

AUTISM SPECTRUM DISORDER: AWARENESS, DIAGNOSIS AND INTERVENTIONS IN MYANMAR

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Autism Spectrum Disorder: Awareness, Diagnosis and Interventions in Myanmar

A thesis submitted in partial fulfillment of the requirement for the degree of

Master of Public Health

by

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Myanmar

Declaration:

Where other people's work has been used (either from a printed source, internet or any other source) this has been carefully acknowledged and referenced in accordance with departmental requirements.

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ABBREVIATIONS

AAN	ASEAN Autism Network
ADDN	Autism and Developmental Disorders
ADOS	Autism Diagnostic Observation Schedule
ADI-R	Autism Diagnostic Interview - Revised
APA	American Psychiatric Association
APCP	Association of Pediatrics Chartered Physiotherapist
ASD	Autism Spectrum Disorder
ASEAN	Association of the South-East Asian Nations
AWWA	Asia Women Welfare Association
CBO	Community-Based Organization
CBR	Community-based Rehabilitation
CD	Communicable Disease
CDC	Centre of Disease Control
CNS	Central Nervous System
CP	Cerebral Palsy
CRC	Convention on the Rights of the Child
CRPD	Convention on the Rights of Persons with Disability
DINF	Disability Information Resources
DPOs	Disabled People's Organizations
DSM	Diagnostic and Statistical Manual of Mental Disorders
DSW	Department of Social Welfare
Dx	Diagnosis
ECCD	Early Childhood Care and Development

EFA-NAP	Education for All - National Action Plan
GDP	Gross Domestic Product
HDI	Human Development Index
HICs	High-income countries
HIV	Human Immuno-deficiency Virus
IAEN	International Autism Epidemiology Network
ID	Intellectual Disability
IE	Inclusive Education
IHLC	Integrated Household Living Condition Survey
IIC	Intellectual-impaired children
INGO	International Non-Governmental Organization
JICA	Japan International Cooperation Agency
KIT	Koninklijk Instituut voor de Tropen
LRC	Local Resource Center
MAA	Myanmar Autism Association
MAS1P	Mental Age Spectrum within 1 Person
MDG	Millennium Development Goal
MOH	Ministry of Education
MR	Mental Retardation
MSWRR	Ministry of Social Welfare, Relief and Resettlement
NCD	Non-Communicable Disease
NGO	Non-Government Organization
PDD-NOS	Pervasive Developmental Disorder-Not Otherwise Specified
PICOWO	Psychological Institute for Consultation, Education and Scientific Research
PWD	Persons With Disability

SEA	South-East Asia
TLMI	The Leprosy Mission International
UN	The United Nations
UNDP	United Nations Development Program
UNESCAP	United Nations Economic and Social Commission for Asia and the Pacific
UNESCO	United Nations Educational, Scientific and cultural Organization
UNICEF	United Nations Children's Fund
USAID	The United States Agency for International Development
WHO	World Health Organization

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ABSTRACT

Autistic Spectrum Disorders (ASDs) are regarded as the life-long neuro-developmental disorders.

Problem statement: The global prevalence of 1 in 160 individuals translates into about 375,000 inhabitants with ASD in Myanmar. Yet, ASD has never been surveyed and research is nearly non-existent in Myanmar. The policy makers and public have limited knowledge about ASD as well as about its burden on individuals, families and the public. Furthermore, there are only a handful of intervention services for ASD in Myanmar which are not accessible for the majority of the population.

Methodology: A literature review and a qualitative study were done to explore the awareness, recognition and interventions for ASD and their challenges in Myanmar. Altogether 23 in-depth interviews were conducted with the parents of ASD individuals and key informants from the ministries, INGOs, DPOs and special and mainstream schools. An adapted framework on effective intervention for ASD was used for data analysis.

Findings: There are no specific laws or policies for ASD and intellectual disabilities in Myanmar. The existing laws on disabilities are not active and the public is not aware of these. There are significant delays in getting the diagnosis and the appropriate interventions. In addition, there is no academic training program on ASD in the country resulting in very few professionals to provide services. Financial, technical and infrastructural support by the government is not in place and international support is still limited. The government and the local NGOs have recently initiated help for ASD and a new disable law is under development.

Conclusion and recommendations: Except limited ASD diagnosis and intervention services in some big cities, nothing exists for people with ASD in Myanmar yet. To establish effective and feasible help for ASD, a comprehensive and multi-sectorial approach is recommended with the participation and support of the beneficiaries, community, government, international partners and local organizations.

Keywords: Autism Spectrum Disorder, ASD in Myanmar, autism help, awareness, diagnosis and interventions for ASD, intellectual disabilities in Myanmar.

Word Count: 13,041

INTRODUCTION

“I can remember the frustration of not being able to talk. I knew what I wanted to say, but I could not get the words out, so I would just scream,” Temple Grandin



Autistic spectrum disorders (ASD) are one of the life-long neuro-developmental disabilities characterized by core problems in two domains: communication and repetitive or stereotypic behavior. Global prevalence of ASD is 1 in 160 individuals while recent estimate in the United State reveals much higher prevalence of 1 in 68 children. It has been recognized as a growing and important public health concern. Global prevalence rate translates into nearly 375,000 inhabitants in Myanmar.

According to the newest insights (the theory of the socioschem with the Mas1P, Delfos, 2006; 2011) people with ASD have mental ages far below, at and far above their mental age at the same time accounting for extreme uniqueness and variation in degree of functional impairment in each child with ASD. However the impact on affected individuals and their families is universally very significant. ASD seriously interferes with the developmental, social and educational attainment causing significant economic burden on their families and societies. To help develop the child with autism is certainly possible, although the challenges and difficulties are great. It is estimated that children with autism have nine times the healthcare expenditure of other children.

ASD awareness and recognition in Myanmar is very low among policy makers, service providers, schools and the community at large. People with ASD are usually regarded as those with mental disorders or extremely ill-raised. ASD is not a subject that is surveyed and nearly no diagnostic services are available and research is nearly non-existent. This indicates very low coverage of services for people with intellectual disability and ASD in Myanmar. There are no laws, policies or national programs for ASD, no multidisciplinary team trained on autism diagnosis, no formal professional training and there are only very few interventional services. Furthermore, all the services are situated in big cities. The lack of evidence-based information and the low awareness are the main barriers for interventions and support for individuals with ASD.

Having a son with Autism, ASD has been a part of my life. We are one of the families in Myanmar who cannot reside in the cities where ASD services are available and who do not receive any protection or support from the government or local/international partners. The challenges and difficulties in helping children with ASD are main motivation for conducting this research. The study is intended to explore the awareness, recognition and interventions for ASD and their challenges in Myanmar in order to inform the respective ministries with evidence-based information and recommendations for further ASD programs. I truly hope that the findings from this research will contribute to raise awareness of decision makers and then recognize and integrate programs for ASD individuals and thus help all the individuals with ASD and their families.

Autism Spectrum Disorder: Awareness, Diagnosis and Interventions in Myanmar

CHAPTER 1. BACKGROUND INFORMATION

1.1 GEOGRAPHY AND DEMOGRAPHY:

Myanmar is the largest country in South-East Asia (SEA). The estimated population in 2011-2012 was 60.38 million with a growth rate of 1.01 percent.¹ About 70 percent of the population resides in the rural areas. The country is divided into Nay Pyi Taw Union territory and 14 states and divisions, 69 districts, 396 towns, and 67285 villages. Myanmar is a union where 135 national races who speak over 100 languages and dialects reside together.¹ (Figure 1)



Figure 1. Myanmar Map
(Source: The World Fact Book, Central Intelligence Agency (US)
[accessed 10August2014]

1.2 GENERAL SOCIO-ECONOMIC SITUATION

The country is situated in a strategic location in SEA and has rich natural resources as well as a large young population.¹ However, according to Myanmar Integrated Household Living Condition Survey (IHLCA- 2010) about a quarter of households in Myanmar are living under the poverty line while poverty incidence is nearly two times (29%) in rural than in urban area (15%) (Figure 2). The survey also reveals a large and widespread social and economic disparity among population in Myanmar.² Myanmar is one of the low human development countries ranking 149 out of 187 countries and territories in Human Development Index (HDI).³ Life expectancy at birth (2009) was 64 years for both sexes.⁴

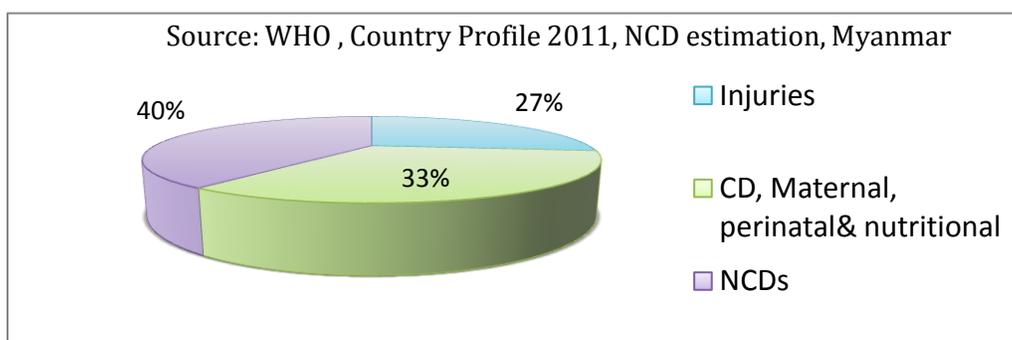
	Urban	Rural	Country
2010	15.7	29.2	25.6
2005	21.5	35.8	32.1

Figure 2. Poverty Incidence by Strata, 2005-2010(%)
(Source: IHLCA Survey 2004-2005, IHLCA Survey 2009-2010)

1.3 HEALTH BURDEN

Myanmar is confronted with a high burden of health: persistent communicable diseases, increase in non-communicable diseases and high maternal and child mortality.⁵ In 2010, crude death rate was 8.9, under-five mortality rate was 66/1000 live births and the maternal mortality ratio was 240/100,000 live births. The diseases of national concern are Human Immunodeficiency Viral Infection (HIV) (prevalence-0.61% of total adult population, 2010), malaria (morbidity 7.3/1000 population, 2011) and tuberculosis (prevalence 525/100,000 population, 2010). Communicable diseases (CD), maternal, perinatal and nutritional conditions account for about 33%, non-communicable diseases (NCD) about 40% and injury 27% of all mortality.^{1,4,6,7} (Fig 3)

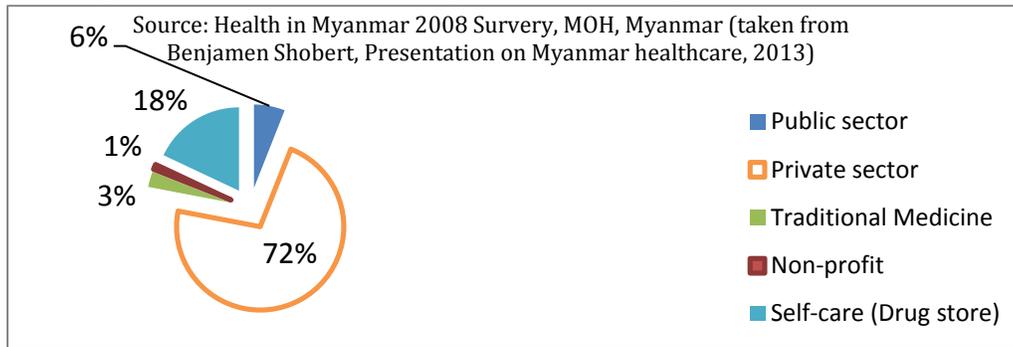
Figure 3. Proportional Mortality (% of total deaths, all ages)



1.4 HEALTH SYSTEM AND SOCIAL PROTECTION

The National Health Committee is a policy making body which provides guidance and directions concerning health. The Ministry of Health (MOH) is responsible for comprehensive health care services. In addition, private for profit and non-profit sectors are providing ambulatory and some hospital care. (Please see [Annex 2](#). Organization structure of Health system, Myanmar.)¹ Figure 4 shows that people seek private service providers for over two third of all out-patient consultations.⁸

Figure 4. Healthcare Seeking Behavior_ Out-patient consultations



Currently, about 99% of the population does not have access to social protection in Myanmar. Public sector health spending per capita in Myanmar is among the lowest in the world. In 2012-2013, 0.76% of Gross Domestic Product (GDP) was spent on health, 1.5% on education and 0.04% on social welfare services.⁹ (Figure 5) Out-of-pocket payment, i.e, the share of expenses that the healthcare seeker needs to pay directly to the health care provider, without a third-party (insurer or state) for health, is very high at about 83% and catastrophic spending is also significant.¹⁰

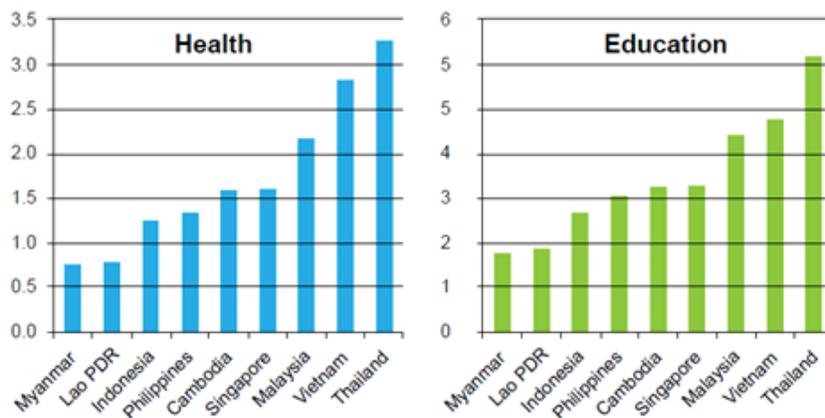


Figure 5. Government spending as % of GDP-ASEAN regional comparison⁹
 (Source: Ministry of Finance and Revenue, Myanmar (2012), ESCAP Statistical Year Book 2011)

Two decades of significant underinvestment and neglect in public health have contributed to a fragile and weak health system and as a consequence, poor health outcomes. Myanmar ranked 190 in health system performance according to WHO survey in 191 countries (2000)¹¹. Myanmar's health information system (HIS) is poor and data availability and use is also very weak. A national consensus was conducted recently in 2014 and the new HIS strategy has been established, so it is hoped that the most important population health information will soon be available. A remarkable voluntary political transition towards a quasi-civilian government occurred in Myanmar with an intent on re-engaging with the international community after decades of repressive military regime and self-isolation.¹¹

1.5 DISABILITY AND ASD

Worldwide, over one billion people live with some form of disability and about 200 million of them are experiencing difficulties in functioning. Disability is often classified according to types of impairment: sensory, physical, mental and intellectual. In any part of the world, persons with disability (PWD) have poorer health outcomes, education achievement and employment status. Poverty is significantly higher among PWDs due to various barriers in accessing services including health, education, employment, transport and information.¹²

There is no specific definition for disability in Myanmar but the concept of persons with disabilities (PWD) generally refers to persons with physical or intellectual disabilities (ID). Traditionally and religiously, disability is believed to be caused by bad deeds in past lives.^{13,14} The first Myanmar National Disability Survey was conducted only in 2010. According to this survey, the number of PWDs is estimated to be 1.2 million (2.3% of the total population) which is comprised of 68.2% of persons with physical impairment, 13.3% with visual impairment, 10.4% with hearing impairment and 8.1% (about 103,356) with some form of ID. Among all PWDs include an estimate of 318,000 children under 15 years and 249,000 of them are within school going age (6-15 years). Almost half of PWDs have never attended school and the high school graduation rate is only 2 percent.¹⁵

First identified by Leo Kanner (1943) and Hans Asperger (1944), Autistic disorders are regarded as one of the life-long neuro-developmental disabilities where 25% of these children has ID.^{16,17,18} People with Pervasive developmental disorders (PDD) are a group of neuro-developmental disorders characterized by core deficits in two domains: communication, and repetitive or stereotypic behavior.¹⁹ According to the Diagnostic and Statistical Manual of Mental Disorder, 4th Edition (DSM-IV), PDD could be diagnosed with four separate disorders: autistic disorder, Asperger's disorder, childhood disintegrative disorder or the catch-all disease of PDD-not otherwise specified (PDD-NOS).^{20,21}

Since the DSM-5, professionals speak of Autism Spectrum Disorders (ASD) and a dimensional model was adopted. The behavior should be specified as: with or without mental disability; with or without a structural language problem; associated to a known medical, genetic or environmental condition; associated to a neuro-developmental disorder, mental disorder or behavior disorder. The characteristics described according to age of onset; with or without loss of capacities; seriousness. (Please see Annex 4. DSM-V) Until recently ASD was regarded as a defect.²² Recent research shows however that it is a delayed or - a simultaneous delayed and an accelerated maturation - of the central nervous system in several areas, especially communication and repetitive behavior. This results in a rainbow of ages within one person, the MAS1P (Mental Age Spectrum within 1 Person).^{18,23}

CHAPTER 2. PROBLEM STATEMENT, JUSTIFICATION, OBJECTIVES AND METHODOLOGY

2.1 PROBLEM STATEMENT

ASD has been recognized as a growing and important public health concern. Global prevalence of ASD is 1 in 160 individuals.²⁴ Reported prevalence varies substantially across studies though higher rate is reported in the studies done in the high-income countries (HICs).^{19,25} Recent (March 2014) estimation of prevalence in the United States by the Center for Disease Control and Prevention (CDC) is 1 in 68 children. The male to female ratio is about 4:1 for classic autism and 9:1 for Asperger syndrome.²⁶ ASD accounts for more than 7.6 million disability-adjusted life years and 0.3% of the global burden of disease.^{26,27}

People with ASD have mental ages far below, and far above their biological age. These phenomena account for an extreme uniqueness and variation in degree of functional impairment in each child with ASD.¹⁸ However, the impact on affected individuals and their families is universally significant. ASD seriously interferes with the developmental, social and educational attainment causing significant economic burden on their families and societies.^{19,24} The estimated ASD support and lost productivity cost is more than €32bn annually in the United Kingdom (UK).²⁸ It is estimated that children with autism have nine times the healthcare expenditures of other children. Average lifetime public expenditures for a person with ASD are estimated to be approximately \$1.4-2.4 million in HICs.²⁹

In the National Health Plan (2011-2016), one of the objectives set by the Ministry of Health (MOH) is “to ensure quality health care for citizens by improving quality of curative services as a priority measure and strengthening measures for disability prevention and rehabilitation.” MOH takes the role in diagnosis, treatment and rehabilitation of PWDs.¹ The Department of Social Welfare (DSW), under the Ministry of Social Welfare, Relief and Resettlement (MSWRR), is the main coordinating body for disability issues.³⁰

General prevalence of 1 in 160 translates into about 375,000 inhabitants with ASD in Myanmar. Among the PWDs, probably many people with ASD are included under a wrong diagnosis like mental retardation or are considered for instance to be ill-raised and are therefore not detected. In diagnostics, some professionals believe that the only reliable instrument proves to be an observation scale, the ADOS (Autism Diagnostic Observation Schedule)^{31,32} (Please see Annex 3. ADOS) while other professionals use DSM-5 and also DSM-4 as appropriate tools. These instruments are not translated in the Myanmar language yet, nor validated for the country. To establish a diagnosis of ASD is a complex matter and can be easily misdiagnosed. It requires a multidisciplinary team trained on autism

diagnosis.^{17,33} In Myanmar no such team exists and no diagnostic tradition has yet been developed meaning that the vast majority of people with ASD are not yet identified.³⁴

In the entire country, there are only 15 special schools for all types of disability and 7 vocational training schools for physical disability in a country with 1.2 million people with disabilities. Some of the schools and services are run by the government but most are run by non-governmental organizations (NGOs) and the private sector. About half of these schools are located in Yangon and the rest in other urban areas where two third of the population resides.^{35,37}

Another problem is the extremely low awareness of ASD, as children with ASD are not expected to be found in regular schools, and not many centers exist that can offer autism-help. ASD is not a subject that is surveyed and nearly no diagnostic services are available and research is nearly non-existent in Myanmar. This indicates a low coverage of services for people with intellectual disability and ASD. Furthermore, all of the services are situated only in the former capital and most important commercial city of Myanmar: Yangon.³⁰

2.2 JUSTIFICATION:

In Myanmar, awareness of ASD is extremely low among the policy makers, service providers, schools and the community at large. People with ASD are usually regarded as those with mental disorders or extremely ill-raised, and most people do not know that the appropriate interventions can improve their lives significantly. Therefore, specific laws, policies and plans are rare for people with ASD and the programs and services are also limited. As a consequence, the coverage of services is completely disproportionate to the demand and people with ASD in Myanmar and their families have nowhere to turn to get access to services and support. The schools do not know how to cope with children with ASD and are refused education, which is not in accordance with the Salamanca Agreement of 1994 that stated the right to education for every child.^{37,38}

Although there are many well-established studies related to ASD, these were conducted mainly in HICs. There is limited number of studies on ASD prevalence in low and middle income countries including Myanmar.²⁵ In Myanmar, ASD has not been included in the agenda of any decision makers or policies yet due to lack of evidence-based information and awareness raising. The findings from this research will render an overview of the current available services and capacity and the gaps and challenges which can contribute to raise awareness of the decision makers and in further implementations for ASD in Myanmar.

2.3 OBJECTIVE AND SPECIFIC OBJECTIVES

Overall Objective:

To explore the existing awareness, recognition and interventions for ASD and their challenges in Myanmar in order to inform the Ministry of Health and Ministry of Social Welfare, Relief and Resettlement with evidence-based recommendations for development of ASD programs.

Specific objectives:

1. To identify the current policies, legislations and programs related to ASD.
2. To explore the awareness and recognition of the policy makers, implementers and the public on ASD.
3. To identify the existing health, education and other integration programs and resources for ASD.
4. To determine the gaps and challenges for ASD interventions.
5. To use the research findings to make recommendations to stakeholders in support of evidence-based decision making by the MSWRR.

2.4 METHODOLOGY

To reach the objectives, a literature review and qualitative research were conducted.

2.4.1 LITERATURE REVIEW

The initial literature review³⁹ was conducted for the development of the research questions, the research proposal and the interview questionnaires. A further literature review was done for interpretation, analysis in comparison with the interview findings and formulation of recommendations.

Search Strategy: The ASD epidemiology, interventions, best practices, action plans, strategies and challenges in HICs and LMICs including in SEA and Asia were searched. Various reports, reviews, strategic plans, national plans, systemic reviews, fact sheets, research/survey reports, scientific/peer-reviewed and grey articles, news articles and published books on disability, ID and ASD in English or Myanmar language were explored. These documents were obtained through websites of Myanmar government ministries, United Nations (UN) agencies, data hub for Asia-Pacific, Autism-related networks and organizations, institutes and universities and also institutes of mental health and websites of NGOs/DPOs (Disabled people's organizations) in Myanmar. These articles and reports were accessed via Pubmed and Google Scholar search engines and also via personal network.

Key words used for this research were a combination of the following terms: ASD/ID/Asperger's/PDD/autism/PWD/social/communication/behavioral and developmental disorder together with the epidemiology, diagnosis criteria, prevalence in developing and developed countries, systematic reviews on intervention, burden of disease, interventions, research, network, advocacy, laws, national policy and strategies, disability rights, CBR, CRPD, CRC, Biwako Millenium Framework, constitution Myanmar, Myanmar Human Rights Commission, ASD policies, ADOS, ADI-R, DSM 4, DSM 5, conceptual framework, national disability survey, Myanmar disability council/law, ASD (early) interventions, inclusive education, special education, mainstreaming, vocational training, barrier-free and rights-based approach.

2.4.2 QUALITATIVE STUDY

At the start of the research project, it was already clear that very little is known about the issue of interest, ASD. For that reason we chose to conduct a qualitative study in addition to literature review due to its flexibility in exploring the details as much as possible and also in consideration of the sensitive nature of ASD and the expected low awareness of ASD in Myanmar. (Please see Annex 7 for the full Research proposal.)

After the initial literature review, a research proposal was prepared and approval from the ethical committee of the KIT was obtained. Interview questionnaires were developed based on the analytical framework and the research table. The consent form and questionnaire were translated into the Myanmar language. Once the approval was granted, pre-testing of the interview was done with one parent and one key informant and also with a friend. Purposive sampling was used and participants were recruited by email, phone or through MAA and then repeated detail planning and revision of activity plan were done.

Fifteen Key Informant Interviews (KIIs) with professionals and ten In-depth Interviews (IDI) with parents of ASD children were planned. Thirteen KIIs and 10 IDI were completed during the study period (March-August 2014). Thirteen professionals from the MOH, INGO, NGOs and DPOs who are working for ASD and public and private special schools participated in the study together with 10 parents of ASD individuals who are currently getting ASD services. Those who were willing and available and who could be reached by telephone/internet were recruited for the study. The researcher also got technical support from a professional working with the latest theories on autism in the Netherlands. She has been contributing to development of strategies for autism in countries including LMICs.

Those organizations or families with whom communication was very difficult or did not respond to invitation for participation were excluded from the study. Four people (a behavior therapist, an occupational therapist, one person from an NGO and one from private mainstream school) replied that they will help in research but later I could not get

in contact with them anymore. I have tried to contact them for at least three times before excluding them from the study. One senior official from MSWRR withdrew from participation when the voice recording was explained. I could not get contact with any senior official from the Ministry of Education (MOE).

Ethical consideration: Ethical approval was obtained from the Ethic Committees of University of Medicine (II), Yangon, Myanmar and KIT. Complete research information was also sent to DSW to inform about this research. The complete information about the current research was informed to all participants before getting their voluntary consent. The respondents were treated with respect while ensuring privacy, confidentiality, non-maleficence and justice.

Data analysis: After interviews, raw notes and recordings were transformed into transcripts using computer or handwriting. The analysis of the data was started by ordering the data according to the research themes emerged. These were then coded in categories according to research questions and were summarized and analyzed. Data obtained from IDIs with parents, KII with professionals and literature was triangulated to compare, contrast and draw conclusions.

