey DB, Hebbeler KM, Spiker D, Scarborough A, Mallik S, Nalson L (2005). 36 Month Outcomes For Families Of Children With Disabilities Participating In Early Intervention
5. Bowe FW (2004). Early Childhood Special Education: Birth to Eight. 3rd ed. Clifton Park, NY: Delmar Learning.
6. Bull, M. J., & the Committee on Genetics. (2011). Health supervision for children with Down syndrome.
7. Cullen CC MacLeod JA, Williams PD, Williams AR (1991). Coping, Satisfaction, And The Life Cycle In Families With Mentally Retarded Persons Issues.
8. D. L. Rezendes and A. Scarpa, Associations between parental anxiety/depression and child behavior problems related toautism spectrum disorders: The roles of parenting stress and parentinf self-efficacy, Autism Research and Treatment, 2011.
9. Down syndrome. (2012). In A.D.A.M. Medical Encyclopedia. Retrieved June 11, 2012,
10. Fidler DJ, Most DE, Booth-LaForce C, et al. (2006). Stress trajectories in families of young children with Down syndrome
11. H. Dzalani and K. Shamsuddin, A review of definitions and identifications of specific learning disabilities in Malaysia and challenges in provision of services, Pertanika Journal of Social Sciences & Humanities, vol. 22(1), pp. 1-18, 2014.

12. J. Blacher and L. L. McIntyre, Syndrome specificity and behavioural disorders in young adults with intellectual disability: cultural differences in family impact, Journal of Intellectual Disability Research, vol. 50(3), pp. 184-198, 2006.
13. M. McPherson, P. Arango, H. Fox, C. Lauver, M. McManus, P. W. Newacheck, et al., A new definition of children with special health care needs, Pediatrics, vol. 102, pp.137-139, 1998
14. Martin SL, Ramey CT, Ramey S (1990). The Prevention of intellectual impairments in children of impoverished families: findings of a randomized trial of educational daycare.
15. National Dissemination Center for Children with Disabilities (NICHCY), Down syndrome, Disability Fact Sheet, No. 4. 2010.
16. R. J. McGrath, M. L. Stransky, W. C. Cooley, and J. B. Moeschler, National profile of children with Down syndrome: Disease burden, access to care, and family impact, The Journal of Pediatrics
17. R. J. McGrath, M. L. Stransky, W. C. Cooley, and J. B. Moeschler, National profile of children with Down syndrome: Disease burden, access to care, and family impact, The Journal of Pediatrics, vol. 159, pp. 535-540, 2011.
18. S. Gallagher and A. Hannigan, Depression and chronic health conditions in parents of children with and without developmental disabilities: The growing up in Ireland cohort study, Research in Developmental Disabilities
19. S. Gallagher, A. C. Phillips, and D. Carroll, Parental stress is associated with poor sleep quality in parents caring for children with developmental disabilities, Journal of Pediatric Psychology, vol. 35(7), pp. 728-737, 2010.
20. S. Werner and C. Shulman, Subjective well-being among family caregivers of individuals with developmental disabilities: The role of affiliate stigma and psychosocial moderating variables, Research in Developmental Disabilities, vol. 34, pp. 4103-4114, 2013.
21. S.J. Buckley. Down Syndrome Issues and Information. Portsmouth, UK : Down Syndrome Educational Trust, 2000. (living with Down's syndrome)
22. T. Benjak, G.V. Mavrinac, and I. P. Šimetin, Comparative study on self-perceived health of parents of children with autism spectrum disorders and parents of non-disabled children in Croatia, Croatian Medical Journal, vol. 50(4), pp. 403-409, 2009.

23. T. S. Hoe, N. Y. Boo, and M. M. Clyde, Incidence of Down's syndrome in a large Malaysian maternity hospital over an 18 month period, SingaporeMedical Journal, no. 30, pp. 246-248, 1989.
24. Ulrich, D. A., Burghardt, A. R., Lloyd, M., Tiernan, C., & Hornyak, J. R. (2011) Physical activity benefits of learning to ride a two-wheel bicycle for children with Down syndrome: A randomized trial.
25. V. Merkaj, M. Kika, and A. Simaku, Symptoms of stress, depression and anxiety between parents of autistic children and parents of tipically developing children, Academic Journal of Interdisciplinary Studies, vol. 2(2), pp. 345-352, 2013.
26. Watts BH (1980). Evaluation of early intervention programs for young handicapped children. Brisbane: August Workshop of the Schonell Educational Research Centre
27. Watts BH (1982). Early Intervention Programs For Young Handicapped Children In Australia 1979–1980. Canberra: Australian Government Publishing Service.

Websites

1. http://apdsf.org/apdsf-country-reports/Myanmar.pdf
2. http://www.annwphoto.com/down-syndrome-in-myanmar
3. http://www.intellectualdisability.info/diagnosis/articles/downs-syndrome
4. http://www.ndss.org/wp-content/uploads/2017/10/Health_Care_Information_for_Families_of_Children_with_Down_Syndrome-1.pdf
5. https://library.down-syndrome.org/en-gb/research-practice/online/2008/families-down-syndrome-what-need/
6. https://library.down-syndrome.org/en-us/research-practice/04/3/families-down-syndrome/
7. https://www.ds-int.org/asia-pacific
8. https://www.ndss.org/about-down-syndrome/down-syndrome/
9. https://www.ndss.org/about-down-syndrome/down-syndrome/

APPENDIX
Survey Questionnaire

This study will not attribute any comments to your personal as responses are confidential. The information gathered from these survey questionnaires will be used merely for MPA Thesis only. Participation in this research is voluntary. Your open and true answers will be very supported to this thesis. Thank you very much for your kind contribution.