ANALYTICAL FRAMEWORK

So far, a specific framework that can cover most of the elements of interest in this research could not be found. Therefore, *Therapeutic interventions of ASD framework* from the Agency for Healthcare Research and quality⁴⁰ (The United States Department of Health and Human Services) and *the Framework on the Strategic Directions and Guiding Principles for ASD services in Saskatchewan*⁴¹ were adapted for comprehensive analysis in this research. (Please see Annex 5. Referenced Analytical frameworks)

A comprehensive, multi-sectorial and multi-level approach is necessary for effective help for persons with ASD and their families. This framework was developed by integration of Individual level factors and the strategic level factors from the above-mentioned frameworks with policy and legislation level factors to help analyze the current situation and responses to ASD in Myanmar comprehensively. The new framework was designed to be able to demonstrate the factors influencing the accessibility to intervention services by the families at each level.

The study findings will be analyzed in the following seven areas: (Figure 6)

1. Political, General socio-economic, Policy and legislation factors
2. Health system and Health care factors
3. Coordination and Networking factors
4. Service Provider factors

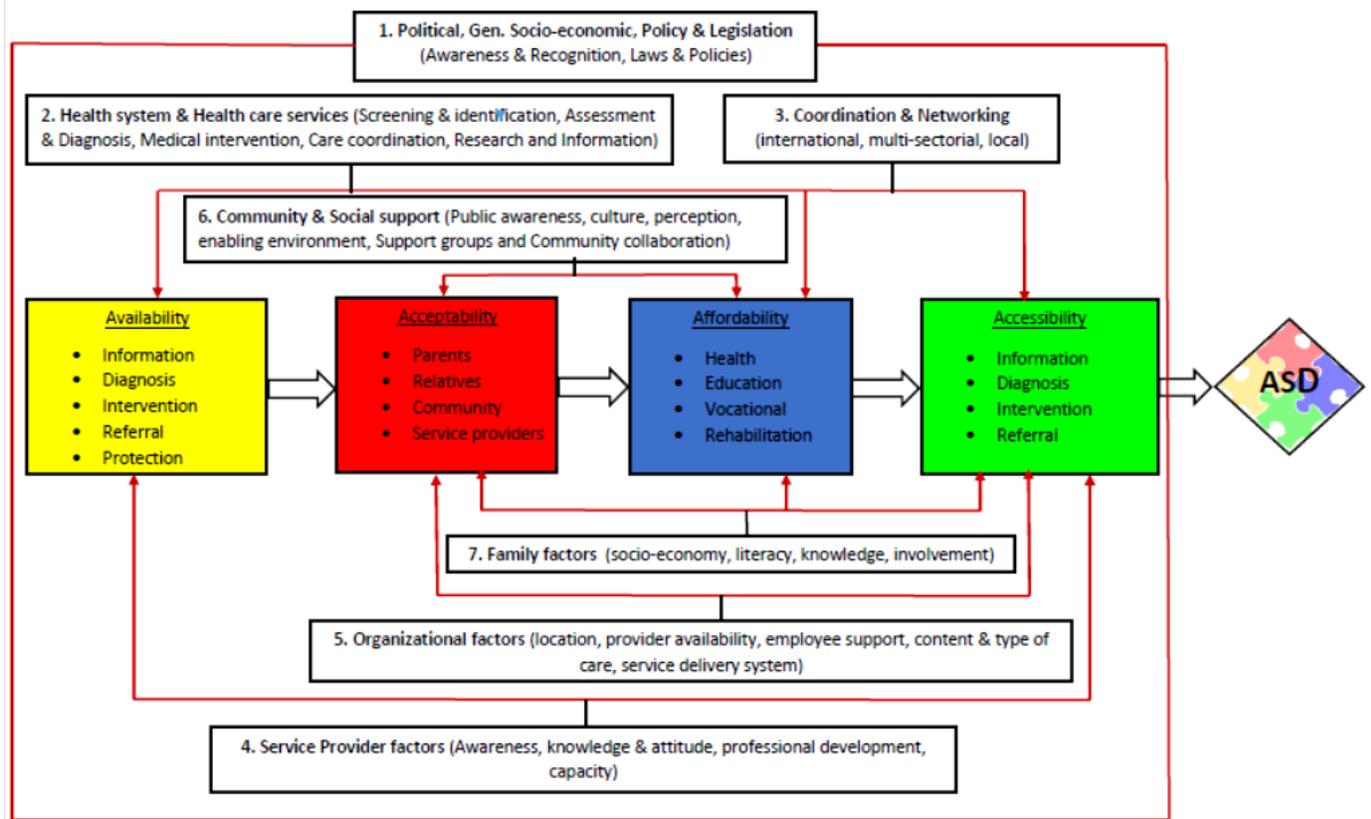
5. Organizational factors
6. Community and societal support
7. Family factors

The policy, general socio-economy and legislation are the underlying factors which influence all other factors. There is no stand alone factor as all seven factors are inter-linking to each other.

ASD services can be utilized by persons with ASD only when availability, acceptability and affordability were fulfilled. Political, general socio-economic, policy and legislation factors are the crosscutting factors which influence all levels of accessibility. Health system, coordination and networking and service provider factors directly influence availability of information, diagnosis, intervention, referral services and protection services. After services are made available, we need to consider factors surrounding acceptability which are influenced by organizational, family and community factors. When acceptable services are available, affordability, which was influenced by all except service provider factors, needs to be addressed to ensure utilization.

As this framework is designed to address in broader perspective, individual factors like functioning level and type of disorder were left out.

Figure 6. Autism Spectrum Disorder Effective Intervention Analytical Framework



Source: Developed by the author

Limitations before the study: The prevalence and current situation of ASD in Myanmar cannot be covered in this study because of limitations of time, money and human resources in addition to a non-existent diagnostic tradition on ASD in Myanmar. Some literature in Myanmar cannot be included in this study since these are not available in soft copy or are typed in very old fonts which were not used anymore and are outdated. According to various constraints as mentioned previously, there is a selection bias of study participants. All of the parent participants will be those who live in Yangon city, whose children are diagnosed with ASD in one way or another and who are currently receiving interventions.

CHAPTER 3: STUDY FINDINGS

This chapter describes the results of literature review and the interviews.

Background data of participants: Two types of respondents participated in the study: parents of ASD children and the officials/service providers on ASD interventions.

	M	F	Total
Housewife	0	7	7
Staff	1	0	1
Own business	1	1	2
Total	2	8	10

Table 1. Study population: Parents

Table Ten parents from the age range of 34 to 51 years participated in the IDIs. Most of them are university graduates while two are primary and secondary education level. Eight out of ten parents were female and most parents were housewives. (Table 1)

	M	F	Total
Private special schools	1	5	6
Private mainstream		1	1
Therapist		1	1
MOH	1		1
INGO	1		0
DPOs		1	1
NGOs	2		2
Total	5	8	13

Table 2. Study population: Key Informants

Altogether 13 key informants participated in this study (Table 2). Eight out of 13 are female and about two third of participants are from private special and mainstream schools. The rest of participants are from the Ministry of Health, therapy centers, INGO and NGO/CBO. Table 2 shows that people working directly with a child with ASD are more often female, while people working indirectly in staff functions are more often male.

Study findings

Literature review and interview findings will be presented in seven categories according to the analytical framework.

3. 1. POLITICAL, GENERAL SOCIO-ECONOMIC, POLICY AND LEGISLATION

Under this heading, awareness and recognition of policy makers, existing laws, policy and plans and the financial protection will be discussed.

3.1.1 AWARENESS AND RECOGNITION

Literature review findings: On 27 June 2012, a celebration to 'Make the Right Real', a promotion of the UNCRPD convention, was organized by the DSW, MSWRR with the participation of high level officials from various ministries, UN and international partners, local organizations and PWDs. That was the first ceremonial event on the rights of PWDs organized by the Myanmar government in history. Myanmar also celebrated the International Day of Disabled Persons every year with the aim of encouragement and empowerment for PWDs ^{42,43} but the information on when it was started could not be found.

According to the observation report (March 2012) by the UN Committee on the Rights of the Child, the committee appreciated ratification of CRC and CRPD by Myanmar Government, the constructive dialogue organized with a cross-sectoral delegation of the State party and the effort of the government in addressing disability matters. However, any national activities specifically related to ASD were not found in literature research.⁴³

Interview findings: All key informants mentioned that after the political transformation since 2011, there were some awareness raising programs in government and private media regarding ASD. According to MAA, since the last four years, MAA initiated autism awareness day activities in collaboration with DSW, UNICEF, Save the Children, private special schools/training centers and DPOs. 11 out of 13 key informants mentioned that DSW is familiar with ASD since it is the focal governmental coordinating body for all types of disability including ASD. Awareness of Ministry of Health and the Ministry of Education are also increased during the same period but ASD is still not in the agenda of both ministries.

According to respondents from three schools and the MAA, during 2014, MOH started to show interest in ASD as two nursing institutions did research on ASD and are planning to include ASD in the school curriculum. The key informant from MOH mentioned that general awareness and interest of many doctors in Myanmar also increased. However, ASD is still not included in the curriculum of basic medical schools. All study participants stated that there is no appropriate recognition of ASD by the government in any of the health, education, social inclusion, employment or safety matters yet.

'MOH has to prioritize five most common communicable diseases and top five mortality diseases and so cannot pay attention to ASD.' (Child neurologist)

3.1.2. LAWS, POLICIES AND PLANS ON ASD AND DISABILITY:

Literature review findings: So far, any laws, policies or national plans which mention specifically ASD were not found. Myanmar has ratified CRC in 1991^{43,44,45} and the UN CRPD in December 2011.^{43,46} Section 18 of The Child Law (1993) stipulates that "a mentally or physically disabled child shall enjoy basic education (primary level) or vocational education in special schools run by the Department of Social Welfare or private individuals or non-governmental organizations; he should have the right to enjoy special care and assistance provided by the Government; should enjoy a full and decent life in conditions which ensure dignity, promote self-reliance and facilitate the child's active participation in the community".⁴⁴ The 2008 constitution⁴⁷ pledges that the Union shall 'care for mothers and children, orphans, fallen Defense Services personnel's children, the aged and the disabled,'. In addition, there is a Disabled Person Employment Act which was promulgated in 1958 and was revised and amended later. It includes "... The president can form a new department or organization to provide vocational education and medical care to those who are physically disabled or mentally defective".⁴⁸

'Rights of the Persons with Disability law' draft was developed by the DSW with the participation of DPOs and PWDs themselves and has been submitted to the Attorney General's Office in early 2014. Once approved, the draft law will proceed to be submitted to the Parliament (Pyithu Htuttaw) and the President's Office.⁴⁹ Inclusive education (IE) is an important strategy for 'Education for All' National action plan (EFA-NAP 2003-2015), Myanmar. According to the comments by the United Nations Committee on the Rights of the Child, IE strategy has not been sufficiently disseminated or communicated and limited human, technical, teaching aid and financial resources are allocated for implementation and there is no proper mechanism for monitoring.⁵⁰

In 2010, a national plan of action for PWDs (2010-2012) was launched with the objective of improving opportunities for PWDs to contribute to the country's development. It was aimed to reach ten percent of PWDs, that was about 130,000 in 120 townships nationally

and in it was a small part targeting intellectual disability.⁵¹ Myanmar National Disability Survey was conducted in 2008 and 2009 by the DSW and The Leprosy Mission International (TLMI) in which 108,000 households across the country were surveyed.¹⁵

In spite of government's progress in laws and policies in disability rights, adaptation to CRPD and proper action to operationalize these laws has yet to enhance.^{29,43,52}

The interview findings: showed that all of the respondents were not aware of any existence or execution of the laws, government policies/plans or conventions related to ASD. One parent and three key informants from MAA, special schools and ministries had knowledge on or participated in drafting the 'Rights of the Persons with Disability law'.

All study participants mentioned that either there was no policy or they have never heard of national or government-organized policies, plans or programs with a focus on ASD either by MOH, MSWRR or MOE. According to a participant from an INGO, the implementation phase of the national plan of action for PWDs (2010-2012) has already been over but the evaluation or monitoring report of the plan has not been accessible to the public.

'Since the beginning, participation of PWDs was very weak and since the report was not accessible, nobody knows if it is successful or not.' (A key informant from an INGO)

3.1.3. FINANCIAL PROTECTION:

Literature review findings: Social protection in Myanmar covers about 1% of the population by means of social insurance schemes available only for formal workers.^{9,10} Government expenditure on social and health sector are mentioned in the introduction section.

Interview findings: All the parent participants mentioned that they have never received financial or other support from the government for their ASD children. There are some projects related to ASD with the financial support of international partners. International interest on disability started to increase in recent years. MAA has one small project (of 13,000 euro) in the Yangon area on awareness raising and advocating of teachers, parents and students in the schools where ASD children are attending. It has been delayed for one month already because they have not received approval from the MOE yet.

3.2 HEALTH SYSTEM AND HEALTH CARE FACTORS

Under this section, findings on health-related factors: screening, case identification and diagnosis, medical intervention and care coordination and research and information will be presented.

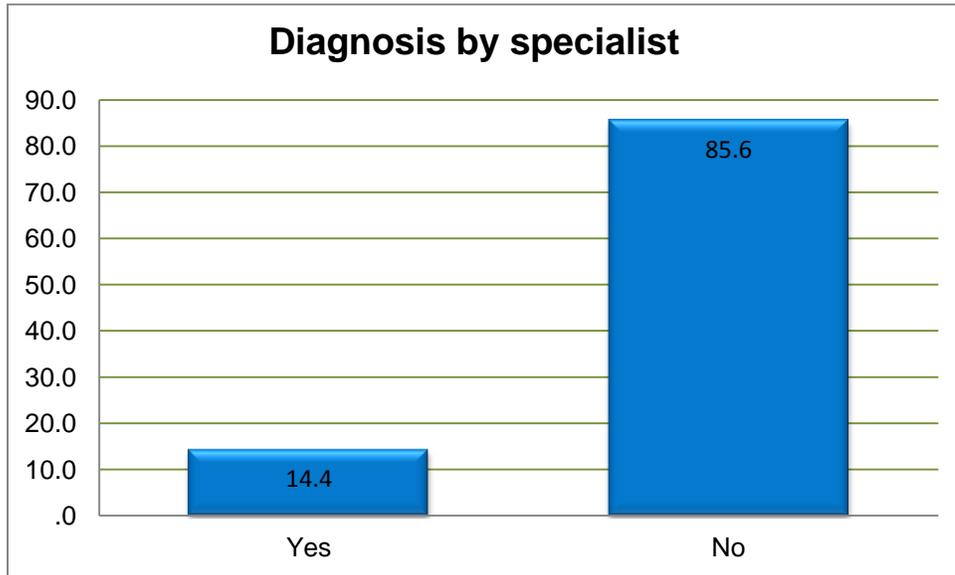
3.2.1 SCREENING, CASE IDENTIFICATION AND DIAGNOSIS

Literature review findings:

Women and Child Health Development Section of the MOH formulated and implemented a Five-year Strategic Plan for Child Health Development in Myanmar (2010-2014). Plans on intellectual disabilities or developmental disabilities were not mentioned in this plan.⁵³

In one study recently done on intellectual disabilities and education in 2012 by the Local Resource Center (LRC), autism was taken into account under the intellectually-impaired children (IIC). Generally for IICs, 14.4% had access to the diagnosis decision by a health professional while 85.6% were never diagnosed or improperly diagnosed by parents or the community. Most parents of IICs did not have knowledge on the fact that they need to consult a doctor for to get diagnosis and manage accordingly.³⁴ No other literature related to developmental/ASD screening, case identification or diagnosis was found. (Figure 7)

Figure 7. Diagnosis given by a health specialist for IICs



Source: LRC, Myanmar: Exploring strategy and means for Inclusion IIC in the Education Policy, 2014

Interview findings: Most parents participated in the study started to notice that their child was different when the child was around one year of age by comparing with other children of same age or by previous experience. All ten parents except one did not seek medical help immediately. They just waited to see if the child would improve. Six of them sought medical help from general pediatricians of which five of them were advised to wait and see if their child would become normal later. Therefore the parents waited for some years. The age of child when they started to seek medical help ranged from 1.3 to 3.5 years and the age of getting diagnosis is from 2.3 to 10 years. The gap between starting to notice a difference and seeking medical help is 0 to 2.5 years and the gap between getting medical help and getting a diagnosis ranged from 0.7 to 6.5 years. (Table 3)

Participants	P1	P2	P3	P4	P5	P6	P7	P8	P9	P10
Start to notice difference (Year)	1.5	0.7	1	1.5	1	1	1	2	1	2
Start to consult a doctor (Yr)	1.5	1.6	1.3	2.5	2	1.5	2	3	3.5	2.5
Gap: notice difference & consult a doctor(Yr)	0	0.9	0.3	1	1	0.5	1	1	2.5	0.5
Age of Diagnosis (Yr)	3.5	2.3	2.5	5	3	3	4	8	10	4
Gap: health seeking and getting Dx (Yr)	2	0.7	1.2	2.5	1	1.5	2	5	6.5	1.5

Table 3. Age of child on notice of difference, seek help and get diagnosis

The gap between recognition and seeking help is generally not very long. When parents discover something is the matter with their child, first they observe and then they seek help most of the time within a year. The gap between seeking help and getting the diagnosis, generally takes much longer and most of the time around two years. (Figure 8)

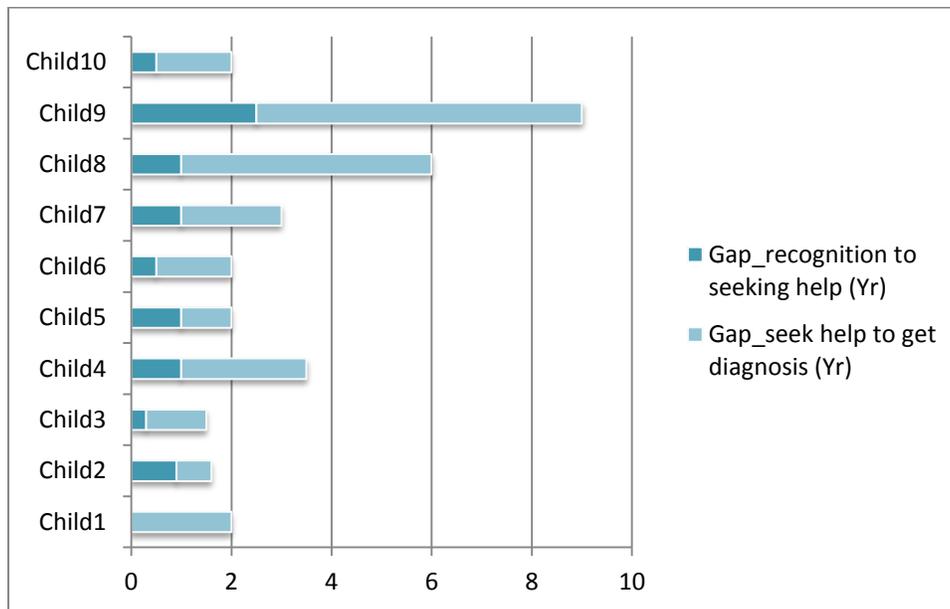


Figure 8: Gaps to seek help and get diagnosis (Years)

One of the children was diagnosed as 'deaf' but later they found out that this was wrong. The pediatrician gave the diagnosis or referred to the child neurologist after some time and the children were then referred to a special school or to therapy once diagnosed. (Table 4)

All participants said that they have never heard of or never encountered any system on developmental screening in Myanmar. Among the parent participants, about half of them were diagnosed by a child neurologist or a pediatrician while the rest were by special school or self-diagnosed by parents using the pamphlets distributed by MAA.

Table 4. Dx given by	
Child Neurologist	4
General Pediatrician	2
Special School	2
Self	2
Total	10

All parent participants mentioned that there was no multidisciplinary professional involvement in diagnosis of their children. All were diagnosed by one professional or by the parents themselves. Key informants also mentioned that diagnoses were provided by only one professional. The child neurologist uses DSM-4 criteria in addition to detailed history and clinical observation to decide the diagnosis. According to the key informant from MOH, some other psychiatrists are also providing diagnosis, however the criteria they use are not known.

"Children are referred to special schools without the proper diagnosis process. Some parents decided upon diagnosis themselves using knowledge they got from pamphlets and internet. Some of the diagnoses were controversial."(A key informant from an INGO)

The child psychologist stated that she used the following diagnostic tools to diagnose ASD:

1. Detailed History Check
2. Observation in the home situation
3. Observation in the school
4. Clinical Observation (therapeutic room)
5. Auti-R Questionnaire (Scale to observe and detect early autism)
6. Hearing test
7. Eye-check
8. Other medical check-up if necessary, e.g. neurological assessment.

3.2.2. MEDICAL INTERVENTION AND CARE COORDINATION

Literature review findings: Myanmar has a mental health policy which was last revised in 1995 and the mental health plan (revised in 2006). Mental Health Legislation Lunacy Act was enacted in 1912 and has hitherto never been revised. Expenditure of mental health is 0.3% of total health care expenditure. In 2005, 1% of primary health care doctors, 3% of nurses and 2% of other primary health care workers have received at least two days of refresher training on mental health. In 2006, there were 25 outpatient facilities, two day treatment facilities, two mental hospitals and 17 community-based psychiatric inpatient units. One of two day treatment facilities is the School for Disabled Children, which is for children with autism, Down's Syndrome, mental retardation and cerebral palsy.^{54,55}

A study showed that parents of IIC viewed that many health professionals were still not adequately aware of the disability and related issues. In addition, they also expressed about the additional barriers: long distance to medical service centers, long queue, irregular accessibility of health care services. As a result, accessibility to health services are compromised and these children are left without a diagnosis, treatment or interventions.³⁶

Interview findings: Currently, there is no guideline or standard protocols for medical interventions and a referral system, according to the key informant from MOH. Five parents and respondents from six special schools mentioned that since there is one well-known child neurologist (in Yangon), some pediatricians/doctors refer to him for diagnosis and he usually refer these children to special education schools. According to the child neurologist, about 3 psychiatrists are also diagnosing for ASD children in Yangon city. He stated that there is no recognized guideline for medication or proper care coordination system. So far he has diagnosed about 400 ASD cases. As far as is known, he is the only child neurologist in Myanmar. Most of them were referred to special schools or private mainstream schools or occasionally to public mainstream schools and medical treatment is provided to those who needed according to the prescription guideline. One of the criteria to accept for attendance in New World special training center is to get diagnosis by the child neurologist. This center also organized regular six-monthly follow-up consultations with the child neurologist for all students.

3.2.3. RESEARCH AND INFORMATION

Literature review findings: Myanmar Country report for the 7th ASEAN and Japan high-level officials meeting on Caring Societies mentioned that a survey was done on Types and Severity levels of Disabilities in Khayan Township, Yangon Division in 2007. It was done by a community-based rehabilitation project of the MOH participated by 153,398 population. 1.9% of the study population was found to have a disability and about 1.98% of them were mental or intellectual disabilities.⁴² However, the survey report was not found and the detail information was not accessible. ASD specific data was not collected in the National Disability Survey conducted in 2008-2009.¹⁶ Three studies related to ASD were found: Prevalence and risk factors of depression in mothers of autistic children and Analysis on the Training, Development Program of Lighthouse Learning centre and Exploring Strategy and Means for Inclusion of Intellectually Impaired Children in the Education Policy and Inclusive Education Policy for People with Disabilities^{36,56,57,58}. These studies were discussed elsewhere in this thesis.

Interview findings: Three special schools and two key informants stated that they participated in ASD related research conducted by some individuals, one NGO and two nursing institutes during recent years. One key informant revealed that ASD information was also not collected in the 2014 National Census but intellectual disability is covered in it. ASD is not included in any kind of national data collection and health information system yet. Within the last 2-3 years, a number of small-scale research on ASD and ID has been initiated and so far, around ten ASD specific research projects have been done according to two key informants from special schools.

3. 3. COORDINATION AND NETWORKING FACTORS

In this session, international coordination and support, multi-sectorial and internal coordination and collaboration and local coordination and networking will be discussed.

3.3.1 INTERNATIONAL COORDINATION AND SUPPORT

Literature review findings: International interest, coordination and support on ASD in Myanmar have increased significantly since the Myanmar's democratic transition. Myanmar Constitution (2008)⁴⁷ mentions that the State shall care for the PWDs and the Union is collaborating more and more with UN agencies, INGOs, NGOs and well wishers. Being a member state of UN ESCAP and ASEAN, the government is undertaking the ASEAN Decade for PWDs, Bali Declaration on the Enhancement of the Role and Participation of the PWDs in

ASEAN Community, BIWAKO Millennium Framework, and BIWAKO plus Five in close collaboration with regional countries.⁴⁹

There are a number of UN and INGOs working in cooperation with the MOH, DSW and MOE in disability issues: WHO, Asia-Pacific Development Center on Disability (APCD), The Nippon Foundation (TNF), JICA, Association for Aid and Relief (AAR), Japan, World Vision, ADRA, The Leprosy Mission International (TLMI), New Humanity FOSIV (NHF), Thailand embassy, USAID, UNICEF, etc. Interest on disability issues by international partners have increased only in recent years.^{42,59} Literature on international coordination and support related to ASD could not be found.

Interview findings: In addition to the international organizations working with DSW, Partner Asia Group, World Learning, University of Wolverhampton, United Kingdom, Thailand embassy and Rainbow foundation (Thailand), Special schools from Singapore (Asian Women Welfare Association AWWA, Rainbow, CP schools), European Union, Handicap International, APILIX, Autism speaks and some other organizations are in network with the local organizations and private special schools, mentioned by 5 special schools and MAA. They provide technical, funding and material support for ASD interventions in public and private sectors but these supports are scattered and somewhat small in scale and not well-established yet mentioned by some special schools, INGO and NGO study participants. According to the key informant from MOH, there is no coordination and support related to ASD between international partners and MOH.

On the other hand, one of the participants mentioned that many foreign visitors came to her training centre which is situated in a slum area of Yangon. Some of them took information and pictures of the center and children and promised to help however, thereafter no action or information was received from them. Some DPOs felt that they need to work hard to show their ability and reliability so that international donors will trust and coordinate with them more.

'We need to show that we can do activities very well. Only then the government and international partners will trust our capability and become interested in supporting us.'
(MAA)

3.3.2. MULTI-SECTORIAL AND INTERNAL COORDINATION

Literature review findings: According to DSW, four government organizations are responsible for disability matters ^{42,49}:

- DSW - social rehabilitation, education, vocational training, training for care providers for PWDs and establishment of disability-related laws and committees
- DOH - medical treatment and medical rehabilitation and
- Department of Education Planning and Training, MOE - inclusive education for children with disabilities and
- Myanmar Disabled Sports Federation - organizing, management and training sports for PWDs.

There was a joint program on educational rehabilitation for children with disabilities, persons with visual impairment and persons with hearing impairment co-managed by the MOE and DSW.⁴⁸ Literature on other inter-sectorial coordination plans/ strategies or activities were not found.

Interview findings: All the study participants are not aware of any inter-ministerial collaboration activities. Two key informants stated that there were some participation of high level officials from different ministries in some advocacy and awareness raising activities of a national level.

3.3.3. LOCAL COORDINATION & NETWORKING

Literature review findings: There are a number of organizations working for disabled people or those led by PWDs themselves in Myanmar⁶⁰ (Table 5). Literature on networking activities or systems among local organizations was not found.

No.	Name
1	Myanmar Independent Living Initiative (MILI)
2	Myanmar Autism Association
3	Kachin Baptist Convention (KBC)
4	Zion Disabled Women's Development Center
5	The Myanmar Council of Churches
6	Myanmar Christian Fellowship of the Blind
7	Eden Handicap Service Center
8	Myanmar Disabled Persons Association
9	The Myanmar Disabled Sports Federation
10	Myanmar Blind development ssociation
11	Myanmar Physically Handicapped Association
12	Myanmar national Association of the Blind
13	Eden Home for the Children with Disabiliti
14	Special Olympic Myanmar
15	Myanmar Parlympic Sports Federation
16	Network for Myanmar Disabled People (NMDP)
17	Unity Group of Intellectual Disability
18	Family Support Network for Intellectual Disability
19	Yangon Deaf Association
20	Blind Massage Development Foundation
21	Myanmar National Association for the Blind
22	Myanmar Christian Blind Fellowship
23	Myanmar Physically Handicapped Association
24	Home for the Deaf Mandalay
25	Disabled People Development Organization
26	Deaf Resource Centre Yangon
27	Saint Mary Shelter for the Blind
28	Su PaungArman Blind Workers Association
29	Myanmar Disabled Women Association

Table 5. Organizations for persons with disabilities

(Source: DSW website, <http://www.dsw.gov.mm/en/rehabilitation/rehabilitation-persons-disabilities>)

Interview findings: According to MAA, it is acting as an informal focal point for coordination regarding ASD among private special schools, DPOs and international partners. Some private special schools mentioned that they usually participated in knowledge sharing, training or meetings organized by MAA and they also provide support to it. Some coordination activities are happening among DSW, some private special centers, child neurologist, some therapists and DPOs in organization of trainings, workshops, meetings, organization and planning of a diagnostic team, sharing information, etc. There are many small DPOs in Myanmar but many of them do not have proper registration. MNDC was organized by general election in June 2014. Once operational, it will become the main focal coordinating body in Myanmar for the rights and other matters of the persons with disabilities abiding by the UNCRPD.

3. 4. SERVICE PROVIDER FACTORS

In this session, the awareness and attitude of service providers, professional development, specialty and comprehensive and coordinated activities will be presented.

3.4.1 AWARENESS, KNOWLEDGE AND ATTITUDE OF SERVICE PROVIDERS

Literature review findings: Some studies^{14,36,56,62} revealed that the awareness of the public mainstream teachers and principals on disability is still weak. The majority of the public and private mainstream schools do not accept the intellectually disabled children and ASDs since they do not have enough technical skills, teaching aids and favorable environment and also due to over-workload they have to handle every day. Many teachers from public mainstream schools assumed these children are not able to learn at all. Teachers are not well-prepared for inclusion of children with disabilities in regular schools. That study also revealed that less intellectually disabled children are found in regular schools than physically impaired children.³⁶

Interview findings: All participants mentioned that awareness of public school teachers on ASD is low. About half of parents tried to keep their children at government or private mainstream schools but they faced a lot of difficulties to get acceptance or dropped-out later due to either refusal by the teachers, inability of the teacher to manage the child or refusal by other parents. So currently all the children of parent participants (10) are not attending mainstream schools.

A key informant from one private mainstream school mentioned difficulties in maintaining teachers to teach special children. *"Other people viewed us like ones who are teaching 'mad' children. Furthermore, teaching these children is very tiring. So many teachers cannot stand*

these kind of hard work and discrimination and they resigned. For me, I am used to it and I am happily teaching these children." (a special school teacher from a private mainstream school)

Respondents from all six special schools mentioned that they provide continuous in-house trainings and discussions to learn more and to solve problems together. Two of them mentioned about providing recreational trips and bonus for staff retention in addition to salary. The working hours and salaries are according to current status in Myanmar. School managements tried to motivate the teachers by means of capacity building, giving space for decision, creating family type working environment and some incentive/recreation.

3.4.2. PROFESSIONAL DEVELOPMENT

Literature review findings: DSW is conducting Diploma in Social Works at the Yangon University with collaboration and cooperation of Psychology Department. Social work education for social workers from the government and voluntary social workers is also organized by DSW. Other training courses are conducted in cooperation with the UN, NGOs and INGOs.⁵⁹ Literature on academic trainings for special education, various therapies, or child psychology was not found.

Interview findings: According to interviews with special schools, only two teachers from current special schools interviewed are professionally trained from abroad while the rest of them are informally trained. They have knowledge and skills through in-house trainings, some occasional short-term training provided by international and local partners, on-the-job training in Singapore, a study trip to Japan and knowledge sharing workshops among each other. All teachers mentioned that they had to learn from the children. One Dutch Psychologist who has been working in Myanmar for about 14 years organized 6 one-year evening courses participated by about 100 teachers from some private special centers and private mainstream schools on how to deal with special needs children. Three parents reported their children being bullied by other students when they were kept in mainstream schools but the teacher was not aware of it.

'Everyday, my son's pencils and erasers were taken by other students. He couldn't tell who took these from him. I have to put new ones in his bag every day.' (A mother)

3.4.3. TYPES OF INTERVENTIONS

Literature review findings: The government provide limited special education and inclusive education under the term of 'education for all' and some vocational training for children and adolescents with disability in Myanmar. While the government subscribes to a policy of IE in principle⁶⁰, in practice, most of the PWDs gain little or no benefit from it. PWDs are facing many barriers to access formal education. Many special schools are able to provide barrier-free environment by trained teachers while formal educational schools do not have enough trained teachers and supporting materials to be able to manage this kind of situation.^{14,50,56} There is one special training school for physically handicapped children and mentally retarded children established by DSW in Yangon which accepts children from the age of 6 to 12 years. Special education and daily living skills, primary education in order to continue middle and higher education in main stream schools and basic vocational training are provided in the school. There is another DSW organized special school for older children in Yangon.^{14,51,55}

According to a study on employment opportunities for PWDs, current vocational trainings are still concentrating on traditional types like handicrafts, hairdressers, massage, etc. Most of current public vocation training centers are for deaf, blind or physically handicapped people. Actually, employment opportunity is still low even for university graduates in Myanmar and a lot of people work as migrants in other countries. Recent political and economic transition in the country has created some more job opportunities.⁶²

Employment and social security department from the Ministry of Labor is responsible for creating employment opportunities for the citizens. This entails; Promoting and protecting the legal rights for employees and establishing a cordial relationship between employers and employees in employment. However, in practice, this department has a limited budget and human resource and facing challenges in carrying out its responsibilities. The policies and regulations of the Ministry of Labor are found to be not clearly mentioned for PWDs.^{48,62}

Interview findings:

Private schools accept children as young as 2 years to as old as 34 years. However most of the schools provide services for young children. 9 out of 10 parents mentioned that early childhood, day care and adolescent programs are more scarce than young children services.

Special Education: Currently, there are two free-of-charge/cost-sharing special schools organized by local NGO/DPO, two public and 8 private-for-profit special schools/training centers where ASD children can join in Myanmar, mentioned by four participants from special schools and MAA. Three parents and three key informants stated that one public

special school operated by DSW accepts both physical and mental disabled children between 6 to 18 years of age with the fees of 10,000 Kyats (just over \$10) per year. This school uses the standard primary school curriculum up to primary four while the other public schools provide training to older children. Two special schools stated that they accept mainly ASD and intellectual disabilities while other schools also provide services in separate classes for normal children (without ASD). Among 12 special schools, 10 are in Yangon city and one each in Mandalay and Pyin-Oo-Lwin towns. Only one school/center has capacity to accept more than 80 children, the other schools can take up only a small number of ASD children. All special schools provide behavioral, speech and language, social and occupational therapies while some other schools also provide academic skills, physiotherapy, arts and music therapies.

Vocational training: According to two key informants and 3 parents, five schools (two public and three private) are providing pre-vocational/vocational training to older ASD and ID children. All of these schools are situated in Yangon and Mandalay cities. Parents expressed their worries for future of their children since there are only a few vocational training centers.

Therapies: According to all study participants, there are no specific therapeutic centers for ASD in Myanmar. So far, one occupational therapist, one speech therapist, one behavior therapist, one child psychologist, two adult psychologists and some physiotherapists share their time to many schools to provide therapies, mentioned by three key-informants. For instance, a physiotherapist will come to MAA every other week to provide therapy to children as well as to train the parents and teachers.

Inclusive Education: Most of the key informants knew about IE implementation in public schools though most of the parents were not aware of this implementation. Two participants from INGO and NGO mentioned that No.25 Basic Education Primary School (Yangon) (Myayadanar school) is a school where IE is integrated properly and some other schools started to accept children with intellectual disabilities but parents need to provide a helper during the school hour. Currently, none of the ASD children of all parent participants is attending mainstream school. Some parents mentioned about their friends who had to advocate and discuss with school headmasters and teachers to get their children accepted. Some of them were successful in getting acceptance while others were not successful.

All study participants felt that IE is still not properly implemented yet. Teachers do not have the necessary capacity and skills, infrastructure and teaching aid are scarce, technology. *'I have sent five children from our school to private and public mainstream schools but most teachers did not understand them. Most of these children didn't fit in or faced a lot of difficulties and had to drop out.'* (A special-school in-charge)

According to 3 key-informants, there are two private mainstream schools which integrate IE approach but the school fees of these schools are high and only the children from high socio-economic family can attend. Some participants mentioned that inclusion of ASD and ID children in mainstream education is nearly impossible for the time being.

'I sent my son to a nearby primary school because he really wanted to go to school when he saw other children with school uniform. But later, the teacher said that she could not keep him in class anymore since he couldn't follow the lessons and she couldn't give individual attention on him. I really felt sad for him.' (A parent)

3.4.4. COMPREHENSIVE & COORDINATED APPROACHES

No literature on comprehensive and coordinated approaches on ASD was found. Currently there is no system or policy on comprehensive and coordinated ASD intervention, according to the study participants. MAA mentioned that in coordination with some DPOs and private schools, they are planning to organize a diagnosis team together with the child neurologist and other therapists.

3.5. ORGANIZATIONAL FACTORS

Organizational factors will be presented in four categories: equitable access and service delivery system, provider availability, employee support and content and type of care.

3.5.1. EQUITABLE ACCESS AND SERVICE DELIVERY SYSTEM

Literature review findings: Jomtien World Conference on 'Education for All (EFA) set up the framework of EFA in 1990. Myanmar established the Education for All National Action Plan (EFA-NAP) in 2003. In this plan, IE is an essential component to reduce illiteracy rates of PWDs. IE policy provides the opportunity to children with disability to join mainstream schools but for the time being, it is obviously limited to the children with mild disabilities.^{37,56,63}

MOE stated that in line with the Salamanca Statement (1994) and reinforcement of IE in the global 'education for all' plan (2004), MOE has made special arrangements for disabled children to attend formal schools and formulated IE programs to accommodate all children regardless of their physical, intellectual, social, emotional, linguistic or other conditions.^{50,59}

According to the Ministry of Education report from 2010-11, "There were 801 disabled children in formal schools, 1450 children in special schools for the blind and the deaf, 30 disabled students in universities and colleges and 6 disabled students in master degree courses" which is a small number compared to the estimated population of school age children with disabilities of around 460,000 according to the national disability survey figure (2.32%).⁵² In 2005, 10268 children joined mainstream schools through inclusive education programs and 9227 disadvantaged children participated in monastic schools.³⁵ Almost half of PWDs have never attended school and the high school graduation rate is only 2 percent.¹⁵ These data are from different sources and the explanation of the significant difference in numbers is not known.

In 2012, the UN CRC committee concerned that the social sector (health, education and social) spending is very low and concluded to introduce a child rights budget system and to define strategic budgetary lines for children especially including children with disabilities. It also worried about the persistence of multiple forms of discrimination and stigma that increase the vulnerability of children with disability. It is also concerned that efforts made by the government to facilitate the inclusion of children with disabilities into educational system and the society are insufficient, especially in rural and remote areas.⁴³

Interview findings: All the study participants stated that existing special schools and vocational training centers are situated in only three cities of Myanmar. MAA has been providing free-of-charge services to ASD children but children from longer distance cannot

come because they cannot afford transportation, MAA cannot provide support for transportation or the parents cannot give time to send these children to school. Teachers from two training centers for disabled individuals in a slum area, Hlaing Thar Yar, Yangon township mentioned that parents from that area are poor and they cannot afford transport fees or do not have time to send their children to the center even though the services are provided free-of-charge. So ASD and intellectual disable people are usually locked in their homes without any kind of intervention or treatment.

Fees of private special schools start from 100,000 Kyats per month for 2hour per day/ 5 days per week which is high for most of the population. Services are usually provided 1-2 hour per day, five days per week. All parents mentioned that the amount of school hours is too short and they face difficulties to send their children to school and bring them back. None of the parents that participated in the study are employees or civil servants. Most of them are housewives or self-employed, and they can attribute most of their time to their children or can adjust their time to send their children to school.

3.5.2. PROVIDER AVAILABILITY

Literature review findings: Currently, there are no formal trainings for special education, behaviour/occupational/language and speech therapists as well as no child neurologist or child psychologist in Myanmar.⁵² According to mental health department, In 2005, there were 89 psychiatrists (0.016 per 100,000 population, four psychologists (0.01 per 100,000) population, 23 social workers (0.04 per 100,000 population) and one occupational therapist (0.002 per 100,000 population)^{54,55}. Literature about the number of available service providers for ASD is not available.

Interview findings: According to an estimation based on the interviews, there are less than 200 informally-trained special school teachers, one occupational therapist, one behavior therapist, five psychologists, one speech therapist and a number of physiotherapists in the private sector in Myanmar. The number of therapists and special education teachers in the public sector is not available so far. There are always long waiting lists in almost all schools and it takes months to years to get a chance to attend.

3.5.3. EMPLOYEE SUPPORT

Literature findings: According to a study by National Management College, Department of Economics, Analysis on the Training and Development Program of Lighthouse Learning centre, most of the teachers at Lighthouse Learning Center joined the center to teach ASD children out of their interest, are satisfied with the trainings they receive and also thought that set rules and regulations were appropriate. Half of the teachers thought that the salary was fair.⁵⁸ No other literature in this area was available.

Interview findings: Special schools interviewed mentioned that they provide capacity building opportunities for the teachers by means of in-house trainings, giving opportunities to attend trainings occasionally organized by other organizations, sharing trainings and continuous education programs. Respondents from 5 special schools discussed how they provided moral support, incentive and family type working environment for employee motivation.

3.6. COMMUNITY AND SOCIETAL FACTORS

Under community and societal factors, public awareness, culture and perception and community support group and collaboration will be presented.

3.6.1 PUBLIC AWARENESS, CULTURE AND PERCEPTION

Literature review findings: Public awareness on intellectual disability is very low. As a consequence, these children and adults are viewed by the community as mad persons or spoiled persons. A widely shared traditional belief in Myanmar is that disabilities are punishment for bad deeds done in previous life. Therefore, stigma, discrimination and social exclusion around PWDs are high in most communities. These negative societal attitudes and perceptions are important factors for access of interventions for individuals with disabilities including ASD. ^{42,59}

Interview findings: All study participants expressed that the public awareness and understanding on ASD is very low though there were some awareness raising programs in mass media or events. But these activities can reach to only some people from capital cities. Three participants mentioned that educated parents of ASD individuals have some knowledge but the knowledge of low literate parents is low. Except for about 4 major cities, other areas -especially rural areas- have almost no way to get the knowledge on ASD.

All parents experienced a lot of difficulties in the community: people stared at them when their child behave strangely in public, some were angry, some scolded the parents or child for spoiling the child, some were afraid of the child. As mentioned by some parents and special schools, many parents of other normal children do not want their children to play with ASD children or keep them together in classes. Relatives of most families did not accept the diagnosis and thought that the child would later become normal again. All families participated in this study have changed their mind and adapted gradually according to the lessons learnt while raising their children.

'I have to stay low to get the acceptance to our children by other people. We have to explain a lot to other people. They told us about the bad behavior of my daughter or even if they don't tell, I can see it from their look. My daughter is also very difficult to control in public. So we almost never go out to public places or even visit our relatives' houses.' (A parent)

3.6.2. SUPPORT GROUPS AND COMMUNITY COLLABORATION

Literature review findings: Currently there are 13 local support groups and councils which are working for intellectual and ASD individuals.⁵⁸

No.	Name of organization
1	Myanmar National Disability Council ⁶⁴
2	Myanmar Autism Association (MAA)
3	Eden Center
4	New Life foundation
5	MILI Myanmar Independent Living Initiative
6	Physical Handicap Association
7	Family sports network - Special Olympic Myanmar
8	Local Resource Center (LRC)
9	Shwe Min Thar Foundation
10	Myanmar Unity self-advocacy group of intellectual disabilities
11	Disabled People Development Organization.
12	The Leprosy Mission International (TLMI)
13	Human Rights Commission

Table 6. Organizations working for Intellectual and ASD (Source: Interview findings)

Interview findings: Children of 8 out of 10 parent participants are currently attending at day-care center of MAA and they mentioned that this was the only center they are getting free support for their children. 7 out of 10 parents are the peers and close friends after they got to know each other at intervention centers. They mentioned that it was very encouraging to talk to each other and to express their feelings openly. Some volunteer parents from MAA mentioned that they became active in helping others due to their ASD children and they were very happy for that.

3.7. FAMILY FACTORS

Family/parental socio-economy and literacy and the parent/family knowledge and family involvement will be presented in this session.

3.7.1 STUDY FINDINGS: FAMILY FACTORS

Literature review findings: One-fifth of households in Myanmar is living under poverty line. Even though literacy rate is 93% for the whole country, secondary school participation rate is just around 50%.²

Interview findings: Nine in ten families participated in this study has a high socio-economic status and can afford private special services. They spent 100,000 (US\$133) Kyats to 1,000,000 Kyats (over US\$1,000) per month for school fees of at least two hours per day, five days a week special education. Parents and key informants from organizations mentioned that this amount of money is high for most of the ordinary families and there is no way for low income families to be able to send their children to special schools. According to interviews with the private special schools, only the rich families (higher or middle socio-economic class) who have knowledge about the existence of the special centers seek their services. They have never come across any poor families who tried to seek service from them. For those children who attend government special school or day-care centre at MAA, do not need to pay. However, only children from families who live near these schools/centers can attend these schools.

'All of our students are from rich or middle income families. Don't see any from poor families.. Don't know why they don't come and seek service.' (A special training center)

A volunteer teacher who has been teaching disabled children in a slum area in Yangon mentioned that most of the families in that area are so poor that they have to work hard whole day even for their living. So they cannot give time or do not have knowledge to seek health and interventions for their disabled children. Furthermore, ASD and intellectual disability children are usually accepted as 'Wut-nar-kan-nar' (bad thing happened due to past life deeds) and the parents do not seek health or any intervention. Many of these children from poor and/or low literate families are usually left without any intervention. She also mentioned that in that slum area, violent bullying and rape on PWDs were common. She said one of her current ASD students was pretty and was in her puberty. She was very worried about her safety although she did not know how to protect her. Three parents of female ASD children equally mentioned their worries about the safety and security of their children.

3.7.2. PARENT KNOWLEDGE AND FAMILY INVOLVEMENT

Literature review findings: According to the Myanmar National Disability Survey 2010, awareness on existence of public intervention services of the PWDs and their families was only 24.1% of which only one third of them made contact to get interventions. Awareness on existence of DPOs/NGOs was 14.7% but only 2.7% of them took service from these organizations.¹⁵

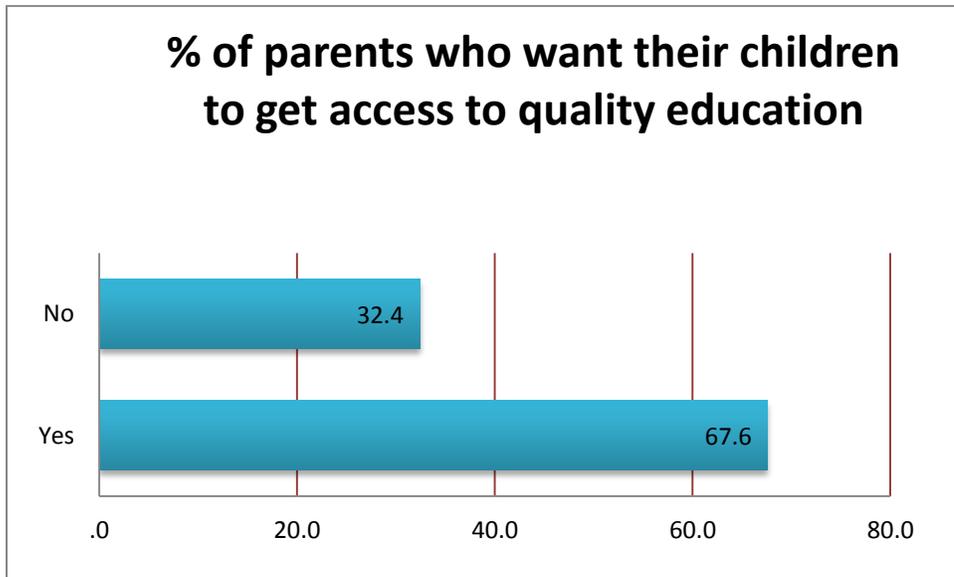


Figure 1 Percentage of parents who want their children to get access to quality education

(Source: Local Resource Center, Myanmar, Exploring Strategy and Means for Inclusion of Intellectually Impaired Children in the Education Policy, January 2014.)

Figure 9 shows that 32.4% of the parents of IICs do not have hope for their children and thought that education was not necessary. They thought that their children could not learn and just keep them at home. That study also showed that only one-third of parents wanted their children to get vocational training. In addition, the majority of participants (85.6%) did not know the existence of law and policy related to disability.

Interview findings: ASD knowledge of parents is higher among higher literates, mentioned by key informants from INGO and NGOs. However, there is not much ASD related literature in Myanmar language except some pamphlets produced by special schools and MAA. It needs time and involvement together with the ability to understand the terms and meaning of the literature in other language. According to all the study participants, they are provided with parent education and educational pamphlets by special schools. Three participants from special schools mentioned that they arrange parent trainings for occupational,

behavioral and physiotherapies according to availability and contribution by the therapists. Key informants from two schools expressed that they provide home-based trainings for those parents who cannot send their children to school or who live in other parts of the country to be able to train their children at home.

All parent participants mentioned that they are able to give time to their ASD children since they can afford, have other helpers at home and/or they do not work or can manage their time since they are self-employed. 6 in 10 parents train their children at home and they believe that their children improved a lot due to their commitment and involvement.

'I do everything that I can for my son while I am able to do. I am trying my best to help my son as independent as possible before we die.' (A parent)

LIMITATIONS OF THE STUDY:

Not all the schools and training centers could participate or be reached due to poor internet access and phone line access to Myanmar. It was assumed that there are no other special training centers in other parts of the country except in three cities, according to the key informants reached so far. Therefore, we cannot say that the study findings are representative of the country. Furthermore, accurate information on human/financial/material/ technical resources cannot be obtained. Some interviews needed to be conducted repeatedly due to communication difficulties.

One senior government staff from DSW did not want to participate when explained about voice recording and dropped out of the study while communication with another one from DSW was so difficult to conduct interview since he does not live in Yangon City. Since the research had to be done from abroad, there are significant sensitivities among government staffs and difficult to get their participation. Furthermore, there had been significant delays in getting approval from the respective ministry, conducting interviews and getting response for participation. Even though the country has been transforming, the civil servants are still sensitive to research as in times under the strict rules of military government. Two more senior officials from MSWRR and MOE whom I had brief contact were not available for further contact.

In IDI with the parents, parents of ASD children who are not seeking ASD intervention are not accessible for interview. Hence, the perspectives of poor, less educated and hard to reach population might not be fully represented in this study and the generalization of the study finding should be done with caution.

DISCUSSIONS

Research objectives will be discussed based on literature and study findings.

1. CURRENT POLICIES, LEGISLATIONS AND PROGRAMMES RELATED TO ASD

Literatures showed that Myanmar has three laws in place for people and children with disabilities and has ratified CRC and CRPD. However, study findings revealed that people are not aware of their existence and do not know that PWDs have their rights for health, education or employment. Implementation and enforcement of the existing laws and integration and harmonization of ratified international conventions on rights and disabilities are still weak. There is no specific law, policy or national plans for ASD and intellectual disabilities or any law for protection of PWDs in terms of their safety and security yet. Financial and social protection for PWDs and their families also do not exist.

2. AWARENESS AND RECOGNITION OF THE POLICY MAKERS, IMPLEMENTERS AND THE PUBLIC ON ASD

ASD awareness of the government (MOH, MSWRR and MOE) is still low though it showed improvement in the last two years. Both the literature and interview findings showed that the government has participated or led some high ministerial level disability activities and ASD specific activities. But there is no recognition of ASD by government in any of health, education, social inclusion, employment or safety matters yet.