Nan Su Yi Myo
MPAII-12(18th Batch)

Section 1 General Information

In this section, respondents have to answer questions concerned with the general information of participants.

1. Gender

☐ Male ☐ Female

2. Age of respondent

☐ Less than 30 ☐ 30-35 ☐ 36-40 ☐ More than 40

3. Education of respondent

☐ Middle-School ☐ High-School ☐ Bachelor Degree ☐ Above Graduate

☐ Other

4. Marriage Status

☐ Single ☐ Married ☐ Divorced/ Separated

☐ Widow/Widower

5. Occupation of respondent

☐ Own-Business ☐ Private-Employee ☐ Public-Employee ☐ Other

6. Family Income (Per Month)

☐ Less than 300,000 ☐ 300,000-500,000 ☐ 500,000-800,000

☐ Above 800,000

7. Family Members

☐ Less than 5 ☐ 5-7 ☐ 8-12 ☐ Over 12

Section 2 Characteristic of down's Syndrome Children

1. Age of Down's syndrome

☐ Under 5 years ☐ 6-8 ☐ 9-12 ☐ Over 12 years

2. Gender of Children

☐ Male ☐ Female

3. Education of Children

☐ Pre-School or special school ☐ 1st – 4th ☐ Over 4th

☐ No Education

Section 3 Health Condition and Knowledge about Down's syndrome

1. Does Down's syndrome children suffer illness than other normal children?

Yes ☐ No ☐

2. Does Down's syndrome children take more time to get recovery well than other children?

Yes ☐ No ☐

3. Does Down's syndrome children have serious medical problems (heart problems, poor immune system, obstructed gastrointestinal tract?

Yes ☐ No ☐

4. Does family member suffer illness or injuries because of Down's syndrome children?

Yes ☐ No ☐

5. Does existing disease of family members become worse because of Down's syndrome child?

Yes ☐ No ☐

6. Does family member have mental illness because of Down’s syndrome children?

Yes ☐ No ☐

7. Does family member have more stress because of Down’s syndrome children?

Yes ☐ No ☐

8. Do you know why Down’s syndrome causes?

Yes ☐ No ☐

9. Is there medicine or treatment to recover from Down’s syndrome?

Yes ☐ No ☐

10. Can Down’s syndrome symptom diagnose before birth?

Yes ☐ No ☐

11. Do you know physical characteristic (physical appearance) of Down’s syndrome?

Yes ☐ No ☐

12. Can you do medical checkup regularly for Down’s syndrome children?

Yes ☐ No ☐

Section 4 Problems of caregivers of Down’s syndrome children

1. Does Down’s syndrome children more taking care than other children?

Yes ☐ No ☐

2. Does family member delay on performance of daily routine because of taking care of Down’s syndrome

Yes ☐ No ☐

3. Does family member delay on performance of their respective responsibility because of taking care of Down’s syndrome children?

Yes ☐ No ☐

4. Does a Down ’s syndrome child train to rely on their own as independent child?

Yes ☐ No ☐

5.Does Down’s syndrome children involvement in household chores?

Yes☐ No ☐

Section 5 Difficulties Faced by Caregivers of Down's syndrome Chilren

For each of the statement below, please indicate the extent of your agreement or disagreement by circling in the appropriate box. The response scale is as follow.

1. Strongly disagree 2. Disagree 3. Neural 4. Agree 5. Strongly agree

Difficulties relating to take care of Down's syndrome children

Questions	1	2	3	4	5
Taking care of Down's syndrome children is difficult than other normal children	1	2	3	4	5
Down's syndrome behavior (fussy, aggressive, love to destroy, lack of sleep), family is difficult.	1	2	3	4	5
Families is difficult because Down's syndrome children are lacking consideration of other people (being noisy while other people are being rest)	1	2	3	4	5
Family is difficult for Down's syndrome inability to look after himself.	1	2	3	4	5

Difficulties relating to social issue

Questions	1	2	3	4	5
Because of the child with Down's syndrome family suffer social isolation.	1	2	3	4	5
Activities (excursion trip) and plans of the family have to postpone because it is difficult to take him/her with or leave him/her at home	1	2	3	4	5
Problems and misunderstandings occur among family members because of a child with Down's syndrome, it makes family difficult.	1	2	3	4	5
Because of the child with Down's syndrome, family feels embarrassment in society.	1	2	3	4	5

Difficulties in financial

Questions	**1**	**2**	**3**	**4**	**5**
Give up job and consequently losing income problem for taking care of Down's syndrome is difficult.	1	2	3	4	5
Financial difficulty for health care consistent to Down's syndrome children is difficult.	1	2	3	4	5
Caring services fees and therapies for Down's syndrome children is difficult for family.	1	2	3	4	5