However, both literature and research revealed that awareness and knowledge of the teachers from public and private mainstream schools are very limited. They do not get a proper training on how to deal with children of special needs. Most of the teachers and school headmasters are not familiar with the concept of inclusive education. According to Myanmar tradition and culture, teachers are highly-respected and a teacher is expected to have good will (Say-ta-nar), hobby (war-tha-nar) to teach and dedication (anit-nar). These three attitudes are even more important for teachers and professionals working with ASD children. Special schools use various means for staff retention so that they can provide continuous and effective services for ASD children. Some private mainstream schools mentioned about difficulty in maintaining teachers to teach special children.

Recently public awareness raising activities have started but these have not essentially reached the majority of the population especially rural dwellers, poor and illiterate people. Therefore, public awareness and understanding on ASD is extremely low among those people. ASD children whose parents have knowledge and awareness and involve in management are found to make better and faster improvement. High literate families are found to seek service more than lower literate families.

3. EXISTING HEALTH, EDUCATION AND OTHER INTEGRATION PROGRAMS FOR ASD

In Myanmar multidisciplinary team trained on autism diagnosis does not exist. There are no guidelines, protocols or strategies for ASD screening, identification, diagnosis and treatment. Most of the diagnoses are given individually by the professionals or by parents themselves. With the estimation on ASD population and those diagnosed in one way or another, not more than 4% of persons with ASD get diagnosis.

There is a scarce number of trained professionals in either health, education or other interventions. There is no professional academic training program in Myanmar yet, except for the general programs of physiotherapy and psychology. Further, there still is no coordination or networking among these existing professionals. MAA, in coordination with some private special centers and therapists, is planning to organize a diagnosis team soon. As far as this study found out, ten special schools/training centers and two vocational training centers are providing special education and vocational services to ASD children in the whole country and the schools are always overly occupied.

Government reports mentioned that IE programs were implemented in most part of the country but the study results indicated that IE implementation in mainstream schools is hitherto hardly functioning. Hence, accessibility of services for people residing in other parts of the country is impossible even if they are affordable to the high fees of special schools. Access is also difficult even in these three cities due to transport difficulties. It is high for most of the population. Since the majority of population in Myanmar is in lower and middle socio-economic level, while they have to struggle for daily living, they cannot afford high fees of special schools/therapies. In addition, school hours are too short and the parents face difficulties to send their children to school and bring them back.

A number of international donors provide technical, funding and material support for ASD interventions in public and private sectors but these supports are scattered and somewhat small scale and not well-established yet. High level multi-ministerial participation occurred in some advocacy and awareness for PWDs but there still is no effective inter-ministerial or intra-ministerial collaboration yet.

Literature and research findings show that, currently, information sharing, capacity building activities and planning for diagnosis team activities are happening among DSW, private special centers and DPOs together with MAA. Meanwhile, coordination and networking are still occurring in the clusters and there is a need to systematize and expand the involvement of all the stakeholders. There are many small DPOs in country but coordination with them is difficult for the reason that many of them do not have registration. The registration of organizations in Myanmar is difficult but it is hoped to become easier since the Civil Society Law for formation of local organization is recently approved.

4. GAPS AND CHALLENGES FOR ASD INTERVENTIONS

There are significant gaps in seeking health service, in getting diagnosis and also getting appropriate services for the individuals with ASD. Regular check up and follow up visits are also uncommon in Myanmar. Traditional and cultural factors and lack of proper knowledge are the causes of mis-diagnosis and delay in seeking intervention services for ASD. There is no recognized guideline for medication and no proper care coordination system.

ASD is not included in any survey or consensus. There is a considerable knowledge gap on ASD in Myanmar. ASD is not included in any kind of national data collection and health information system yet. Within the last 2 to 3 years, the ASD specific research has increased.

One of the main barriers for access to interventions by PWDs is the traditional belief on intellectual disabilities as a punishment due to bad deeds of past life, which worsen the stigma, discrimination and social exclusion for these children and adults. All parents experienced a lot of difficulties in the community: stigma, discrimination and isolation in relation to their ASD children. Therefore parents usually avoid going to public places as much as possible or lock their children in their house. Safety and security of these children is also a big concern for the parents especially for girls.

There is a regular and supportive coordination and collaboration between MAA, private special schools, local DPOs, DSW and international partners and there are tentative plans for more collaboration with the hard work and enthusiasm of MAA members. The establishment of Myanmar National Disability Council (MNDC) is seen as a good start for the rights and development of people with disabilities and it will be the focal body for all the disability issues.

There is no way for poor families to be able to send their children to special schools. Only the rich families (higher or middle socio-economic class) who live in the three cities where services exist and who have knowledge about the services seek necessary services. Cultural and traditional perceptions of the family plays a significant role in getting intervention for their ASD children. Many people believe ASD and intellectual disability children are 'Wut-nar-kan-nar' (bad thing happened due to past life deeds) and the parents do not seek health or any intervention. Many of these children from poor and/or low literate families are usually left without any intervention.

CONCLUSIONS

The Myanmar government has made positive efforts for addressing rights of persons with disabilities in recent years and ASD awareness by the policy makers has burgeoned in recent years to some extent. Nonetheless, deeper understanding is still inadequate to know the extent of burden of ASD on individuals, families, society and the country. There is lack of ASD related policies and action plans at national level and all the principles and provisions of the disability-related laws and international conventions have not been incorporated sufficiently.

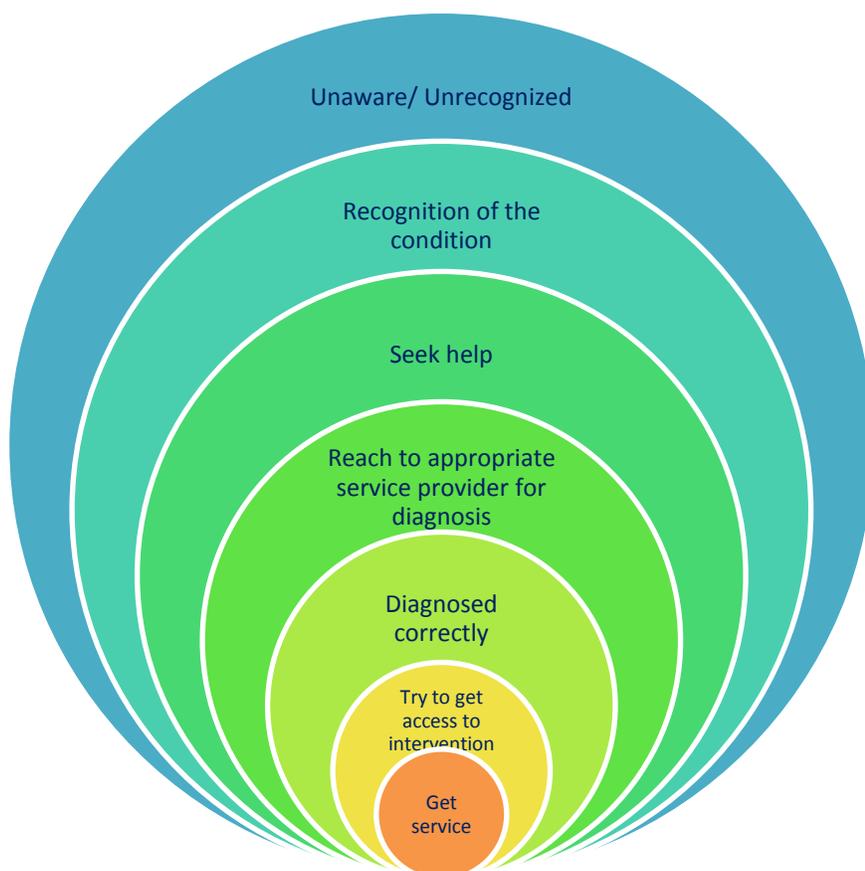


Figure 10. Steps of getting services for ASD individuals (Source: Developed by the author)

Figure 10 evolved from the knowledge provided by the study participants which shows various levels for the families of persons with ASD to get to the necessary service. In Myanmar, with some exceptions mostly in people in Yangon, people are still in the first circle, which is a position of unawareness. Most people who do not have enough education and knowledge are not aware of the condition of their child and with the influence of traditional or religious beliefs, they do not seek any kind of interventions for their child. Some of the parents/caregivers recognize the condition, yet only part of the group seek for

help from appropriate professionals usually after adopting the strategy of 'wait and see' for some time. The study reveals that there is a gap in recognition and seeking help. Only a small fraction of those who seek help, who are knowledgeable and live in an area where intervention services exist, try to get proper diagnosis. Yet, out of this already small fraction only some of them get correct diagnosis. After getting a correct diagnosis, some families who can afford the fees for interventions try to get access to interventions. Those who live in accessible geographic area, who are affluent enough to cover the fees and who are knowledgeable about the service centers get to these centers. However, most of the time, these centers are full and they were put into a waiting list.

Accessibility to healthcare and education is extremely limited for persons with ASD due to lack of specific integration in health system and education system. Though ASD individuals can be included in inclusive education, there is no proper implementation, infrastructure and capacity in most part of the country. Availability of service providers and professionals is extremely limited especially for two-third of the country's population who live in rural areas. Likewise, most of the families cannot afford to seek interventions for their children as the cost of ASD interventions is very expensive and there is almost no support by government, national or international partners.

RECOMMENDATIONS

An estimate of 375,000 people with ASD live in Myanmar. With an extremely scarce diagnosis, care and support, people with ASD and their families should be a priority. From the results we can formulate the following recommendations. (Please see Annex 6. Detail Recommendations)

Ministry of Health

- To lead the development of multi-sectorial national plan for ASD and other disabilities in cooperation with the MOE, MSWRR, Ministry of Labor and international partners. This plan should be supported by sufficient human, financial and technical resources and capacity building.
- Development of standard guidelines and protocols on assessment, diagnosis and treatment of ASD. Translation and validation of the contextually appropriate diagnostic instrument, like the ADOS and the DSM-IV and DSM-5 interview.

Department of Social Welfare (MSWRR)

- Establishment or encouragement of at least one public or private special schools in every state and division with technical and infrastructural support.
- Establishment of professional training programs organized by the government in special teaching, child psychology, art/music/occupational therapy, speech/language/ behavioral therapy.. etc.

Ministry of Education

- IE program: raising awareness, capacity building, promote implementation and monitoring of IE programs in all states and division of the country together with creation of barrier free environment for children with ASD.

Ministry of Labour

- Enforcement, awareness raising and monitoring of 'The Disabled Persons Employment Act' (1958) and to review and revise also taking ASD into account.

Myanmar National Disability Council and DPOs

- To support establishment of more parent groups and to ensure coordination and cooperation of disability-related activities among the DPOs and the ministries

Researchers

- Research activities especially on ASD prevalence and its burden and needs assessment, finding gaps, challenges and barriers on ASD interventions

Special Schools

- To promote sharing of knowledge, best practices among service providers

International partners and INGOs working for disability

- To collaborate with local NGOs, DPOs and government more extensively and to provide technical, financial and infrastructural support for ASD and intellectual disabilities

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APPENDICES

ANNEX 1. GLOSSARY

Accessibility⁶⁵

Accessibility describes the degree to which an environment, service, or product allows access by as many people as possible, in particular people with disabilities.

An Inclusive, Barrier-free and Rights-based Society⁶⁶

An “inclusive” society is a society for all, and a “barrier-free” society refers to a society free from institutional, physical and attitudinal barriers, as well as social, economic and cultural barriers. A “rights-based” society means a society based on the human rights of all individuals where peoples with disabilities are valued and placed at the centre of all decisions affecting them.

Assessment⁶⁵

A process that includes the examination, interaction with, and observation of individuals or groups with actual or potential health conditions, impairments, activity limitations, or participation restrictions. Assessment may be required for rehabilitation interventions, or to gauge eligibility for educational support, social protection, or other services.

Assistive devices; also assistive technology⁶⁵

Any device designed, made or adapted to help a person perform a particular task. Products may be specially produced or generally available for people with a disability.

Barriers⁶⁵

Factors in a person’s environment that, through their absence or presence, limit functioning and create disability – for example, inaccessible physical environments, a lack of appropriate assistive technology, and negative attitudes towards disability.

CBR (community-based rehabilitation) ⁶⁵

A strategy within general community development for rehabilitation, equalization of opportunities, poverty reduction, and social inclusion of people with disabilities. CBR is implemented through the combined efforts of people with disabilities themselves, their families, organizations, and communities, and the relevant governmental and nongovernmental health, education, vocational, social, and other services.

Contextual factors⁶⁵

Factors that together constitute the complete context of an individual’s life, and in particular the background against which health states are classified in the ICF. There are two components of contextual factors: environmental factors and personal factors.

CRC⁹

The CRC applies to all children in the world, including children with disabilities. It spells out the basic human rights that children everywhere have: the right to survival; to develop to the fullest; to protection from harmful influences, abuse and exploitation; and to participate fully in family, cultural and social life. It also recognizes the importance of family assistance and support. Two articles make specific reference to children with disabilities: Article 2 outlines the principle of non-discrimination and includes disability as grounds for protection from discrimination; Article 23 highlights the special efforts States Parties must make to realize these rights. In General Comment 9, the Committee on the Rights of the Child which oversees the implementation of the CRC has provided guidance to States Parties in their efforts to implement the rights of children with disabilities, covering all the provisions of the Convention. In addition General Comment 7 and General Comment 9 of the CRC specifically highlight that children with disabilities: are entitled to active participation in all aspects of family and community life; require equal opportunities in order to fulfill their rights; and should be treated with dignity at all times. Furthermore, they state that children with disabilities “are best cared for and nurtured within their own family environment” and they “should never be institutionalized solely on the grounds of disability”. States Parties must protect children with disabilities from discrimination and provide access to a range of services and supports which are specifically designed to help them achieve their full potential. This was reinforced in the 2010 UN General Assembly Resolution A/65/452.

CRPD⁶⁷

The purpose of CRPD is to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity. Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others. As stated in Article 24 of the CRPD, children with disabilities should not be excluded from the general education system on the basis of disability and should have access to inclusive, quality and free primary and secondary education on an equal basis with others in the community in which they live. In article 1, reads as follows: Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others. The Convention on the Rights of Persons with Disabilities (United Nations 2006a) provides two descriptions of disability. The first, paragraph (e) of the Preamble, states the following: Disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others.

Disability⁶⁵

In the ICF, an umbrella term for impairments, activity limitations, and participation restrictions, denoting the negative aspects of the interaction between an individual (with a health condition) and that individual's contextual factors (environmental and personal factors).

Disability discrimination⁶⁵

Any distinction, exclusion, or restriction on the basis of disability that has the purpose or effect of impairing or nullifying the recognition, enjoyment, or exercise on an equal basis with others, of all human rights and fundamental freedoms: includes denial of reasonable accommodation.

Disability management⁶⁵

Interventions and case management strategies used to address the needs of people with disabilities who had experience of work before the onset of disability. The key elements are often effective case management, supervisor education, workplace accommodation, and early return to work with appropriate supports.

Disabled people's organizations⁶⁵

Organizations or assemblies established to promote the human rights of disabled people, where most the members as well as the governing body are persons with disabilities.

Early childhood⁶⁴

Early childhood is the period from prenatal development to eight years of age. It is a crucial phase of growth and development because experiences during early childhood can influence outcomes across the entire course of an individual's life.

Early intervention⁶⁵

Involves strategies which aim to intervene early in the life of a problem and provide individually tailored solutions. It typically focuses on populations at a higher risk of developing problems, or on families that are experiencing problems that have not yet become well established or entrenched.

Enabling environments⁶⁵

Environments which support participation by removing barriers and providing enablers.

Functioning⁶⁵

An umbrella term in the ICF for body functions, body structures, activities, and participation. It denotes the positive aspects of the interaction between an individual (with a health condition) and that individual's contextual factors (environmental and personal factors).

Global Burden of Disease (GBD)⁶⁵

A measurement of impact of disease combining years of life lost to premature mortality plus years of life lost to time lived in states of less than full health, measured by disability-adjusted life-years.

Human Development Index (HDI)³

The HDI is a summary measure for assessing long-term progress in three basic dimensions of human development: a long and healthy life, access to knowledge and a decent standard of living. As in the 2011 HDR a long and healthy life is measured by life expectancy. Access to knowledge is measured by: i) mean years of schooling for the adult population, which is the average number of years of education received in a life-time by people aged 25 years and older; and ii) expected years of schooling for children of school-entrance age, which is the total number of years of schooling a child of school-entrance age can expect to receive if prevailing patterns of age-specific enrolment rates stay the same throughout the child's life. Standard of living is measured by Gross National Income (GNI) per capita expressed in constant 2005 international dollars converted using purchasing power parity (PPP) rates.

Impairment⁶⁵

In the ICF loss or abnormality in body structure or physiological function (including mental functions), where abnormality means significant variation from established statistical norms.

Incidence⁶⁵

The number of new cases during a specified time period

Inclusive Education⁶⁵

Education which is based on the right of all learners to a quality education that meets basic learning needs and enriches lives. Focusing particularly on vulnerable and marginalized groups, it seeks to develop the full potential of every individual.

Inclusive society⁶⁵

One that freely accommodates any person with a disability without restrictions or limitations.

Independent living⁶⁵

Independent living is a philosophy and a movement of people with disabilities, based on the right to live in the community but including self-determination, equal opportunities, and self-respect.

Intellectual disability⁶⁸

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.

Intellectual impairment⁶⁵

A state of arrested or incomplete development of mind, which means that the person can have difficulties understanding, learning, and remembering new things, and in applying that learning to new situations. Also known as intellectual disabilities, learning disabilities, learning difficulties, and formerly as mental retardation or mental handicap.

International Classification of Functioning, Disability and Health (ICF) ⁶⁵

The classification that provides a unified and standard language and framework for the description of health and health-related states. ICF is part of the “family” of international classifications developed by the World Health Organization.

Mainstream services⁶⁵

Services available to any member of a population, regardless of whether they have a disability – for example, public transport, education and training, labour and employment services, housing, health and income support systems.

Nongovernmental organization (NGO) ⁶⁵

An organization, with no participation or representation by government, which works for the benefits of its members or of other members of the population, also known as a civil society organization.

Occupational therapy⁶⁵

Promoting health and well-being through occupation. The primary goal of occupational therapy is to enable people to participate in the activities of everyday life. Occupational therapists achieve this outcome by enabling people to do things that will enhance their ability to participate, or by modifying the environment to better support participation.

Physiotherapy⁶⁵

Provides services to individuals to develop, maintain, and maximize movement potential and functional ability throughout the lifespan. Also known as physical therapy.

Prevalence⁶⁵

All the new and old cases of an event, disease, or disability in a given population and time.

Psychologist⁶⁵

A professional specializing in diagnosing and treating diseases of the brain, emotional disturbance, and behaviour problems, more often through therapy than medication.

Rehabilitation⁶⁵

A set of measures that assists individuals who experience or are likely to experience disability to achieve and maintain optimal functioning in interaction with their environment.

Schools – inclusive⁶⁵

Children with disabilities attend regular classes with age-appropriate peers, learn the curriculum to the extent feasible, and are provided with additional resources and support depending on need.

Special schools⁶⁵

Schools that provide highly specialized services for children with disabilities and remain separate from broader educational institutions; also called segregated schools.

Social protection⁶⁵

Programmes to reduce deprivation arising from conditions such as poverty, unemployment, old age, and disability.

Special Education⁶⁵

Includes children with other needs – for example, through disadvantages resulting from gender, ethnicity, poverty, learning difficulties, or disability – related to their difficulty to learn or access education compared with other children of the same age. In high-income countries this category can also include children identified as “gifted and talented”. Also referred to as special needs education and special education needs.

Speech and language therapy⁶⁵

Aimed at restoring people’s capacity to communicate effectively and to swallow safely and efficiently.

Therapy⁶⁵

The activities and interventions concerned with restoring and compensating for loss of function, and preventing or slowing deterioration in functioning in every area of a person’s life.

The Salamanca Statement on Special Needs Education³⁷

- every child has a fundamental right to education, and must be given the opportunity to achieve and maintain an acceptable level of learning,
- every child has unique characteristics, interests, abilities and learning needs
- Education systems should be designed and educational programmes implemented to take into account the wide diversity of these characteristics and needs,
- those with special educational needs must have access to regular schools which should accommodate them within a child -centered pedagogy capable of meeting these needs
- Regular schools with this inclusive orientation are the most effective means of combating discriminatory attitudes, creating welcoming communities, building an inclusive society and achieving education for all; moreover, they provide an effective education to the majority of children and improve the efficiency and ultimately the cost-effectiveness of the entire education system.

Vocational rehabilitation and training⁶⁵

Programmes designed to restore or develop the capabilities of people with disabilities to secure, retain and advance in suitable employment – for example, job training, job counselling, and job placement services.

Children with Disabilities (Explanation in Myanmar Language)⁶³

‘မသန်စွမ်းကလေးများ’ ဆိုသည်မှာ ရုပ်ပိုင်းဆိုင်ရာ၊ အာရုံခံစားမှုပိုင်းဆိုင်ရာ သို့မဟုတ် ဉာဏ်ရည်ဖွံ့ဖြိုးမှုပိုင်းဆိုင်ရာ ချို့တဲ့သော ကလေးများနှင့် ကျောင်းမှ အထုတ်အပယ်ခံကြရရန် ပညာသင်ယူခွင့်မရရှိသော ကလေးများ ပါဝင်ပါသည်။ အဆိုပါကလေးများသည် ကိုယ်ကာယပိုင်းဆိုင်ရာ သို့မဟုတ် စိတ်ပိုင်း ဆိုင်ရာချို့တဲ့ မသန်စွမ်းမှုဖြင့် မွေးဖွားလာသော ကလေးများ သို့မဟုတ် မကျန်းမာခြင်း၊ ထိခိုက်ဒဏ်ရာရရှိခြင်း သို့မဟုတ် အခြားသောအကြောင်းကြောင့် ချို့ယွင်းပျက်စီးမှု၊ အားနည်းမှုရှိသော ကလေးများဖြစ်ကြသည်။

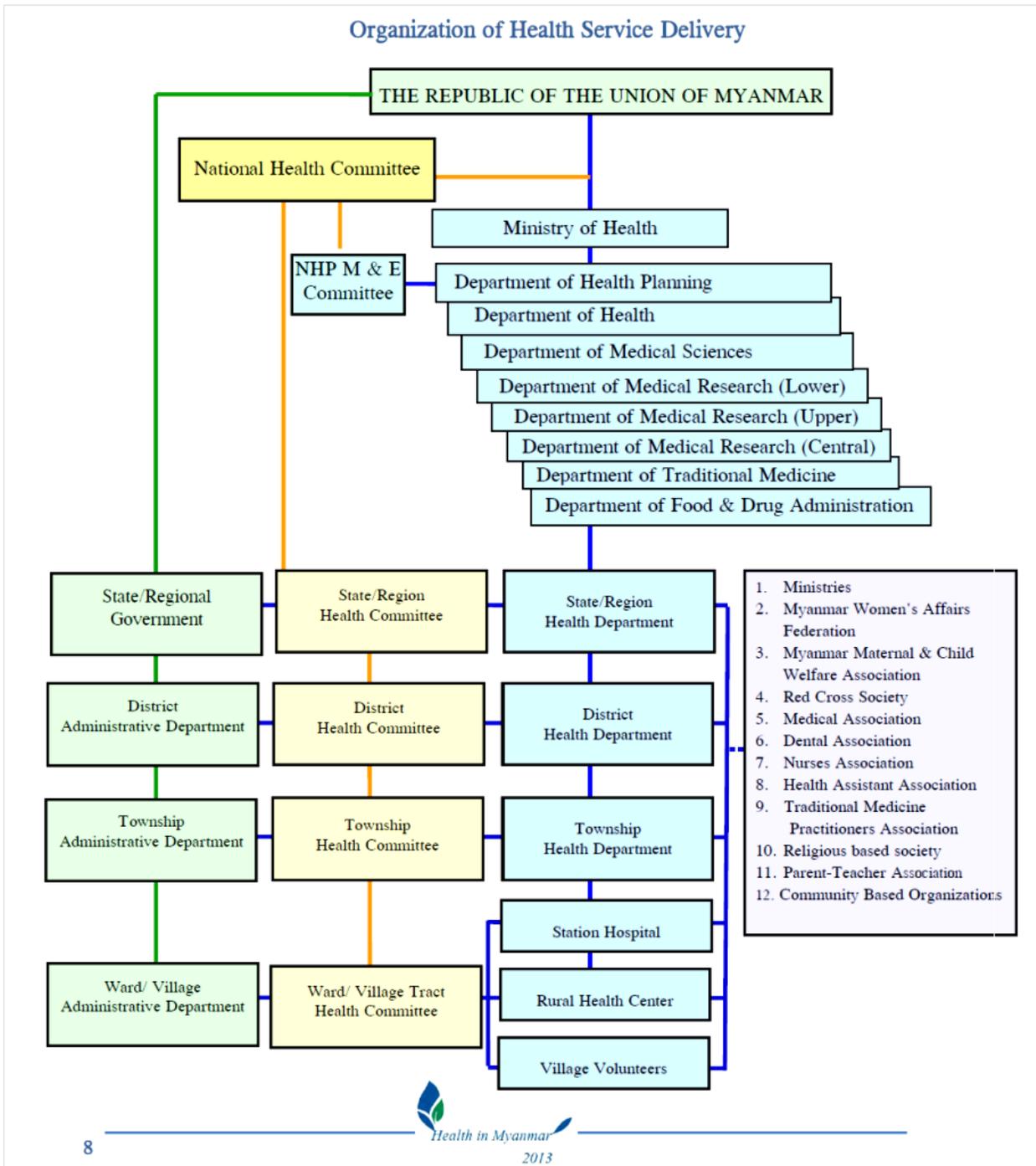
အားနည်းမှုဆိုသည်မှာ ကလေးများအမြင် အကြားအားနည်းခြင်း၊ သွားလာလှုပ်ရှားနိုင်မှုအားနည်းခြင်းတို့ဖြစ်ပြီး အခြားသောကလေးများနှင့်

မတူဘဲ သင်ယူမှုရေးဆွဲရေးသဖြင့် သာမန်နှင့်မတူသည့် နည်းလမ်းများဖြင့် သင်ယူကြရသူများ ဖြစ်ပါသည်။ နိုင်ငံအများစုတွင် မသန်စွမ်း ကလေးများအဖြစ် သတ်မှတ်သော ကလေးများကို ပညာရေးအထူးလိုအပ်ချက်ရှိသော ကလေးများ အဖြစ်ဖြင့်လည်း အပြန်အလှန်အားဖြင့် သတ်မှတ်ပါသည်။ ထို့ကြောင့်ဤအုပ်စုနှစ်စုသည် တသီးတခြား မဟုတ်ကြပါ။ မသန်စွမ်းကလေးများသည် သင်ယူနိုင်စွမ်းရှိကြပါသည်။ ထို့အတူ အခြားကလေးများကဲ့သို့ ကျောင်းတက် ရောက်နိုင်သော အခွင့်အလမ်းလည်း တူညီစွာရှိကြပါသည်။ မည်သို့ဆိုစေ အာရှ-ပစိဖိတ် ဒေသရှိနိုင်ငံများ၏ ကျောင်းများတွင် အဆိုပါကလေးများအား ကျောင်းမှ မကြာခဏဖယ်ထုတ်ခြင်း ခံနေကြရပါသည်။

Children with Special Needs (Explanation in Myanmar Language) ⁶³

‘သင်ယူမှု အထူးလိုအပ်ချက်ရှိသောကလေးများ’ သို့မဟုတ် ‘ပညာရေးဆိုင်ရာအထူးလိုအပ်ချက်ရှိသော ကလေးများ’ ဆိုသည်မှာ သူတို့၏သင်ယူမှုတွင် အခြားသူများ၏ဂရုစိုက်မှုကြီးကြီးဖြင့် အကူအညီ ပေးရန် လိုအပ်သောကလေးများကို ဆိုလိုပါသည်။ နိုင်ငံပေါင်း များစွာတွင် ဤအထူး ဂရုပြုမှုကိုအထူးကျောင်း/စာသင်ခန်းများ သို့မဟုတ် သာမန်ကျောင်း/ စာသင်ခန်းများတွင်ပေးနေကြပြီဖြစ်ပါသည်။ များစွာသောနိုင်ငံတို့သည် ပညာရေးဆိုင်ရာ အထူးလိုအပ်ချက်ရှိသောကလေးများ သို့မဟုတ် သင်ယူမှု အထူးလိုအပ်ချက်ရှိသော ကလေးအဖြစ် ကျောင်းသားများကို အုပ်စုအမည် အမျိုးမျိုးသတ်မှတ်ပြီး ပုံမှန်ကျောင်းသားများနှင့် တသီးတခြားစီထား၏။ ထို့ကြောင့် လက်စွဲစာစဉ်တွင် ဤဝေါဟာရများ ထွက်ပေါ်လာသည့်အခါတွင် ဤအမည်သတ်မှတ်သည့်အလေ့အထရှိနေခြင်းကို သိစေသည်။ သို့သော်လည်း ၎င်းသည်သင်ယူမှု အထူးလိုအပ်ချက်ရှိသောကလေးများ သို့မဟုတ် ပညာရေး အထူးလိုအပ်ချက်ရှိသောကလေး များနှင့် ပုံမှန်ကလေးများကြားတွင် ပညာရေးဆိုင်ရာကွာဟမှု အမှန်တကယ်ရှိနေသည်ဟု မဆိုလိုပါ။

ANNEX 2. ORGANIZATION STRUCTURE OF HEALTHCARE SYSTEM (MYANMAR)



ANNEX 3. AUTISM DIAGNOSTIC OBSERVATION SCHEDULE-GENERIC (ADOS)

The Autism Diagnostic Observation Schedule-Generic

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Table II. Modules 1–4: Algorithm and Other Items for Diagnosis of Autism DSM-IV/ICD-10 for Social and Communication Domains^a

Module 1 Preverbal/ single words/ simple phrases	Module 2 Flexible phrase speech	Module 3 Fluent speech child/adolescent	Module 4 Fluent speech adolescent/adult
Algorithm items			
Stereotyped/idiosyncratic words or phrases	Stereotyped/idiosyncratic words or phrases	Stereotyped/idiosyncratic use of words or phrases	Stereotyped/idiosyncratic use of words or phrases
Gestures	Descriptive, conventional, instrumental gestures	Descriptive, conventional, instrumental gestures	Descriptive, conventional, instrumental gestures
Unusual eye contact	Unusual eye contact	Unusual eye contact	Unusual eye contact
Facial expressions directed to others	Facial expressions directed to others	Facial expressions directed to others	Facial expressions directed to others
Quality of social overtures	Quality of social overtures	Quality of social overtures	Quality of social overtures
Response to joint attention ²	Amount of reciprocal social communication	Amount of reciprocal social communication	Amount of reciprocal social communication
Shared enjoyment ^{2,3,4}	Quality of social response	Quality of social response	Quality of social response
Use of other's body to communicate	Conversation	Conversation	Conversation
Pointing	Pointing to express interest		Emphatic or emotional gestures
Showing ²	Overall quality of rapport	Overall quality of rapport	
Frequency of vocalization directed to others	Amount of social overtures	Insight ⁴	Empathy/comments on others' emotions ³
Spontaneous initiation of joint attention	Spontaneous initiation of joint attention	Reporting of events ⁴	Responsibility
Other Items			
Immediate echoing	Immediate echoing	Immediate echoing	Immediate echoing
Speech abnormalities	Speech abnormalities	Speech abnormalities	Speech abnormalities
Imagination/functional play	Imagination/functional play	Imagination	Imagination
Mannerisms	Mannerisms	Mannerisms	Mannerisms
Unusual sensory behaviors	Unusual sensory behaviors	Unusual sensory behaviors	Unusual sensory behaviors
Repetitive interests and behaviors	Repetitive interests and behaviors	Excessive, specific interests	Excessive, specific interests
		Rituals and compulsive behaviors	Rituals and compulsive behaviors
Overactivity	Overactivity	Overactivity	Overactivity
Negative behavior	Negative behavior	Negative behavior	Negative behavior
Anxiety	Anxiety	Anxiety	Anxiety

^a Whenever possible, items on the same horizontal line reflect similar or identical codes but, for the sake of space, this is not always true. Superscripts indicate items that appear in other modules, but are not in other algorithms. Nonalgorithm items that only occur in one or two modules are not included here.

DSM-5 AUTISM SPECTRUM DISORDER

GUIDELINES & CRITERIA EXEMPLARS

General Guidelines

- One example of a specific criterion may not be sufficient to assign the criterion as being present.
 - *Is the example behavior clearly atypical?*
 - *Is the example behavior present across multiple contexts?*
 - Distinguish between behaviors that are clearly atypical and present across multiple contexts, versus behaviors that are on the borderline of being atypical or rarely occur/occur in only one context. For example, while toe walking may be an example of criterion B1, it may not be sufficient by itself to assign the criterion if there is a physical explanation for the behavior (and thus not clearly atypical) and/or if it occurs only in one context (e.g. at the beach when barefoot in the sand). By contrast, a preoccupation with lawnmowers that involves obsessively drawing lawnmowers, seeking out lawnmowers, and talking about lawnmowers is sufficient to meet criterion B3 even if no other examples exist. This preoccupation is clearly atypical and is present across multiple contexts.
- Avoid using the exact same behavioral exemplar to satisfy two criteria.
 - Some behaviors may appear to satisfy multiple DSM-5 criteria. It is the responsibility of the clinician to decide where the behavior is best represented. For example, 'repetitively putting hands over ears' may satisfy B1 because it is a repetitive motor movement, or it may be considered under B4 because it represents an adverse reaction to sounds.
 - Some behaviors are multi-faceted and may satisfy multiple DSM-5 criteria. For example, a child who is obsessed with string and insists on always carrying string with him at all times may meet criteria for B3 due to a strong attachment to an unusual object. If the same child also frequently waves string in front of his face and watches it flop up and down, then B4 should also be considered due to the visual sensory aspect of this behavior.
- Behaviors that are not currently present may be considered.
 - A behavior that only occurred in the past may be sufficient to assign a criterion.
 - It is important to consider whether a behavior that occurred in the past is atypical for developmental norms (e.g. handflapping should not be counted if it only occurred from 6-9 months of age).
- Everything is subject to change.
 - The final publication of the DSM-5 (May 2013) may provide more guidance on the number of behavioral exemplars required.
 - The number of required criteria may change.
 - Major changes possible....

DSM-5 Criteria for ASD With Examples

A. PERSISTENT DEFICITS IN SOCIAL COMMUNICATION AND SOCIAL INTERACTION ACROSS CONTEXTS, NOT ACCOUNTED FOR BY GENERAL DEVELOPMENTAL DELAYS, AND MANIFEST BY 3 OF 3 SYMPTOMS:

A1. Deficits in social-emotional reciprocity; ranging from abnormal social approach and failure of normal back and forth conversation through reduced sharing of interests, emotions, and affect and response to total lack of initiation of social interaction.

- *Abnormal social approach*
 - Unusual social initiations (e.g. intrusive touching; licking of others)

- Use of others as tools
- *Failure of normal back and forth conversation*
 - Poor pragmatic/social use of language (e.g. does not clarify if not understood; does not provide background information)
 - Failure to respond when name called or when spoken directly to
 - Does not initiate conversation
 - One-sided conversations/monologues/tangential speech
- *Reduced sharing of interests*
 - Doesn't share
 - Lack of showing, bringing, or pointing out objects of interest to other people
 - Impairments in joint attention (both initiating and responding)
- *Reduced sharing of emotions/affect*
 - Lack of responsive social smile (*note: the focus here is on the response to another person's smile; other aspects of emotional expression should be considered under A2*).
 - Failure to share enjoyment, excitement, or achievements with others
 - Failure to respond to praise
 - Does not show pleasure in social interactions
 - Failure to offer comfort to others
 - Indifference/aversion to physical contact and affection
- *Lack of initiation of social interaction*
 - Only initiates to get help; limited social initiations
- *Poor social imitation*
 - Failure to engage in simple social games

A1 reflects problems with social initiation and response

A2. Deficits in nonverbal communicative behaviors used for social interaction; ranging from poorly integrated-verbal and nonverbal communication, through abnormalities in eye contact and body-language, or deficits in understanding and use of nonverbal communication, to total lack of facial expression or gestures.

- Impairments in social use of eye contact
- Impairment in the use and understanding of body postures (e.g. facing away from a listener)
- Impairment in the use and understanding of gestures (e.g. pointing, waving, nodding/shaking head)
- Abnormal volume, pitch, intonation, rate, rhythm, stress, prosody or volume in speech
- Abnormalities in use and understanding of affect (*note: responsive social smile should be considered under A1, while affect that is inappropriate for the context should be considered under A3*)
 - Impairment in the use of facial expressions (may be limited or exaggerated)
 - Lack of warm, joyful expressions directed at others
 - Limited communication of own affect (inability to convey a range of emotions via words, expressions, tone of voice, gestures)
 - Inability to recognize or interpret other's nonverbal expressions
- Lack of coordinated verbal and nonverbal communication (e.g. inability to coordinate eye contact or body language with words)
- Lack of coordinated non-verbal communication (e.g. inability to coordinate eye contact with gestures)

A2 reflects problems with non-verbal communication

A3. Deficits in developing and maintaining relationships, appropriate to developmental level (beyond those with caregivers); ranging from difficulties adjusting behavior to suit different social contexts through difficulties in sharing imaginative play and in making friends to an apparent absence of interest in people

- *Deficits in developing and maintaining relationships, appropriate to developmental level*
 - Lack of "theory of mind"; inability to take another person's perspective (CA \geq 4 years)

- *Difficulties adjusting behavior to suit social contexts*
 - Does not notice another person's lack of interest in an activity
 - lack of response to contextual cues (e.g. social cues from others indicating a change in behavior is implicitly requested)
 - Inappropriate expressions of emotion (laughing or smiling out of context) (*note: other abnormalities in the use and understanding of emotion should be considered under A2*)
 - Unaware of social conventions/appropriate social behavior; asks socially inappropriate questions or makes socially inappropriate statements
 - Does not notice another's distress or disinterest
 - Does not recognize when not welcome in a play or conversational setting
 - Limited recognition of social emotions (does not notice when he or she is being teased; does not notice how his or her behavior impacts others emotionally)
- *Difficulties in sharing imaginative play (Note: solitary imaginative play/role playing is NOT captured here)*
 - Lack of imaginative play with peers, including social role playing (>4 years developmental age)
- *Difficulties in making friends*
 - Does not try to establish friendships
 - Does not have preferred friends
 - Lack of cooperative play (over 24 months developmental age); parallel play only
 - Unaware of being teased or ridiculed by other children
 - Does not play in groups of children
 - Does not play with children his/her age or developmental level (only older/younger)
 - Has an interest in friendship but lacks understanding of the conventions of social interaction (e.g. extremely directive or rigid; overly passive)
 - Does not respond to the social approaches of other children
- *Absence of interest in others*
 - Lack of interest in peers
 - Withdrawn; aloof; in own world
 - Does not try to attract the attention of others
 - Limited interest in others;
 - Unaware or oblivious to children or adults
 - Limited interaction with others
 - Prefers solitary activities

A3 reflects problems with social awareness and insight, as well as with the broader concept of social relationships

B. RESTRICTED, REPETITIVE PATTERNS OF BEHAVIOR, INTERESTS, OR ACTIVITIES AS MANIFESTED BY AT LEAST 2 OF 4 SYMPTOMS:

B1. Stereotyped or repetitive speech, motor movements, or use of objects; (such as simple motor stereotypies, echolalia, repetitive use of objects, or idiosyncratic phrases).

- *Stereotyped or repetitive speech*
 - Pedantic speech or unusually formal language (child speaks like an adult or "little professor")
 - Echolalia (immediate or delayed); may include repetition of words, phrases, or more extensive songs or dialog
 - "Jargon" or gibberish (mature jargonizing after developmental age of 24 months)
 - Use of "rote" language
 - Idiosyncratic or metaphorical language (language that has meaning only to those familiar with the individual's communication style); neologisms
 - Pronoun reversal (for example, "You" for "I"; not just mixing up gender pronouns)
 - Refers to self by own name (does not use "I")
 - Perservative language (*note: for perseveration on a specific topic, consider B3*)

B1 includes atypical speech, movements, and play

- Repetitive vocalizations such as repetitive guttural sounds, intonational noise-making, unusual squealing, repetitive humming
- *Stereotyped or repetitive motor movements*
 - Repetitive hand movements (e.g., clapping, finger flicking, flapping, twisting)
 - Stereotyped or complex whole body movements (e.g., foot to foot rocking, dipping, & swaying; spinning)
 - Abnormalities of posture (e.g., toe walking; full body posturing)
 - Intense body tensing
 - Unusual facial grimacing
 - Excessive teeth grinding
 - Repetitively puts hands over ears (*note: if response to sounds, consider B4*)
 - Perseverative or repetitive action / play / behavior (*note: if 2 or more components, then it is a routine and should be considered under B2*)
 - Repetitive picking (unless clear tactile sensory component, then consider B4)
- *Stereotyped or repetitive use of objects*
 - Nonfunctional play with objects (waving sticks; dropping items)
 - Lines up toys or objects
 - Repetitively opens and closes doors
 - Repetitively turns lights on and off

B3 includes preoccupations with objects or topics

B2. Excessive adherence to routines, ritualized patterns of verbal or nonverbal behavior, or excessive resistance to change; (such as motoric rituals, insistence on same route or food, repetitive questioning or extreme distress at small changes).

- *Adherence to routine*
 - Routines: specific, unusual multiple-step sequences of behavior
 - Insistence on rigidly following specific routines (*note: exclude bedtime routines unless components or level of adherence is atypical*)
 - Unusual routines
- *Ritualized Patterns of Verbal and Nonverbal Behavior*
 - Repetitive questioning about a particular topic (distinguish from saying the same word or phrase over and over, which goes under B1)
 - Verbal rituals - has to say one or more things in a specific way or requires others to say things or answer questions in a specific way
 - Compulsions (e.g. insistence on turning in a circle three times before entering a room) (*note: repetitive use of objects,, including lining up toys, should be considered under B1*).
- *Excessive resistance to change*
 - Difficulty with transitions (should be out of the range of what is typical for children of that developmental level)
 - Overreaction to trivial changes (moving items at the dinner table or driving an alternate route)
- *Rigid thinking*
 - Inability to understand humor
 - Inability to understand nonliteral aspects of speech such as irony or implied meaning
 - Excessively rigid, inflexible, or rule-bound in behavior or thought

B2 includes rituals and resistance to change

B3. Highly restricted, fixated interests that are abnormal in intensity or focus; (such as strong attachment to or preoccupation with unusual objects, excessively circumscribed or perseverative interests).

- *Note: Consider B1 for perservative speech*

- Preoccupations; obsessions
- Interests that are abnormal in intensity
- Narrow range of interests
- Focused on the same few objects, topics or activities
- Preoccupation with numbers, letters, symbols
- Being overly perfectionistic
- Interests that are abnormal in focus
- Excessive focus on nonrelevant or nonfunctional parts of objects
- Preoccupations (e.g. color; time tables; historical events; etc)
- Attachment to unusual inanimate object (e.g., piece of string or rubber band)
- Having to carry around or hold specific or unusual objects (not common attachment objects such as blankets, stuffed animals, etc.)
- Unusual fears (e.g. afraid of people wearing earrings)

B4. Hyper- or hypo-reactivity to sensory input or unusual interest in sensory aspects of environment; (such as apparent indifference to pain/heat/cold, adverse response to specific sounds or textures, excessive smelling or touching of objects, fascination with lights or spinning objects).

- High tolerance for pain
- Poking own eyes
- Preoccupation with texture or touch (includes attraction/aversion to texture)
 - Tactile defensiveness; does not like to be touched by certain objects or textures
 - Significant aversion to having hair or toenails cut, or teeth brushed
- Unusual visual exploration / activity
 - Close visual inspection of objects or self for no clear purpose (for example, holding things at unusual angles) (no vision impairment)
 - Looks at objects, people out of corner of eye
 - Unusual squinting of eyes
 - Extreme interest or fascination with watching movement of other things (e.g., the spinning wheels of toys, the opening and closing of doors, electric fan or other rapidly revolving object)
- In all domains of sensory stimuli (sound, smell, taste, vestibular, visual), consider:
 - Odd responses to sensory input (e.g. becoming extremely distressed by the atypical sound)
 - Atypical and/or persistent focus on sensory input
- Unusual sensory exploration with objects (sound, smell, taste, vestibular)
 - Licking or sniffing objects (*note: as part of a ritual, consider B2; licking or sniffing people consider A1*)

B4 includes atypical sensory behaviors

C. Symptoms must be present in early childhood (but may not become fully manifest until social demands exceed limited capacities)

- Early primary caregiver report no longer essential
- "Early Childhood" approximately age 8 and younger (flexible)

D. Symptoms together limit and impair everyday functioning.

- Select one severity level specifier for Social Communication and one for Restricted Interests and Repetitive Behaviors.
- **Minimal social impairments:** “Without supports in place, deficits in social communication cause noticeable impairments. Has difficulty initiating social interactions and demonstrates clear examples of atypical or unsuccessful responses to social overtures of others. May appear to have decreased interest in social interactions.” *(from DSM 5 severity rating)*
- **Minimal RRB impairments:** “Rituals and repetitive behaviors (RRB’s) cause significant interference with functioning in one or more contexts. Resists attempts by others to interrupt RRB’s or to be redirected from fixated interest.” *(from DSM 5 severity rating)*

Severity Level for ASD	Social Communication	Restricted Interests & Repetitive Behaviors
Level 3 ‘Requiring very substantial support’	Severe deficits in verbal and nonverbal social communication skills cause severe impairments in functioning; very limited initiation of social interactions and minimal response to social overtures from others.	Preoccupations, fixated rituals and/or repetitive behaviors markedly interfere with functioning in all spheres. Marked distress when rituals or routines are interrupted; very difficult to redirect from fixated interest or returns to it quickly.
Level 2 ‘Requiring substantial support’	Marked deficits in verbal and nonverbal social communication skills; social impairments apparent even with supports in place; limited initiation of social interactions and reduced or abnormal response to social overtures from others.	RRBs and/or preoccupations or fixated interests appear frequently enough to be obvious to the casual observer and interfere with functioning in a variety of contexts. Distress or frustration is apparent when RRB’s are interrupted; difficult to redirect from fixated interest.
Level 1 ‘Requiring support’	Without supports in place, deficits in social communication cause noticeable impairments. Has difficulty initiating social interactions and demonstrates clear examples of atypical or unsuccessful responses to social overtures of others. May appear to have decreased interest in social interactions.	Rituals and repetitive behaviors (RRB’s) cause significant interference with functioning in one or more contexts. Resists attempts by others to interrupt RRB’s or to be redirected from fixated interest.

Behaviors/symptoms that are not/may not be captured in DSM-5 ASD

- Problems with play/imagination
 - Impairments in imaginative/symbolic play
 - Lack of functional play skills
 - Difficulty distinguishing fantasy from reality
- Shyness/social anxiety
- Language and developmental delays
 - Milestone delays/developmental delays
 - Speech delays (expressive or receptive)
 - Language disorder
- Behavioral difficulties/temper tantrums
- Poor imitation skills (poor SOCIAL imitation skills ARE captured)

Author:

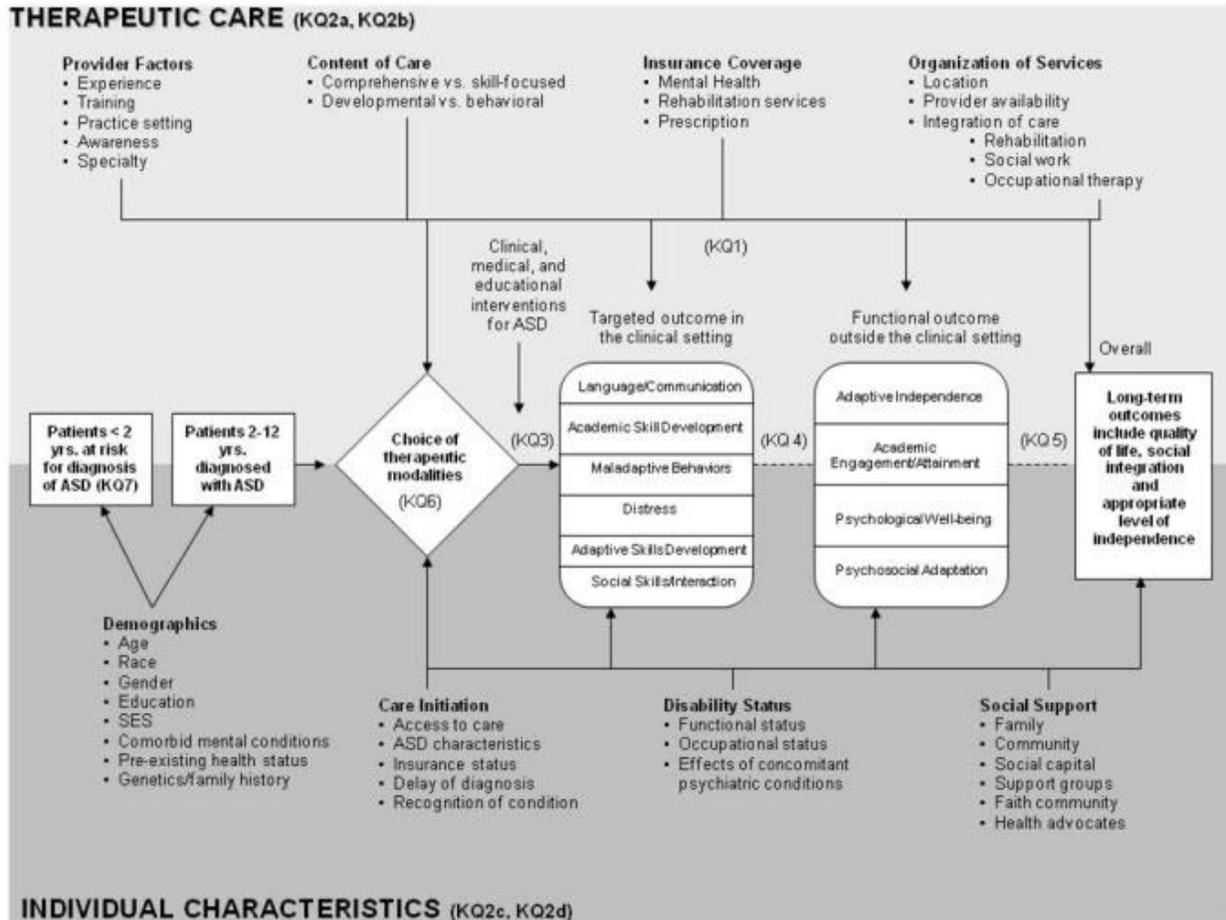
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ANNEX 6. REFERENCED ANALYTICAL FRAMEWORKS

Therapeutic interventions of ASD framework from the Agency for Healthcare Research and quality⁴⁰ (The United States Department of Health and Human Services)



Framework on the Strategic Directions and Guiding Principles for ASD services in Saskatchewan⁴¹



ANNEX 7. DETAIL RECOMMENDATIONS FOR ASD INTERVENTIONS IN MYANMAR

Responsible body	Recommendations
Ministry of Health	A comprehensive ASD intervention could be performed with involvement of various stakeholders. MOH should take the lead to develop multi-sectorial national plan for ASD and other disabilities in cooperation with the MOE, MSWRR and Ministry of Labor and international partners. This plan should be supported by sufficient human, financial and technical resources.
	Development of standard guidelines and protocols on assessment, diagnosis and treatment of ASD. Translation and validation of the correct diagnostic instrument, like the ADOS.
	MOH should initiate development of multidisciplinary diagnosis team participated by the child neurologist/development specialist and the therapists.
	Establishment of professional training courses in post-graduate level and to include a curriculum about ASD in basic medical education.
	Integration of developmental screening, promotion and monitoring of child and adolescent development in primary health care services for early detection and in-time referral after building capacity of the basic health staffs accordingly.
	Establishment of a diagnosis center at least in each state and division level tertiary hospitals.
	To include ASD in health information and surveillance system to capture data on ASD and other developmental disorders and to promote research activities especially prevalence, needs assessment, finding gaps, challenges and barriers
	Promoting inter-ministerial, local and international collaboration and coordination. Resource mobilization and to get technical support from international experts. Organization of in-country training with invited professionals from abroad so that many people can get the training. Occasional learning trips to abroad would also be very beneficial. Promote interest and involvement of respective ministries in the work for PWDs including ASD. MNDC will soon become a focal body for all matters related to disability. This committee should be supported with building, finance, technical and other support so that they can perform their constitution well. Members from MNDC should also be provided with opportunities for capacity building and empowerment. Systematic coordination and collaboration of the local DPOs, NGOs and INGOs is essential for the better coverage, avoidance of overlapping and comprehensive service provision.
	To ensure participation of people with ASD in planning, implementation and

	monitoring of policies and national plans.
Department of Social Welfare (MSWRR)	Enforcement, awareness raising and monitoring of The Child Law, 2008 Constitution and The Disabled Persons Employment Act (1958) and to review and revise these laws also taking ASD into account.
	Social protection scheme and employment policy development for people with disabilities since majority of families cannot seek interventions for their children due to huge the socio-economic burden.
	Heighten the awareness of people in Myanmar of ASD. With its typical position of not being a typical disability, but as a kind of disability at one side and a strength at the other side. Not to be considered as a defect or a simple disability, but as a condition that is open to development in the aspects of delayed maturation of the brain.
	To strengthen and manage infrastructure need for comprehensive ASD interventions.
	Establishment of government organized special schools in every state and division
	Establishment of professional training programs organized by the government in special teaching, child psychology, art/music/occupational therapy, speech/language/ behavioral therapy.. etc.
Ministry of Education	Awareness raising about IE: Refresher trainings on IE strategy and promotion of the developed IE strategy booklet (in Myanmar language) among the school principals and teachers.
	Capacity building of special school teachers, mainstream teachers on IE and child development: to provide refresher training to existing teachers on IE and how to create barrier free environment for children with ASD.
	Proper implementation, monitoring and evaluation of IE programs in all state and divisions including remote areas to make sure inclusion of PWDs in education and recognition of those schools for high performance.
	Motivate participation of PTA parent-teacher associations in ASD interventions to get more coordination and networking activities and to create barrier-free learning and enabling environment.
Ministry of Labour	Enforcement, awareness raising and monitoring of 'The Disabled Persons Employment Act' (1958) and to review and revise also taking ASD into account.
	Development of national plan for employment of PWDs.

Myanmar National Disability Council and DPOs	To advocate for the approval of the 'Rights of the persons with disability law' quickly and to promote implementation throughout the country.
	To advocate harmonization and integration of CRC and CRPD in national laws and policies
	To organize campaigns for stigma and discrimination reduction in every state and division through state and division sub-committees.
	To ensure coordination and cooperation of disability-related activities planning and implementation among the DPOs and the ministries
	Resource mobilization: finance, technical, material and human resources
	Support establishment of more parent groups.
	Awareness raising in public and school environments: more awareness raising activities for ASD through information, education and communication materials
Special Schools	Providing comprehensive and systematic interventions.
	To provide training and support to parents, as they are the key-figures in development of people with autism.
	Maintain and/or promote motivation and staff retaining strategies in special centers and mainstream schools.
	To promote sharing of knowledge, best practices among service providers
	Establishment of long hour schools, more day care centers and vocational training centers
International partners and INGOs working for disability	Increase resource mobilization by means of program proposal development, providing funding to DPOs and by advocating interest of more international partners
	To support in development of community and social security system for families of ASD individuals
	To provide technical, financial and infrastructural support for government as well as the INGOs, NGOs and DPOs in Myanmar

ANNEX 8. RESEARCH PROPOSAL

Project title

Identification of interventions and gaps for people with Autism Spectrum Disorders in Myanmar

Principal investigator(s)

Names: Swe Swe Aye

Positions: ICHD Student, KIT

Institution responsible for the research

Name:

Postal address

E-mail and phone numbers:

Collaborating institutions

Co-investigators, affiliation and role

Contact details

SECTION A STUDY OUTLINE

A.1 TITLE OF PROJECT:

Identification of interventions and gaps for people with Autism Spectrum Disorders in Myanmar

A.2 EXECUTIVE SUMMARY

Background: Myanmar is the largest country in South-East Asia.¹ The estimated population in 2010-2011 was 59.78 million with the growth rate of 1.1 percent. According to the first Myanmar National Disability survey (2010) the number of persons with disabilities (PWD) is estimated to be 1.2 million which is equivalent to 2.3% of the total population. It comprised of 68.2% of persons with physical impairment, 13.3% with visual impairment, 10.4% with hearing impairment and 8.1% with some form of intellectual disability. From this result, the calculated number of people with intellectual disability will be about 103356 in Myanmar.⁵

According to the epidemiological data, the global prevalence of Autism Spectrum Disorder (ASD) is estimated to be one person in 160, accounting for more than 7.6 million disability-adjusted life years and 0.3% of the global burden of disease. Reported prevalence rates vary substantially across studies, whereas higher rates are reported in the studies conducted in developed countries.⁹ According to Center for Disease Control and Prevention (CDC), the prevalence in the United States is estimated to be 1 in 88 children.¹⁰ According to a recent release of new data by CDC on 27th March 2014, the estimation of prevalence in the United States is 1 in 68 children (1 in 42 among boys and 1 in 189 among girls). The male to female ratio of about 4:1 for classic autism and 9:1 for Asperger syndrome.¹¹

ASD has not been well-known in Myanmar and the awareness of this disorder among the policy makers, health care workers, school teachers and the community is still very low. Though the number of children diagnosed with ASD has increased, most of diagnosed cases are from the high literate families. In Myanmar, all the steps of services for ASD: from diagnosis to interventions, are very scarce. There is an urgent need for the government to address this issue to help the children, adolescents and adults with ASD to be able to live their lives more independently and to support their families by reduction their burden.

Although there are many well-established studies related to ASD, these were conducted mainly in developed countries. There is very limited number of studies on ASD prevalence in low and middle income countries.⁹ In Myanmar, the ASD has not been included in the agenda of any decision makers or policies yet due to lack of evidence-based information and awareness raising. The findings from this research will contribute to know the current available services and capacity and the gaps and challenges which can contribute to raise awareness of the decision makers and in further implementations for ASD in Myanmar.

This study aims to explore the intervention gaps and challenges of ASD in Myanmar in order to inform the Ministry of social welfare, relief and resettlement and other line ministries with evidence-based recommendations for ASD programs.

This will be a small-scale qualitative study to elaborate more on existing interventions and challenges and gaps for ASD interventions in Myanmar. A series of in-depth interviews will be conducted with various key informants who are persons in-charge or representatives of the Department of Social Welfare (DSW), Ministry of Social Welfare, Relief and Resettlement (MSWRR), Ministry Health (MOH) and Ministry of Education (MOE), public and private special schools and training centers, INGOs working for ASD and the community based organizations. An estimated 25 people/organizations will be included in the study and it will be from the last week of March 2014 until first week of August 2014. The findings of this research will be analysed using an analytical framework and the

recommendations will be made accordingly taking feasibility, effectiveness, acceptability and equity into account.

A3 Introduction; Background and justification

Autism spectrum disorders (ASDs) are a group of neuro-developmental disabilities characterized by core deficits in three domains: social interaction, communication, and repetitive or stereotypic behavior.¹¹ According to the Diagnostic and Statistical Manual of Mental Disorder, 5th Edition (DSM-5), ASD patients could be diagnosed with four separate disorders: autistic disorder, Asperger's disorder, childhood disintegrative disorder or the catch-all disease of pervasive developmental disorder-not otherwise specified (PDD-NOS).¹²

The degree of functional impairment among individuals with ASD is highly variable, but the impact on affected individuals and their families is universally very significant. "It is one of the most important causes of lifelong disability with support and lost productivity costs estimated at more than €32bn annually in the UK." The public health impact of ASD is due to the core impairment and associated morbidities. Preliminary estimates suggested that children with autism have nine times the healthcare expenditures of other children and three times those of children with mental retardation. Average lifetime public expenditures for a person with ASD are estimated to be approximately \$4.7 million. According to scientific evidence, interventions specific for the ASD reduced this burden significantly.¹¹

Myanmar has ratified some of the UN Human Rights documents, including the CRC in 1991 and the UN Convention on the Rights of Persons with Disabilities (CRPD) in December 2011. The government has stipulated and enacted some laws for persons with disabilities: in new constitution (2008), The Child Law from 1993 and a law on Rehabilitation and Employment of persons with disabilities 1958 which has been revised and amended. A National Plan of Action for Persons with Disabilities (2010-2012) was launched in 2010 with the target to reach 130,000 persons with disabilities nationally. But an adaptation to CRPD vis-à-vis these laws and policies still need to be done.⁵

In the entire country, there are only 15 special schools for people who are deaf, blind, physical and intellectual disability and 7 vocational training schools for physical disability. Some of them are run by the government but most are by non-governmental organizations and private sector and about half of them are located in Yangon and the rest in other urban areas. The Ministry of Social Welfare, Relief and Resettlement (MSWRR) is the main government body responsible for the welfare of children, youth, women, national races residing in underserved areas, rural populations, PWDs and the elderly. The Department of Social Welfare (DSW) is the coordinating body for disability issues.¹³

According to the Ministry of Education report from 2010-11, “there were 801 disabled children in formal schools, 1450 children in special schools for the blind and the deaf, 30 disabled students in universities and colleges and 6 disabled students in master degree courses” which is a very small number compared to the estimated population of school age children with disabilities of around 460,000 according to the national disability survey figure (2.32%).⁵ In 2005, 10268 children joined mainstream schools through inclusive education programmes and 9227 disadvantaged children in monastic schools.¹³ The estimated number of people with intellectual disability will be about 103356 according to calculation of 8.1% among 2.3% of PWDs in the Myanmar National Disability Survey 2010. This indicates a very low coverage of services for people with intellectual disability including ASD. Furthermore, all of the services are situated only in the capital city of Myanmar, Yangon. Thus the rural population has scarce access to these services.¹⁴

In Myanmar, awareness of ASD is extremely low among the policy makers, service providers, schools and the community at large. People with ASD are usually regarded as those with mental disorders or those who are spoiled and most people do not know that the appropriate interventions can improve their lives significantly. Therefore, specific laws, policies and plans are rare for people with ASD and the available programs and services are also very limited. As a consequence, the coverage of services is completely disproportionate to the demand and people with ASD in Myanmar and their families have nowhere to turn to for services and support. Furthermore, there is very scarce research conducted on ASD or even on disability in general. Lack of evidence-based information and the low awareness are the main barriers for interventions and in addressing this issue.

Search Strategy: Literatures related to ASD in Myanmar were searched through internet and also by personal network. Seven research papers from Myanmar were obtained through friends: some were directly sent by researchers via email. Then the ASD epidemiology, interventions, best practices, action plans, strategies and challenges in developed countries and developing countries including Lower and Middle Income Countries in South-east Asia and Asia were searched. Various reports, reviews, strategic plans, national plans, systemic reviews, fact sheets, survey reports, scientific/peer-reviewed and grey articles, news articles and published books on disability and ASD related information were explored. These documents were obtained through websites of Myanmar government ministries including Ministry of Health, Ministry of Social Welfare, relief and resettlement, Ministry of Education, Department of Social Welfare, Ministry of National Planning and Economic Development, WHO, JICA, ESCAP, UNICEF, UNDP, World Bank, data hub for Asia-Pacific, Autism research, Research Autism, Autism speaks, Autism Society, Centre for Disease Control, National Autism Centre, National Database for Autism Research, Interactive Autism Network, National Institute of Mental Health, American Psychiatric

Association, European Agency for special needs and inclusive education, International Disability Alliance, ADDM Autism and Developmental Disorders Monitoring Network, National University of Singapore, DINF Disability information resources, Oxfam and websites of non-governmental organizations/ community based organizations in Myanmar. These were accessed via Pubmed and Google Scholar search engines.

Key words used for search: Combination of ASD/ID/Asperger's syndrome/PDD/autism/PWD/social/communication/behavioral/developmental disorder together with the epidemiology, diagnosis criteria, prevalence in developing and developed countries, systematic reviews on intervention, burden of disease, interventions, research, network, advocacy, laws, national policy and strategies, disability rights, WHO, WB, JICA, WV, ESCAP, SIDA, MSWRR, DSW, TLMI, UNESCO, APCD, CBR, CRPD, CRC, BMF, constitution Myanmar, Myanmar Human Rights Commission, Asia-Pacific/ Singapore/Thailand/ Nepal/ India ASD policies, DSM 4, DSM 5, conceptual framework, national disability survey, Myanmar disability council/law, ASD (early) interventions, psycho-social intervention, parent-mediated intervention, behavioral modification, inclusive education, special education, mainstreaming, vocational training, capacity building, barrier-free and rights-based approach.

Relevance and how the research findings will be used:

In Myanmar, awareness of ASD is extremely low among the policy makers, service providers, schools and the community at large. People with ASD are usually regarded as those with mental disorders or those who are spoiled and most people do not know that the appropriate interventions can improve their lives significantly. Therefore, specific laws, policies and plans are rare for people with ASD and the programs and services are also very limited. Furthermore, there is very scarce research done on ASD or even on disability in general, only seven studies were found so far.^{15, 16,17,18} Lack of evidence-based information and the low awareness are the main barriers for the interventions and in addressing this issue.

The findings from this research will contribute to know the current available services and capacity and the gaps and challenges which can be addressed in further implementations and policy making for ASD in Myanmar.

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A.4 OBJECTIVES

Overall goal of the research

To explore the intervention gaps and challenges of ASD in Myanmar in order to inform the Ministry of social welfare, relief and resettlement with evidence-based recommendations for ASD programs.

Specific objectives of the research:

6. To identify the current policies, legislations and programmes related to ASD and other developmental disorders
7. To explore the human, institutional and financial capacities for ASD interventions
8. To identify the existing public health programs, special education and other integration programs for ASD
9. To determine the gaps and challenges for ASD interventions
10. To use the research findings to make recommendations to stakeholders in support of evidence-based decision making by the MSWRR

A.5 METHODOLOGY

Methodology

This is a qualitative study using key-informant interviews (KII) and literature review. The KII will be conducted with key informants who are responsible for ASD interventions or who know about ASD. These Key Informants will be from the Department of Social Welfare (DSW), Ministry of Social Welfare, Relief and Resettlement (MSWRR), Ministry Health (MOH) and Ministry of Education (MOE), public and private special schools and training centers, INGOs working for ASD and the community based organizations in addition to some parents of ASD individuals. An estimated 25 people will be included in the study and it will be from the last week of March 2014 until first week of August 2014 by means of viber/skype or by phone.

Literature review will be done to identify the current policies, laws, services, plans and practices related to ASD or disability in Myanmar, accessibility and coverage of these services, international best practices for ASD interventions, global and developing country specific ASD epidemiological data.

<p>2. To explore the human, institutional and financial capacities for ASD</p>	<ul style="list-style-type: none"> • existing resources and plans: <ol style="list-style-type: none"> 1. Infrastructures (special schools, training centers, vocational centers, day care centers, pre-schools, inclusive education and mainstreaming, institutions) 2. HR (specialists for child development, psychologists, nurses, speech-language professionals, audiologists, occupational therapists, social workers, behavioral and educational specialists, applied behavior analysts, special education teachers, etc), 3. financial (government budget allocation, external funding, private spending) and 4. technical to address resource mobilization (criterion, evidence-based guidelines, specialist trainings, training of teachers for special education, training of teachers for inclusive education, publications, distribution of technical resource books, • capacity of health and social care systems as appropriate to provide services for individuals with ASD and their families. • coordination and collaboration with local and international partners • networking, guidance and support for local organizations, schools and training centers 	<p>Literature review</p> <p>KII</p>	<p>ASD Knowledgeable persons from</p> <ul style="list-style-type: none"> • MSWRR • DSW • DOH • MOE • Myanmar Autism Association • INGO • Schools/ training centres
<p>3. To explore the existing special education, integration and other programs for ASD.</p>	<ul style="list-style-type: none"> • screening (1-5 years old children, older children, adolescents and adults) <ol style="list-style-type: none"> 1. cognitive and academic functioning (current developmental or cognitive level, as indicated-academic and pre-academic skills, as indicated- neuropsychological functioning) 2. Adaptive functioning (level of day-to-day functioning in domains relevant to the individual's developmental level) 3. Social, emotional, and behavioral functioning (overall level of social emotional functioning including impact of ASD symptoms such as stereotypic preoccupations or preservations, level of social vulnerability and any experiences of victimization, symptoms of other mental health conditions, presence of any self-harm or suicidal ideation, challenging behaviors including environmental features that trigger problem behaviors or facilitate desired skills and behaviors) 4. Communication (relevant domains of speech and language functioning including functional communication and pragmatic language) 5. Sensory and motor functioning (As indicated, assessment of fine and gross motor skills, feeding and oral motor skills and sensory functioning, assessment of sensory functioning should give specific attention to both negative reactions and strong preferences for specific sensory stimuli) 6. Comprehensive medical examination (comprehensive health history including review of systems, definitive hearing and vision examination, general physical neurodevelopment exam, any indicated laboratory tests or neuroimaging, consultation regarding medication management) 7. Family functioning (level of parenting stress, impact on siblings and family functioning, extent of family's support network, resources accessed and of interest, financial impact 	<p>KII</p>	<p>ASD Knowledgeable persons from</p> <ul style="list-style-type: none"> • MSWRR • DSW • DOH • MOE • Myanmar Autism Association • INGO • Schools/ training centres

	<p>of ASD diagnosis, legal considerations)</p> <ul style="list-style-type: none"> • diagnosis • assessment for intervention planning • early intervention and ongoing support <ul style="list-style-type: none"> 1. language and communication skills 2. social skills 3. academic skills 4. problem behaviors 5. medical 6. mood and coping 7. other adaptive skills • informed professional judgment <ul style="list-style-type: none"> 1. diagnosis 2. tailoring intervention 3. interpreting progress • family centered care <ul style="list-style-type: none"> 1. cultural sensitivity and values 2. family values and preferences consideration 3. family resources consideration 4. education of parents 5. socio-economic condition 6. socio-emotional factors • community collaboration, application of CBR approach <ul style="list-style-type: none"> • Knowledge of existing services in public and private sector for ASD individuals by families • Perspective of existing services in public and private sector 	IDI	Primary Caregivers Parents/ Grandparent/ Aunt/ Uncle/
4. To determine the gaps and challenges for ASD intervention	<ul style="list-style-type: none"> • screening • diagnosis • assessment for intervention planning • early intervention and ongoing support <ul style="list-style-type: none"> • language and communication skills • social skills • academic skills • problem behaviors • medical • mood and coping • other adaptive skills • informed professional judgment <ul style="list-style-type: none"> • diagnosis • tailoring intervention • interpreting progress • family centered care <ul style="list-style-type: none"> • cultural sensitivity and values • family values and preferences consideration • family resources consideration • education of parents • socio-economic condition • socio-emotional factors 	KII	ASD Knowledgeable persons from <ul style="list-style-type: none"> • MSWRR • DSW • DOH • MOE • Myanmar Autism Association • INGO • Schools/ training centres

	<ul style="list-style-type: none"> • community collaboration, application of CBR approach • Knowledge and perceptions on challenges and gaps of ASD interventions and the take up of services by the families 	IDI	Primary Caregivers Parents/ Grandparent/ Aunt/ Uncle/
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A.6 PARTICIPANTS

A.6.1 Age / Sex: (please enter the expected number in each of the boxes)

	Neonates	Infants	Young children	Adolescents	Adults
Males					10
Females					15

Currently, I am still not sure of the exact figures of male and female participants. According to my current knowledge on respondents, there will be slightly more women than men and it is unlikely that they will be less than 19 years of age. I will request all agencies/ministries to be able to interview the most knowledgeable person on ASD.

A.6.2 Describe how the participants are to be recruited?

Study Population: 15 Responsible persons from the MSWRR, DSW, MOH and MOE and all of the private and public special education schools and training centers, Myanmar Autism Association, INGOs, NGOs and CBOs who are working or knowledgeable on ASD interventions currently providing by their respective agency or ministry will be invited in this study. Furthermore, 10 primary caregivers of ASD individuals who are currently getting services from the public or private service providers, willing to participate, can give time and who can be contacted through telephone or internet will also be invited. All

participants should be more than 19 years old. Those organizations or families who do not give consent will be excluded from the study.

The study population will be reached primarily through three networks of friends: Civil servant network, INGO friends network and being a mother of an autistic son, peer friends network who have good linkages with service providers and the associations. I have already got contact with the secretary of the Myanmar Autism Association (MAA) who is willing to give me any information I need. Through MAA and friends network, I will contact the private service providers. I will also approach another friend who is a deputy-director of the Department of Social Welfare, Mon State to get information and contact with government institutions. I also have contacted a researcher who had done some researches on disability and through him, I will try to get more information on how to contact with respondents from public sector. The rest of the service providers will be contacted at the addresses I got through internet websites and the directory.

The families of ASD individuals will be contacted through (MAA) Myanmar Autism Association and through my personal network. Due to limited time and human resource, only 10 family members (one family member per one confirmed ASD child) will be interviewed. Most of them will be from high literate families who had already seek for diagnosis for their children. Thus the potential bias in information is very likely. This limited information cannot be generalized and will be carefully analyzed, interpreted and described in the final report. .

To avoid potential bias among service providers, this study will invite respondents from all types of service providers on inclusive education, special education and training programs currently implementing in Myanmar. Furthermore, the questions are open-ended and the researcher will conduct the interviews carefully without leading questions so that the participants can respond freely and openly.

A.7 PROCEDURES

A.7.1 What procedures or methods will be employed in the collection of data (e.g. patient interviews / focus group discussions) and by whom?

Procedure	To be carried out by (profession):	Experience in procedure:
Key-informant interview	Researcher	nil

A.7.2 Please indicate that the persons are competent to carry out the techniques used as identified in A.5.1 are competent to carry out these procedures. List any training of staff which may be required prior to commencement of the study.

KIIs will be done via viber/skype or phone. The information about the study and the questions will be clearly explained and will also be translated into Myanmar language to avoid mis-interpretation as much as possible. I have some experience of developing questionnaires for project evaluation and monitoring. Though I have never done in-depth interviews, I have conducted some focus-group discussions with the project beneficiaries for project needs assessments, evaluation and monitoring. Recently, I have completed the Health System Research module where interview methods were learnt and practiced. I will also practice with my classmates for in-depth interviews. In addition, I will upgrade my interview skills by means of pre-testing and practicing with 2 service providers and 2 parents of autistic children before the actual data collection.

A.8 SAMPLING

A.8.1 Please justify your choice of sampling method(s) and if relevant sample size(s); For qualitative research provide rationale and criteria for the selection of participants for each technique

Purposive sampling will be used because I would like to collect information from individuals who are key people or professionals or knowledgeable in the specific area of interest. Respondents will be from various backgrounds and professionals to capture the wide perspective and recommendations..

DATA ANALYSIS

A.8.2 Explain how you will analyse the data and, if applicable, which software you will use.

Immediately after each discussion, raw field notes will be transformed into a well-organized set of notes and the recorded tape will be checked. Every day, typed transcripts will be prepared from written notes and tape recordings using computer. Upon completion of the data collection, the analysis of the data will be started by ordering the data and then coding in categories according to discussion topics. The data will be summarized to analyze possible themes, commonalities, differences and their associations.

QUALITY ASSURANCE and STUDY LIMITATIONS

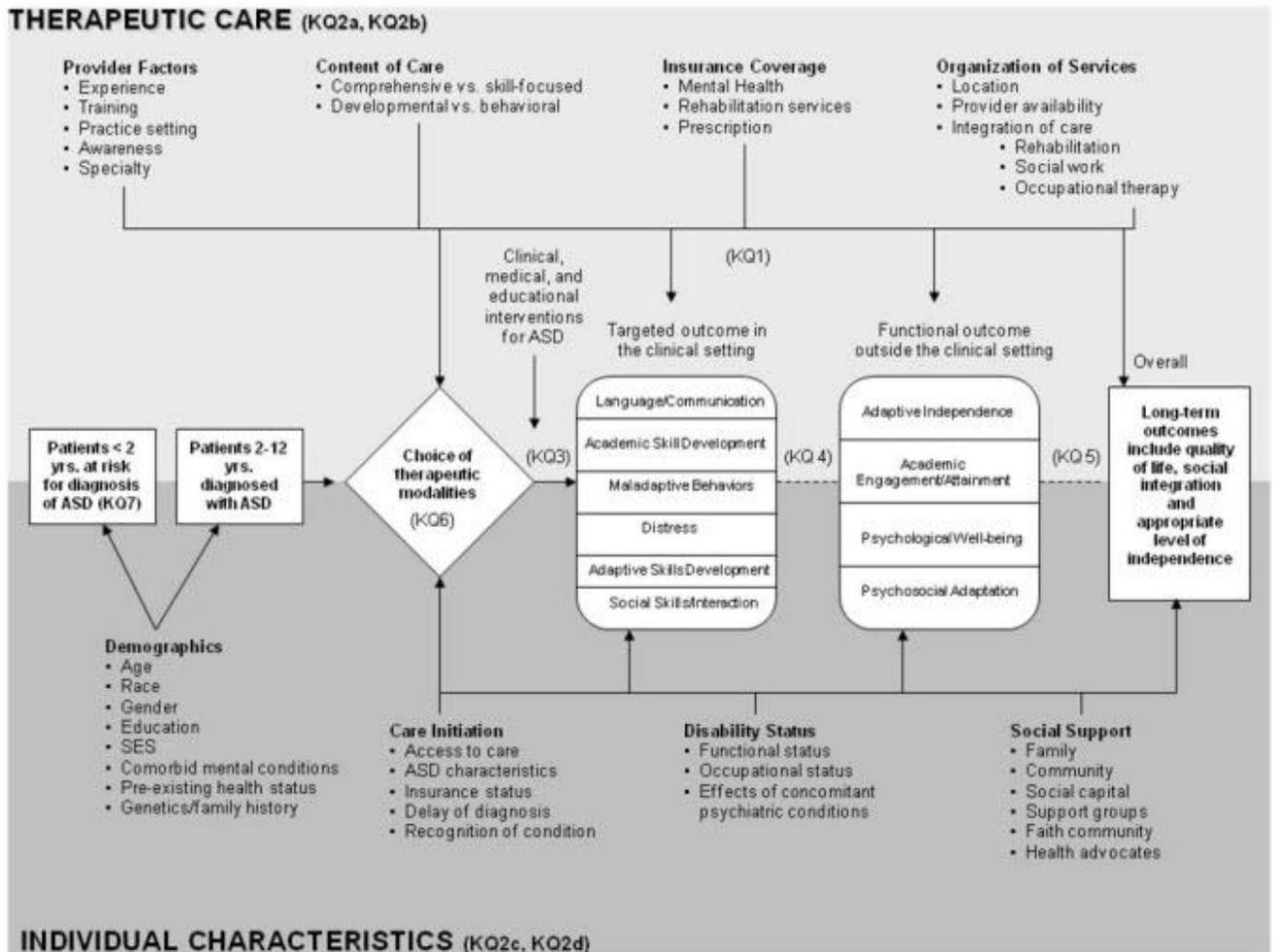
A.8.3 What procedures are in place to ensure the quality of the research?

Data management

Quality assurance will be regarded in every process of the study from selection of study design and respondents to data analysis and report writing. To ensure maximum validity, the data collection tools will be developed with careful contextual consideration, pre-testing and adjustment of the guidelines, translation and back translation of the instruments into local language and reporting as precisely as possible. The data collected from different sources from different study population will be triangulated to get the most accurate data. I will seek the feedback and comments from supervisors before the final reporting.

A.8.4 Explain expected limitations of the study design and how you will deal with these limitation

This study will focus on the existing public and private services and capacities for ASD interventions in Myanmar and then to find out the challenges/gaps and areas needed to address by using an analytical framework: the behavioral, educational, allied health and complementary and alternative medicine therapeutic interventions of ASD framework, Agency for Healthcare Research and quality, The United States Department of Health and Human Services. This framework will be adapted to Myanmar context and some areas such as insurance coverage and demographics will not be covered in the research. The prevalence and current situation of ASD in Myanmar cannot be covered in this study according to the limitations in time, human resource and finance. I will take the global estimation to calculate the prevalence of ASD in Myanmar.



Ethical issues are considered thoroughly before the start of the research and will be addressed intensively throughout this study. Ethical approval will be obtained from National Ethic Committee, Myanmar. The respondents will be treated with due respect while ensuring privacy, confidentiality and justice. The participation in the study will be completely voluntary. The consent form will be sent by email to the participants in advance and explained at the start of the interview by skype/viber/phone. I will request them to reply in the email that they agree or verbal consent will be obtained before the start of the interview and recorded after ensuring understanding about the study, process, right to withdrawal and the potential risk and benefits (See Consent form: Annex). Signed informed consent will be obtained by hardcopy for those who do not have email. One of my friends

will help me collect the signed hard copy and the scanned copies will be sent to me. The conduct of the research will be completely anonymous: each participants will be given identification codes and the information will be treated with high level of privacy and confidentiality. After completion of the study, the participated organizations, schools/training centers and family members will be given feedback on the study results. The recorded files will be kept in a secured place and be deleted permanently at the end of the study.

A.9 DISSEMINATION OF RESULTS

Please outline what plans you have for dissemination of results.

Dissemination and use of results

Upon finalization of the report and policy briefs, the research findings will be disseminated by email/mail to the Department of Social Welfare (DSW), Ministry of Social Welfare, Relief and Resettlement (MSWRR), Ministry of Health, Department of Medical Research, Myanmar (DMR), Public Health University, JICA, UNDP, UNICEF, UNESCO and all the organizations and schools participated in the study. I will also try to publish it in Myanmar Health Research Journal, MMA journal, Myanmar Autism Association newsletter, on-line peer review journals and the websites of the Royal Tropical Institute, Amsterdam and public health in Myanmar blog. During consent taking, we will ask the interest of research participants to receive the research findings and will give individual feedback at the end of the study. The contact information will also be provided for further contact if they want to receive more information later. These findings will be useful in decision making of interventions for ASD in the future.

Work schedule

No	Activities	Mar 2014				April 2014				May 2014				June 2014				July 2014				Aug 2014				Responsible person
					4	1	2	3	4	1	2	3	4	1	2	3	4	1	2	3	4	1	2	3	4	
1	Finalize proposal																									PI
2	Submit & obtain ethical clearance from MSWRR																									PI
3	Develop research questionnaire																									PI
4	Pre-test and translate the questionnaire																									PI
5	Adjust & finalize questionnaire																									PI
6	Recruit respondents																									PI
7	Data collection																									PI
8	Data processing & analysis																									PI
9	Write report & research brief																									PI
10	Disseminate findings & receive feedback & comments from supervisors																									PI

SECTION B ETHICAL CONSIDERATIONS

CONSEQUENCES FOR THE LOCAL COMMUNITY / ENVIRONMENT AND PATIENTS

B.1 State the country(ies) and town(s) / district(s) where the work will be carried out.

The study will be carried out in Myanmar, mainly in Yangon township, Yangon Division since all of the centers, schools and organizations for ASD known so far are situated in Yangon. If later we found out other centers in other townships, I will include them in the study.

B.2 Describe the setting in which the study will be carried out (e.g. community centre / home / village / District Hospital / Health Centre)

The interviews will be conducted by viber/facebook/skype or phone at the convenient time of the respondents.

B.3 Outline the potential adverse effects, discomfort or risks that may result from the study in the following areas:

B.3.1 Participants

There might be some sensitivity in mentioning the challenges they are facing or when discussing about the various capacities. Participants might fear against government investigations when they express the actual challenges. Although the possibility of this to happen is less likely due to the fact that the government is now opening up towards better reformation, these will be addressed by maintaining strict confidentiality and the anonymity by use of coding system, keeping the information collected in private and deleting the recorded audio files at the end of the research.

The family members - especially the parents - might experience psychological distress while discussing about their children. If there is any breakdown during discussion with the family members, being a mother of an autistic child by myself, I will try to comfort them and share my experience and will encourage them that the information they provide will be helpful for the future interventions on ASD. In my knowledge there is no specific counselor for this situation and the social workers from public sector are mainly doing financial counseling and contact tracing. If need be, I will refer them to a counselor, Ms Daw Tin Mya, dtm.care.org@gmail.com, phone: 00959425333944 who has been trained and worked as a

counselor for various people including people with HIV/AIDS, TB and other project beneficiaries. She has been working as a program officer with CARE International, Myanmar and she agreed that she can spare some time after work.

B.3.2 Investigators

The risk to investigator is minimal by assuming that the sensitivity of the government on research is reduced upon current political and administrative transformation but there might be some psychological stress which I can cope with. Under previous military ruling, 'research' was the sensitive issue and much research was conducted without informing respective ministries. Moreover, the application for ethical clearance took too long except for the government operated national surveys.

B.3.3 Members of the public

It is unlikely that there will be any risks for the public since the study includes only about the service provision and the challenges of ASD interventions.

B.4 Outline what steps will be taken to minimize the adverse effects, discomfort or risks described above.

B.4.1 For participants

The risks for the participants will be addressed by ensuring strict anonymity and confidentiality and by getting the ethical clearance from the national ethical committee before carrying out the study. If there is any breakdown during discussion with the family members, being a mother of an autistic child by myself, I will try to comfort them and share my experience and will encourage them that the information they provide will be helpful for the future interventions on ASD. In my knowledge there is no specific counselor for this situation and the social workers from public sector are mainly doing financial counseling and contact tracing. If need be, I will refer them to a counselor, Ms Daw Tin Mya, dttm.care.org@gmail.com, phone: 00959425333944 who has been trained and worked as a counselor for various people including people with HIV/AIDS, TB and other project beneficiaries. She has been working as a program officer with CARE International, Myanmar and she agreed that she can spare some time after work.

B.4.2 For investigators

Getting permission and the ethical clearance from the respective ministry will prevent any adverse effects towards investigator.

B.4.3 For members of the public

There will be no risks or adverse effects for the members of public as I can think of. But all the information collected through the study will be kept in strict confidentiality.

B.5.1 What demands will this research place on local health services?

This research will get the information from the service providers for ASD and the family members. There will be some direct demands on local health services since they will have to allocate some of their time, which may cause some disruption of their normal duties.

B.5.2 Detail how the design of the research project takes into account the above demands.

B.6 What steps will be taken to ensure privacy and confidentiality for participants?

The recorded files will be permanently deleted at the end of the study. Each participant will be given identification code and the information will be treated with high level of privacy and confidentiality.

SOCIAL AND CULTURAL SENSITIVITY ISSUES

B7.1 Describe what cultural and or social sensitivities your research raises

In Myanmar, ASD is not well known or understood and most people think it as a mental disease or think individuals with ASD as spoiled people. The family members of ASD might have experienced stigmatization by the community. The service providers may have various perspectives on the ASD individuals and there might also be stigma on them for giving services for ASDs. Therefore, during the study, some cultural and social sensitivities might be raised through the discussions on challenges and difficulties of ASD interventions in Myanmar.

B7.2 Explain how you plan to deal with cultural and social sensitivities within your research and how you will minimize potential risk.

The participants will be informed of voluntary participation and if there is anything they feel uncomfortable to discuss, they can refuse. All the views will be respected without judgment and the discussions will be kept confidential. I will make sure that all participants understood the objective of the study and that the findings will be of useful for the wellbeing of the ASD individuals and their families in Myanmar.

GENDER ISSUES

B8.1. Describe how the research addresses a demonstrated public health need and a need expressed by women and/ or men

As the awareness of ASD become increased and diagnosis become more advanced, more cases are identified. According to CDC data release in March 2014, he prevalence of ASD is 1 in 69 children and the health, social and economic burden of ASD increased significantly and it becomes the public health concern. This research will address the needs for the ASD interventions as more ASD cases are identified in Myanmar.

B8.2. Explain how the research contributes to identifying and/ or reducing inequities between women and men in health and health care.

Research findings will provide evidence-based recommendations for future decision making for interventions on ASD which can benefit to all the people with ASD in equitable manner.

B.8.3. Does the nature or topic of the research make it important that the researchers are women rather than men or vice versa? Please explain. What is the sex composition of the research team and what are their duties and responsibilities in the proposed research?

This research will be done by one female (principle investigator [PI]) only. The nature of this study does not impose any difference in collecting information.

B.9 INFORMED CONSENT

B.9.1 Information given to *participants*:

The consent from participants will be obtained prior to the interview. Participants will be sent the consent form and asked to sign or to reply in the email that they agree.

CONSENT FORM (KEY INFORMANTS)

This is the informed consent form for the respondents of the study 'Identification of interventions and gaps for people with Autistic Spectrum Disorders in Myanmar' who we have invited to participate.

Introduction: I am Swe Swe and I am conducting research on the 'Identification of interventions and gaps for people with Autistic Spectrum Disorders in Myanmar'. I would like to explain a little bit what 'ASD' is if you are not familiar with it.

Autism spectrum disorders (ASDs) are a group of neuro-developmental disabilities characterized by core deficits in three domains: social interaction, communication, and repetitive or stereotypic behavior.¹¹ According to the Diagnostic and Statistical Manual of Mental Disorder, 5th Edition (DSM-5), ASD patients could be diagnosed with four separate disorders: autistic disorder, Asperger's disorder, childhood disintegrative disorder or the catch-all disease of pervasive developmental disorder-not otherwise specified (PDD-NOS).¹²

The study population includes the individuals or responsible persons who are providing ASD services from the organizations, ministries, school and training centers of ASD in Myanmar. In this research we would like to ask what you know about the current policies, laws, programs and the challenges and gaps in implementation of these services and the capacity of your organization to complete your services.

The participation in this study is completely voluntary. Please clarify with me any time if you are not clear.

Research Information:

The aims of this study are to identify the existing services and capacities for ASD in our country and to explore challenges and gaps for interventions. Based on the study findings, I will make recommendations to the Ministry of Social Welfare, Relief and Resettlement (MSWRR) for further and expanded intervention programs.

You are being invited to participate in our research since your inputs will contribute to achieve the goal of this study. This discussion may take about 45-60 minutes. If you give consent, I would like to take written notes and tape recording to capture our discussion and to get the accurate information.

Participation and process:

Participation is voluntary and your decision to involve or not will not have any effect on you, your school or organizational activity. You may change your mind later and stop participating even if you have agreed earlier or you can refuse to answer some questions which you are uncomfortable with.

Any data connected to you as an individual participant will be kept confidential. The information collected will be kept private and the recorded audio file will be deleted at the end of the research.

Benefits: After having analyzed the findings, the report of the research findings will be sent to the respective ministries in order for them to consider the study and the recommendations regarding decision making of future interventions and contribute to better life of people with ASD.

Discomfort and risks: During discussion, there might be times that you feel uncomfortable in discussing a particular topic. In these circumstances, you can skip answering that topic/question without any explanation. If you feel that you have hurt while expressing your feelings and perspectives, please mention us so that we can seek a solution together within our capacity. If necessary, a counselor, Daw Tin Mya, 0095 9425333944, who has rich experience in counseling will give support. This proposal has been reviewed and approved by the National Ethic Committee which oversees the compliance according to the ethical standard. The researcher takes full responsibility to ensure that the research is implemented in ethical way throughout the study.

Dissemination: The findings of this study will be shared with the Department of Social Welfare (DSW), Ministry of Social Welfare, Relief and Resettlement (MSWRR), Ministry of Health, Department of Medical Research, Myanmar (DMR), Public Health University, JICA,

UNDP, UNICEF, UNESCO and all the organizations and schools participated in the study. If you are interested in more detail information about the research findings, please contact us and we will feedback you at the end of the study.

Consent and contact: Please don't hesitate to ask if you have questions. I hope you have clear understanding on the process and consequences by now. In case you have questions later, you may contact any of the following contact persons. If you agree to participate, I would like to request you to sign hereunder or send an email reply that you agreed to participate or to give verbal consent.

Participant Name:	Interview Name:
Signature:	Signature:
Date:	Date:

Contact persons:

Swe Swe Aye

email address: dr.swesweaye@gmail.com, sweichd2013@gmail.com

Phone: +31 39230766

CONSENT FORM (FAMILY MEMBERS)

This is the informed consent form for the respondents of the study 'Identification of interventions and gaps for people with Autistic Spectrum Disorders in Myanmar' who we have invited to participate.

Introduction: I am Swe Swe and I am conducting research on the 'Identification of interventions and gaps for people with Autistic Spectrum Disorders in Myanmar'. I would like to explain a little bit what 'ASD' is if you are not familiar with it.

Autism spectrum disorders (ASDs) are a group of neuro-developmental disabilities characterized by core deficits in three domains: social interaction, communication, and repetitive or stereotypic behavior.¹¹ According to the Diagnostic and Statistical Manual of Mental Disorder, 5th Edition (DSM-5), ASD patients could be diagnosed with four separate disorders: autistic disorder, Asperger's disorder, childhood disintegrative disorder or the catch-all disease of pervasive developmental disorder-not otherwise specified (PDD-NOS).¹²

The study population includes the family members of ASD people and the individuals or responsible persons who are providing ASD services from the organizations, ministries, school and training centers of ASD in Myanmar. In this research we would like to ask what you know about the current support and services in interventions, and difficulties in taking up of services.

The participation in this study is completely voluntary. Please clarify with me any time if you are not clear.

Research Information:

The aims of this study are to identify the existing services and capacities for ASD in our country and to explore challenges and gaps for interventions. Based on the study findings, I will make recommendations to the Ministry of Social Welfare, Relief and Resettlement (MSWRR) for further and expanded intervention programs.

You are being invited to participate in our research since your inputs will contribute to achieve the goal of this study. This discussion may take about 45-60 minutes. If you give consent, I would like to take written notes and tape recording to capture our discussion and to get the accurate information.

Participation and process:

Participation is voluntary and your decision to involve or not will not have any effect on you, your school or organizational activity. You may change your mind later and stop participating even if you have agreed earlier or you can refuse to answer some questions which you are uncomfortable with.

Any data connected to you as an individual participant will be kept confidential. The information collected will be kept private and the recorded audio file will be deleted at the end of the research.

Benefits: After having analyzed the findings, the report of the research findings will be sent to the respective ministries in order for them to consider the study and the recommendations regarding decision making of future interventions and contribute to better life of people with ASD.

Discomfort and risks: During discussion, there might be times that you feel uncomfortable in discussing a particular topic. In these circumstances, you can skip answering that topic/question without any explanation. If you feel that you have hurt while expressing your feelings and perspectives, please mention me so that we can seek a solution together within our capacity. If necessary, a counselor, Daw Tin Mya, 0095 9425333944, who has rich experience in counseling will give support. This proposal has been reviewed and approved by the National Ethic Committee which oversees the compliance according to the ethical standard. The researcher takes full responsibility to ensure that the research is implemented in ethical way throughout the study.

Dissemination: The findings of this study will be shared with the Department of Social Welfare (DSW), Ministry of Social Welfare, Relief and Resettlement (MSWRR), Ministry of Health, Department of Medical Research, Myanmar (DMR), Public Health University, JICA,

UNDP, UNICEF, UNESCO and all the organizations and schools participated in the study. If you are interested in more detail information about the research findings, please contact us and we will feedback you at the end of the study.

Consent and contact: Please don't hesitate to ask if you have questions. I hope you have clear understanding on the process and consequences by now. In case you have questions later, you may contact any of the following contact persons. If you agree to participate, I would like to request you to sign hereunder or send an email reply that you agreed to participate or to give verbal consent.

Participant Name: Interview Name:

Signature: Signature:

Date: Date:

Contact person:

Swe Swe Aye

email address: dr.swesweaye@gmail.com, sweichd2013@gmail.com

Phone: +31 39230766

B.9.2 Outline who will deliver the above information and how?

The consent form will be sent by email to the participants in advance and explained at the start of the interview by skype/viber/phone. I will request them to reply in the email that they agree or verbal consent will be obtained and recorded after ensuring understanding about the study, process, right to withdrawal and the potential risk and benefits (See Consent form: Annex). Signed informed consent will be obtained by hardcopy for those who do not have email. One of my friends will help me collect the signed hard copy and the scanned copies will be sent to me.

B.9.3 Please indicate how consent will be obtained, given local circumstances.

B.9.4 Are any inducements to be offered to either participants or the individuals who will be recruiting them? (e.g. improved patient care / cash) (please tick appropriate box)

<input type="checkbox"/>	Yes	<input checked="" type="checkbox"/>	No
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B.9.5 If Yes, please give details

B.9.6 Outline any hidden constraints to consent.

The participation in the study will be completely voluntary, no incentives will be offered and there is very minimal risk in participating. Furthermore, the collected information will be kept strictly confidential. Thus there are no hidden constraints to consent.

B.10 Local Ethical Committee

B.10.1 State the name and address of the local ethical committee who is requested for approval

Dr U Tint Swe Latt, Rector, University of Medicine (II), Ministry of Health, Yangon, Myanmar

Director General, Department of Social Welfare, Myanmar.

B.10.2 Indicate a timeline: when is approval expected?

Estimated expected approval will be after five weeks from application.

SECTION C

DECLARATION: TO BE SIGNED BY MAIN APPLICANT

- I confirm that the details of this proposal are a true representation of the research to be undertaken.
- I will ensure that the research does not deviate from the protocol described.
- If significant protocol amendments are required as the research progresses, I will submit these to the Royal Tropical Institute Research Ethics Committee for approval.
- Where an appropriate mechanism exists, I undertake to seek additional local Ethical Approval in the country(ies) where the research is to be carried out.
- I have no conflict of interest in this research

I expect the project to commence on (Date):

and be completed by (Date):

Signed Date

Agreement advisor:

I have seen and agree with the application. I have no conflict of interest in advising this research

Signed Date

Additional comments advisor:

Annexes: Please include the following annexes:

Annex 1 Instruments to be used

Annex 2 CV of applicant

KEY INFORMANT INTERVIEW TOPIC GUIDE

Code of the respondent: Interviewer name:.....

Department/Organization: SexAge.....

Occupation:..... Date:

Address:

Number of teachers Number of current students

Location:.....

Are you in a place where you can talk freely and openly right now?

1. Have you ever come across any children with strange behaviour?

- Have you heard of any children with Autistic spectrum disorder (ASD)?

(Autism spectrum disorders (ASDs) are a group of neuro-developmental disabilities characterized by core deficits in three domains: social interaction, communication, and repetitive or stereotypic behavior. According to the Diagnostic and Statistical Manual of Mental Disorder, 5th Edition (DSM-5), ASD patients could be diagnosed with four separate disorders: autistic disorder, Asperger's disorder, childhood disintegrative disorder or the catch-all disease of pervasive developmental disorder-not otherwise specified (PDD-NOS).)

- Do you know any children with ASD? What do you think the prevalence of ASD in Myanmar?

2. Are you aware of any policies, laws and programs for individuals with ASD? What are your current practices according to these?

- government recognition/awareness,
- current relevant policies and legislations,
- national plans,
- CRPD and CRC implementation and integration,
- public awareness raising,
- Mainstreaming into PHC for early/ timely detection and management,

- inclusive education integration in mainstream education
3. What are the current activities for coordination and collaboration for ASD interventions with other ministries (MOH, MSWRR, MOE) and international partners?
 4. Are there any activities on networking, guidance and support for local organizations, schools and training centers regarding ASD?
 5. How do you think the parents of ASD get diagnosis for their children? Why do they start to seek help for their child and whom do they usually go to?
 6. What are the existing resources for ASD interventions?
 - Human resources (general pediatricians, specialists for child development, psychologists, nurses, speech-language professionals, occupational therapists, social workers, behavioral and educational specialists, special education teachers, etc),
 - infrastructural (care, education, support, interventions, services, rehabilitation) and
 - technical resources (criterion, evidence-based guidelines, specialist trainings, training of teachers for special education, training of teachers for inclusive education, publications, distribution of technical resource books, etc.)?
 - financial (government budget allocation, external funding, private spending),
 7. Are there any kind of support for individuals with ASD and their families?
 - health services,
 - disability benefit,
 - social and psychological support and care,
 - employment
 8. Is there any information and surveillance system? What is the future plan?
 9. What kind of services/activities for ASD are provided by your department/school/centre?
 10. Where and how does special school teachers get training and practice?
 11. What do you see as problems/ challenges for ASD interventions?
 12. How could these be solved in the situation of Myanmar?

သက်ဆိုင်ရာ ဌာန၊ ကျောင်း၊ စင်တာများမှ တာဝန်ရှိသူများကို မေးမြန်းရန် လမ်းညွှန်
(KII- MYANMAR LANGUAGE)

ပါဝင်သူ၏ ကုတ်နံပါတ် မေးမြန်းသူ

ဌာန၊ ကျောင်း၊ အဖွဲ့အစည်းအမည် ကျား/မ.....အသက်.....

ဌာန၊ ကျောင်း၊ အဖွဲ့တည်နေရာ

အလုပ်အကိုင် ရက်စွဲ

အခုပွင့်ပွင့်လင်းလင်းနဲ့ လွတ်လွတ်လပ်လပ် အေးအေးဆေးဆေး ပြောလိုရပါသလား။

1. ထူးထူးဆန်းဆန်းပြုမူတဲ့ ကလေးတွေ တွေ့ဖူးပါသလား၊ အော်တစ်ဇင် ဆိုတာကို ကြားဖူးပါသလား။
အော်တစ်ဇင်ကလေးတွေကို တွေ့ဖူးပါသလား။ မြန်မာနိုင်ငံမှာ ဒီလိုကလေးတွေ ဘယ်လောက်ရှိနေတယ်လို့ ထင်ပါသလဲ။
2. အော်တစ်ဇင်ကလေးနဲ့ ပါတ်သက်ပြီး လုပ်ဆောင်ပေးနေတဲ့ ဥပဒေ၊ ပေါ်လစီ၊ ပရောဂျက်တွေ ရှိမရှိ ကြားဖူး၊ သိဖူးပါသလား။ သင်ကိုယ်တိုင်ရော ပါဝင်လုပ်ဆောင်နေတာမျိုး ရှိပါသလား။
 - အစိုးရအနေနဲ့ အော်တစ်ဇင်နဲ့ ပါတ်သက်ပြီး အကျွမ်းတဝင်ရှိပါသလား။ သိပါသလား။
 - လက်ရှိ ဘာပေါ်လစီတွေ၊ ဥပဒေတွေ ရှိပါသလဲ။
 - အော်တစ်ဇင်အတွက် နိုင်ငံလုံးဆိုင်ရာ စီမံချက် ရှိမရှိ။ (National plan)
 - CRPD and CRC နဲ့ ဆက်နွှယ်ပြီး အော်တစ်ဇင်ကလေးတွေအတွက် လုပ်ဆောင်နေတာများ သိပါသလား။
 - ပြည်သူ့လူထုအများစုက အော်တစ်ဇင်ကို သိကြပါသလား။ ဘယ်လိုလူတွေက သိကြပါသလဲ။
 - အော်တစ်ဇင်ကလေးတွေကို စောစောစီးစီး ရောဂါဖော်ထုတ် သိရှိနိုင်ဖို့နဲ့ ပါတ်သက်ပြီး အစိုးရအနေနဲ့ လုပ်ဆောင်နေမှုများ ကြားဖူးပါသလား။
 - အစိုးရသာမာန်ကျောင်းတွေမှာ ပူးပေါင်းသင်ကြားမှု အစီအစဉ်တွေရှိပါသလား။
3. သင့်ကျောင်း/ဌာနက အော်တစ်ဇင်ကလေးတွေအတွက် ဘယ်လိုဝန်ဆောင်မှုတွေပေးနေပါသလဲ။
4. အော်တစ်ဇင်ကလေးများကို သင်ကြားလေ့ကျင့်ပေးနေတဲ့ဆရာ၊မ များအတွက် သင်တန်းများနှင့် လက်တွေ့သင်ကြားမှုအခြေအနေ
5. အစိုးရအနေနဲ့ အခြားဝန်ကြီးဌာနတွေ၊ နိုင်ငံတစ်ကာအဖွဲ့အစည်းတွေနဲ့ ပူးပေါင်းဆောင်ရွက်မှု အခြေအနေ ဘယ်လိုရှိပါသလဲ။ သင့်ကျောင်း၊ အဖွဲ့အစည်းအနေနဲ့ ရော ဘယ်လို ပူးပေါင်း ဆောင်ရွက်မှုတွေ ရှိပါသလဲ။
6. ပြည်တွင်းမှ အခြားအဖွဲ့အစည်းတွေနဲ့ ပူးပေါင်း၊ ကွန်ယက်တွေ ရှိပါသလား။ ဘယ်လိုမျိုး လုပ်ဆောင်နေပါသလဲ။
7. မိဘတွေအနေနဲ့ မိမိကလေး အော်တစ်ဇင်ဖြစ်နေကြောင်း ဘယ်လိုသိကြပါသလဲ။ ဘယ်လို အခြေအနေမျိုးတွေကြောင့် မိဘတွေအနေနဲ့ ဆရာဝန်၊ဆရာမ၊ အခြားသူများနဲ့ စတင် တိုင်ပင်ပါသလဲ။ ဘယ်သူနဲ့ အရင်ဆုံးတိုင်ပင်သလဲ။ ဘယ်သူနဲ့ ပြသလဲ။
8. လက်ရှိရှိနေတဲ့ အင်အားစုများ

- လူအင်အား (ဥပမာ- ဆရာဝန်၊ ဆရာမ၊ စပါယ်ရှယ်လစ် ဆရာဝန်ကြီး၊ သူနာပြု၊ psychologist, speech-language therapist, occupational therapists, social workers, behavioral and educational specialists, special education teachers)
 - ပစ္စည်းပိုင်းဆိုင်ရာ အင်အား (guidelines, criteria, research, interventions, services, rehabilitation)
 - ပညာရပ်ဆိုင်ရာအင်အား technical resources (guidelines, specialist trainings, publications, etc)
 - ငွေကြေးပိုင်းဆိုင်ရာ အင်အား (အစိုးရဘတ်ဂျက်၊ နိုင်ငံတကာအကူအညီ၊ အခြား)
9. အော်တစ်ဇင်ကလေးတွေနဲ့ မိသားစုတွေအတွက် အစိုးရ သို့မဟုတ် အခြားသူများရဲ့ အထောက်အပံ့ အကူအညီ ရတာတွေ ရှိပါသလား။ (ကျန်းမာရေးစောင့်ရှောက်မှု၊ မသန်စွမ်း benefit၊ စိတ်ပိုင်းဆိုင်ရာ အထောက်အပံ့အကူအညီ၊ အလုပ်အကိုင်)
 10. အော်တစ်ဇင်ဆိုင်ရာ သတင်းအချက်အလက်စုဆောင်းမှုစနစ် (information and surveillance system) ရှိပါသလား။ နောက်ပိုင်း ရော လုပ်မယ့် အစီအစဉ်များရှိပါသလား။
 11. အော်တစ်ဇင် များအတွက် လုပ်ငန်းတွေလုပ်ဆောင်ရာမှာ လိုအပ်ချက်၊ အခက်အခဲ၊ ပြဿနာတွေရှိပါသလား။ ကျေးဇူးပြုပြီး ပြောပြစေချင်ပါတယ်။
 12. အထက်ပါ အခက်အခဲများကို မြန်မာနိုင်ငံရဲ့ လက်ရှိအခြေအနေအရ ဘယ်လို ဖြေရှင်းသင့်တယ်လို့ ယူဆပါသလဲ။

ကျေးဇူးအများကြီးတင်ပါတယ်။

IN-DEPTH INTERVIEW TOPIC GUIDE (FAMILY MEMBERS)

Code of the respondent: Interviewer name:.....

Sex:Age.....

Occupation:..... Date:

Education.....

Are you in a place where you can talk freely and openly right now?

1. When did you realize that your child was different from other children?
2. What happened then? And what did you do?
3. When and how did you get ASD diagnosis for your child/grandchild?
4. What kind of services are you taking/ receiving for your child?
5. Does your child have any other co-morbid condition?
6. How much you have to spend per month for your child?
7. What are the services you know currently exist in Yangon and other towns? Can you tell me what you think about these services? (accessibility, availability, affordability, acceptability)
8. What kind of support are you getting for your child from government, community and others? (policies, laws, programs)
9. What are the difficulties in getting services for your child and how did you overcome?
10. What kind of additional interventions you think would beneficial your child significantly?
11. Can you think of any other problems and difficulties for the ASD interventions in Myanmar?
12. Do you have any other suggestions or comments for future of ASD individuals?

မိသားစု၊ ပြုစုစောင့်ရှောက်သူများအား မေးမြန်းရန် လမ်းညွှန် (IDI- MYANMAR LANGUAGE)

ပါဝင်သူ၏ ကုတ်နံပါတ် မေးမြန်းသူ

ကျား/မ အသက်

အလုပ်အကိုင် ရက်စွဲ

ပညာအရည်အချင်း

အခုပွင့်ပွင့်လင်းလင်းနဲ့ လွတ်လွတ်လပ်လပ် အေးအေးဆေးဆေး ပြောလိုရပါသလား။

1. သင့်ကလေးက တခြားကလေးတွေနဲ့ မတူပဲ ထူးခြားနေတာကို ဘယ်တုန်းကစပြီး သတိထားမိပါသလဲ။
2. အဲဒီတုန်းက ဘယ်လိုမျိုးဖြစ်သလဲ။ မိဘများအနေနဲ့ ဘာတွေလုပ်ဖြစ်ခဲ့သလဲ။
3. သင့်ကလေး အော်တစ်ဇင်ဖြစ်ကြောင်း Diagnosis ဘယ်လိုရခဲ့သလဲ။ ဘယ်တုန်းကလဲ။
4. သင့်ကလေးအတွက် ဘယ်လိုမျိုး ဝန်ဆောင်မှုတွေရယူနေသလဲ။ ဘယ်မှာ ကျောင်း၊ သင်တန်းတွေ တက်နေတာ၊ ကုသမှုခံယူနေတာရှိသလား။
5. သင့်ကလေးမှာ တခြားပူးတွဲဖြစ်နေတဲ့ ရောဂါများရှိပါသလား။
6. သင့်ကလေးပညာရေး၊ ကုသမှုအတွက် တစ်လ ဘယ်လောက် ကုန်ကျပါသလဲ။
7. ရန်ကုန်နဲ့ အခြားမြို့တွေမှာ ဘယ်လို ဝန်ဆောင်မှု service တွေရနိုင်တယ်လို့ သိထားပါသလဲ။ အဲဒီဝန်ဆောင်မှုတွေအကြောင်း ဆွေးနွေးပေးစေလိုပါတယ်။ accessibility, availability, affordability, acceptability
8. မြန်မာအစိုးရ၊ ပတ်ဝန်းကျင်အသိုင်းအဝိုင်း၊ လူမှုရေးအဖွဲ့အစည်းများ စသည်တို့ထံမှ ဘယ်လို အကူအညီ၊ အထောက်အပံ့တွေရနေပါသလဲ။
9. သင့်ကလေးအတွက် ဝန်ဆောင်မှု၊ ကျောင်း၊ သင်တန်းတွေ ထားဖို့ လုပ်ဆောင်ရာမှာ ဘယ်လို အခက်အခဲတွေတွေ့ကြုံရပါသလဲ။ ရှင်းပြပေးပါ။
10. သင့်ကလေး အခြေအနေ ဒီထက်ပိုမိုကောင်းမွန်လာဖို့ ဘယ်လို ဝန်ဆောင်မှုတွေ မြန်မာနိုင်ငံမှာ ထပ်မံလုပ်ဆောင်သင့်သလဲ။
11. မြန်မာနိုင်ငံအတွင်းမှာ အော်တစ်ဇင်ကလေးများအတွက် လုပ်ဆောင်ပေးရာမှာ ဘယ်လို အခက်အခဲ အတားအဆီးတွေရှိနေပါသလဲ။ ရှင်းပြပေးပါ။
12. အော်တစ်ဇင်ကလေးများရဲ့ အနာဂတ် ပိုမိုကောင်းမွန်လာစေဖို့ အခြားအကြံပြုချက်များရှိရင် ပြောပြပေးပါ။

ကျေးဇူးအများကြီးတင်ပါတယ်။

သဘောတူလက်ခံသည့်ပုံစံ (CONSENT FORM- MYANMAR LANGUAGE- KEY INFORMANTS)

ယခုသဘောတူလက်ခံသည့်ပုံစံသည် "မြန်မာနိုင်ငံအတွင်းရှိ အော်တစ်ဇင်ဂေဒနာရှင်များအတွက် လက်ရှိလုပ်ဆောင်ပေးနေသည့် လုပ်ငန်းများကို လေ့လာရန်နှင့် ၎င်းတို့အတွက် လိုအပ်နေသော ပြုစုပျိုးထောင်ရေးလုပ်ငန်းများ၊ ထိုလုပ်ငန်းများလုပ်ရာတွင် တွေ့ကြုံရသည့် အတားအဆီး အခက်အခဲများကိုလေ့လာသည့် သုတေသန" တွင်ပါဝင်ရန် ဖိတ်ကြားခံရသည့် သူများအတွက် ရည်ရွယ်ပါသည်။

နိဒါန်း။ ကျွန်မက ဒီသုတေသနကို ပြုလုပ်မယ့် ဒေါ်ဆွေဆွေအေး ဖြစ်ပါတယ်။ ဒီသုတေသနမှာ ပါဝင်ကူညီပေးမယ့်သူများကတော့ အော်တစ်ဇင်နဲ့ ပါတ်သက်ပြီး လုပ်ဆောင်ပေးနေကြတဲ့ သက်ဆိုင်ရာဝန်ကြီးဌာနများ၊ အဖွဲ့အစည်းများ၊ အထူးကျောင်းများနဲ့ သင်တန်းစင်တာများမှ ကိုယ်စားလှယ်များ၊ တာဝန်ခံများ ဖြစ်ပါတယ်။ ယခုမေးခွန်းများမှာ အော်တစ်ဇင်နဲ့ သက်ဆိုင်တဲ့ လက်ရှိရှိနေတဲ့ ပေါ်လစီများ၊ ဥပဒေများ၊ လုပ်ငန်းများနဲ့ ၎င်းတို့လုပ်ဆောင်ရန် အတားအဆီးများ၊ လိုအပ်ချက်များ၊ လုပ်နိုင်စွမ်းရည်များနဲ့ ပါတ်သက်ပြီး သင်သိထားသည်များ၊ သင့်ထင်မြင်ချက်များကို မေးမြန်းလိုပါတယ်။

ဒီသုတေသနမှာ ပါဝင်သင့်မသင့်ကို လွတ်လပ်စွာဆုံးဖြတ်နိုင်ပါတယ်။ သုတေသနအကြောင်းကို အကျဉ်းချုပ်ရှင်းပြချင်ပါတယ်။ မရှင်းလင်းတဲ့အချက်များရှိရင် ကြားဖြတ်မေးစေလိုပါတယ်။

သုတေသနဆိုင်ရာ အချက်အလက်။ ဒီသုတေသနပြုလုပ်ရတဲ့ ရည်ရွယ်ချက်ကတော့ အော်တစ်ဇင်ဂေဒနာရှင်များအတွက် လက်ရှိလုပ်ဆောင်ပေးနေနိုင်တဲ့ ပြုစုပျိုးထောင်ရေး လုပ်ငန်းများနဲ့ လုပ်နိုင်စွမ်းရည်ကိုသိရှိရန်နဲ့ အခက်အခဲအတားအဆီးများကို သိရှိနိုင်ရန် ဖြစ်ပါတယ်။ အဲဒီအချက်တွေသိပြီးတဲ့အခါမှာ အော်တစ်ဇင် ဂေဒနာရှင်များအတွက် လိုအပ်နေတဲ့ လုပ်သင့်တဲ့ လုပ်ငန်းများ ထပ်မံလုပ်ဆောင်နိုင်ရန် လူမှုဝန်ထမ်း၊ ကယ်ဆယ်ရေးနဲ့ ပြန်လည်နေရာချထားရေး ဝန်ကြီးဌာနနှင့် မြန်မာနိုင်ငံလုံးဆိုင်ရာ မသန်မစွမ်းကောင်စီသို့ တင်ပြမည် ဖြစ်ပါတယ်။

လူကြီးမင်းရဲ့ ပါဝင်ကူညီ ဆွေးနွေးပေးမှုဖြင့် ဤသုတေသနရည်မှန်းချက်ကို ရရှိနိုင်ပါသဖြင့် ယခုသုတေသနမှာ ပါဝင်ပေးဖို့ ဖိတ်ခေါ်ပါတယ်။ ဆွေးနွေးမှုသည် ၄၅-၆၀ မိနစ်ခန့် ကြာမြင့်နိုင်ပါတယ်။ ဆွေးနွေးမှုအချက်အလက်များ တိတိကျကျရရှိဖို့အတွက် သင်လက်ခံမယ်ဆိုရင် လက်ရေးတိုဖြင့်ရေးမှတ်ခြင်းနှင့် အသံဖိုင်ကူးယူထားလိုပါတယ်။

ပါဝင်ခြင်းနှင့် လုပ်ငန်းအဆင့်ဆင့်။ သုတေသနမှာ ပါဝင်သင့်မသင့်ကို လွတ်လပ်စွာ ဆုံးဖြတ်နိုင်ပြီး သင့်ဆုံးဖြတ်ချက်သည် သင့်အတွက်ရော သင့်ကျောင်း၊ ဝန်ကြီးဌာန၊ အဖွဲ့အစည်းအတွက်မည်သို့မှ ထိခိုက်မှုမရှိပါ။ ယခုပုံစံတွင် သဘောတူ ထားပြီးသည့်တိုင်အောင် နောက်ပိုင်းတွင် ဆက်လက်ပါဝင်လိုစိတ်မရှိတော့လျှင် မည်သည့်အချိန်မဆို ပါဝင်မှုရပ်တန့်နိုင်ပါတယ်။ ဆွေးနွေးနေစဉ်အချိန်အတွင်း သင်မမြေဆိုလိုသည့်မေးခွန်း၊ မဆွေးနွေးလိုသည့် အချက်များရှိပါက မဆွေးနွေးပဲနေနိုင်ပါတယ်။ သင့်ဆွေးနွေးမှုအားလုံး၊ သင့်နံမည်အပါအဝင်၊ သင်ဟုသိရှိသွားနိုင်မည့် အချက်အလက်အားလုံးကို လုံခြုံစွာ လျှို့ဝှက်ထားမှာဖြစ်ပြီး သုတေသနပြီးဆုံးချိန်မှာ ဆွေးနွေးမှုမှတ်တမ်းများနဲ့ အသံဖိုင်များကို ဖျက်ဆီးပစ်လိုက်မှာ ဖြစ်ပါတယ်။

ဤသုတေသနတွေ့ရှိချက်များကို အော်တစ်ဇင်ဝေဒနာရှင်များအတွက် ပြုစုပျိုးထောင်ရေး လုပ်ငန်းများလုပ်ဖို့ ဆုံးဖြတ်ရာမှာ အသုံးပြုနိုင်ပြီး ထိုသူတို့ရဲ့ ဘဝနေထိုင်မှု ပိုမိုကောင်းမွန်လာရန် ဝိုင်းဝန်းလုပ်ဆောင်ပေးနိုင်လိမ့်မယ်လို့ ယုံကြည်ပါတယ်။

ဆွေးနွေးနေစဉ်မှာ သင့်စိတ်ထဲမှာ ဖြေကြားရ၊ ဆွေးနွေးရခက်ခဲလာတဲ့အခြေအနေတွေ ဖြစ်လာခဲ့ရင် ထိုမေးခွန်းများကို ကျော်ပြီး အခြားမေးခွန်းများဆွေးနွေးနိုင်ပါတယ်။ သင့်ရဲ့ခံစားချက်များ ပြောပြရင်းနဲ့ စိတ်ထိခိုက်မှုခံစားရတယ်ဆိုရင် ကျွန်ုပ်ကို ပြောပြစေချင်ပါတယ်။ ဒါမှ လိုအပ်သလိုဝိုင်းဝန်းဖြေရှင်းနိုင်မှာ ဖြစ်ပါတယ်။ လိုအပ်ရင် နှစ်သိမ့်ဆွေးနွေးရာမှာ ကျွမ်းကျင်တဲ့ ဒေါ်တင်မြက ဝိုင်းဝန်းနှစ်သိမ့်ပေးမှာဖြစ်ပါတယ်။ ယခုသုတေသနမှာ ပါဝင်ကူညီသူများကို မထိခိုက်စေမယ့် ကာကွယ်မှုများလုပ်ထားမှုနဲ့ ပါတ်သက်ပြီး ကျွန်မအနေနဲ့ တာဝန်ယူပါတယ်။

ဖြန့်ဝေခြင်း။ ။ ဤသုတေသနတွေ့ရှိချက်များကို လူမှုဝန်ထမ်းဦးစီးဌာန၊ လူမှုဝန်ထမ်း၊ ကယ်ဆယ်ရေးနဲ့ ပြန်လည်နေရာ ချထားရေးဦးစီးဌာန၊ ကျန်းမာရေးဦးစီးဌာန၊ ကျန်းမာရေးသုတေသနဌာန၊ ပြည်သူ့ကျန်းမာရေးတက္ကသိုလ်၊ JICA, UNDP, UNICEF, UNESCO အပါအဝင် အဖွဲ့အစည်းများ၊ သုတေသနမှာပါဝင်ခဲ့တဲ့ အော်တစ်ဇင် သင်တန်းစင်တာများ၊ ကျောင်းများသို့ ဖြန့်ဝေသွားမှာဖြစ်ပါတယ်။ သုတေသနတွေ့ရှိချက် အသေးစိတ်အချက်အလက်များကို သိလိုပါက အောက်ဖော်ပြပါ လိပ်စာကို ဆက်သွယ်မေးမြန်းနိုင်ပါတယ်။

သဘောတူလက်ခံခြင်းနဲ့ အဆက်အသွယ်။ ။ မရှင်းလင်းသည်များရှိရင် ကျေးဇူးပြုပြီးမေးစေလိုပါတယ်။ အခုလောက်ဆိုရင် သုတေသနမှာပါဝင်ခြင်းနဲ့ ပါတ်သက်ပြီးအတော် သိရှိနားလည်ပြီးထင်ပါတယ်။ ပါဝင်ကူညီနိုင်မယ်လို့ မျှော်လင့်ပါတယ်။ နောက်ထပ်သိချင်တာများရှိရင် အောက်ဖော်ပြပါလိပ်စာကို မေးမြန်းနိုင်ပါတယ်။

သုတေသနတွင်ပါဝင်ကူညီသူအမည်	မေးမြန်းသူအမည်
လက်မှတ်	လက်မှတ်
နေ့စွဲ	နေ့စွဲ

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သဘောတူလက်ခံသည့်ပုံစံ (CONSENT FORM-MYANMAR LANGUAGE-FAMILY MEMBERS)

ယခုသဘောတူလက်ခံသည့်ပုံစံသည် "မြန်မာနိုင်ငံအတွင်းရှိ အော်တစ်ဇင်ဂေဒနာရှင်များအတွက် လက်ရှိလုပ်ဆောင်ပေးနေသည့် လုပ်ငန်းများကို လေ့လာရန်နှင့် ၎င်းတို့အတွက် လိုအပ်နေသော ပြုစုပျိုးထောင်ရေးလုပ်ငန်းများ၊ ထိုလုပ်ငန်းများလုပ်ရာတွင် တွေ့ကြုံရသည့် အတားအဆီး အခက်အခဲများကိုလေ့လာသည့် သုတေသန" တွင်ပါဝင်ရန် ဖိတ်ကြားခံရသည့် သူများအတွက် ရည်ရွယ်ပါသည်။

နိဒါန်း။ ။ ကျွန်မက ဒီသုတေသနကို ပြုလုပ်မယ့် ဒေါ်ဆွေဆွေအေး ဖြစ်ပါတယ်။ ဒီသုတေသနမှာ ပါဝင်ကူညီပေးမယ့်သူများကတော့ အော်တစ်ဇင်နဲ့ ပါတ်သက်ပြီး လုပ်ဆောင်ပေးနေကြတဲ့ သက်ဆိုင်ရာဝန်ကြီးဌာနများ၊ အဖွဲ့အစည်းများ၊ အထူးကျောင်းများနဲ့ သင်တန်းစင်တာများမှ ကိုယ်စားလှယ်များ၊ တာဝန်ခံများ ဖြစ်ပါတယ်။ ယခုမေးခွန်းများမှာ သင့်ကလေးအတွက် အော်တစ်ဇင်နဲ့ သက်ဆိုင်တဲ့ ကျောင်းတက်နေမှု၊ တခြားသင်ကြားနေမှုများ၊ ထောက်ပံ့ကူညီမှု ရရှိနေမှု အခြေအနေများနဲ့ ပါတ်သက်ပြီး သင်သိထားသည်များ၊ သင့်ထင်မြင်ချက်များကို မေးမြန်းလိုပါတယ်။ အော်တစ်ဇင်ကလေးများအတွက် လိုအပ်တဲ့ (ဥပမာ- သင်တန်း၊ စင်တာ၊ ကျောင်း၊ ကုသမှုများ) ရရယူရာမှာ တွေ့ကြုံရတဲ့ အခက်အခဲများ၊ လိုအပ်ချက်များ ကိုပါ မေးမြန်းလိုပါတယ်။

ဒီသုတေသနမှာ ပါဝင်သင့်မသင့်ကို လွတ်လပ်စွာဆုံးဖြတ်နိုင်ပါတယ်။ သုတေသနအကြောင်းကို အကျဉ်းချုပ်ရှင်းပြချင်ပါတယ်။ မရှင်းလင်းတဲ့အချက်များရှိရင် ကြားဖြတ်မေးစေလိုပါတယ်။

သုတေသနဆိုင်ရာ အချက်အလက်။ ။ ဒီသုတေသနပြုလုပ်ရတဲ့ ရည်ရွယ်ချက်ကတော့ အော်တစ်ဇင်ဂေဒနာရှင်များအတွက် လက်ရှိလုပ်ဆောင်ပေးနေနိုင်တဲ့ ပြုစုပျိုးထောင်ရေး လုပ်ငန်းများနဲ့ လုပ်နိုင်စွမ်းရည်ကိုသိရှိရန်နဲ့ အခက်အခဲအတားအဆီးများကို သိရှိနိုင်ရန် ဖြစ်ပါတယ်။ အဲဒီအချက်တွေသိပြီးတဲ့အခါမှာ အော်တစ်ဇင် ဂေဒနာရှင်များအတွက် လိုအပ်နေတဲ့၊ လုပ်သင့်တဲ့ လုပ်ငန်းများ ထပ်မံလုပ်ဆောင်နိုင်ရန် လူမှုဝန်ထမ်း၊ ကယ်ဆယ်ရေးနဲ့ ပြန်လည်နေရာချထားရေး ဝန်ကြီးဌာနသို့ တင်ပြပေးမည် ဖြစ်ပါတယ်။

လူကြီးမင်းရဲ့ ပါဝင်ကူညီ ဆွေးနွေးပေးမှုဖြင့် ဤသုတေသနရည်မှန်းချက်ကို ရရှိနိုင်ပါသဖြင့် ယခုသုတေသနမှာ ပါဝင်ပေးဖို့ ဖိတ်ခေါ်ပါတယ်။ ဆွေးနွေးမှုသည် ၄၅-၆၀ မိနစ်ခန့် ကြာမြင့်နိုင်ပါတယ်။ ဆွေးနွေးမှုအချက်အလက်များ တိတိကျကျရရှိဖို့အတွက် သင်လက်ခံမယ်ဆိုရင် လက်ရေးတိုဖြင့်ရေးမှတ်ခြင်းနှင့် အသံဖိုင်ကူးယူထားလိုပါတယ်။

ပါဝင်ခြင်းနှင့် လုပ်ငန်းအဆင့်ဆင့်။ ။ သုတေသနမှာ ပါဝင်သင့်မသင့်ကို လွတ်လပ်စွာ ဆုံးဖြတ်နိုင်ပြီး သင့်ဆုံးဖြတ်ချက်သည် သင့်အတွက်ရော သင့်ကလေး၊ သင့်ကျောင်း၊ အတွက်မည်သို့မှ ထိခိုက်မှုမရှိပါ။ ယခုပုံစံတွင် သဘောတူ ထားပြီးသည့်တိုင်အောင် နောက်ပိုင်းတွင် ဆက်လက်ပါဝင်လိုစိတ်မရှိတော့လျှင် မည်သည့်အချိန်မဆို ပါဝင်မှုရပ်တံ့နိုင်ပါတယ်။ ဆွေးနွေးနေစဉ်အချိန်အတွင်း သင်မဖြေဆိုလိုသည့်မေးခွန်း၊ မဆွေးနွေးလိုသည့် အချက်များရှိပါက မဆွေးနွေးပဲနေနိုင်ပါတယ်။ သင့်ဆွေးနွေးမှုအားလုံး၊ သင့်နံမည်အပါအဝင်၊ သင်ဟုသိရှိသွားနိုင်မည့် အချက်အလက်အားလုံးကို လုံခြုံစွာ လျှို့ဝှက်ထားမှာဖြစ်ပြီး သုတေသနပြီးဆုံးချိန်မှာ ဆွေးနွေးမှုမှတ်တမ်းများနဲ့ အသံဖိုင်များကို ဖျက်ဆီးပစ်လိုက်မှာ ဖြစ်ပါတယ်။

ဤသုတေသနတွေ့ရှိချက်များကို အော်တစ်ဇင်ဝေဒနာရှင်များအတွက် ပြုစုပျိုးထောင်ရေး လုပ်ငန်းများလုပ်ဖို့ ဆုံးဖြတ်ရာမှာ အသုံးပြုနိုင်ပြီး ထိုသူတို့ရဲ့ ဘဝနေထိုင်မှု ပိုမိုကောင်းမွန်လာရန် ဝိုင်းဝန်းလုပ်ဆောင်ပေးနိုင်လိမ့်မယ်လို့ ယုံကြည်ပါတယ်။

ဆွေးနွေးနေစဉ်မှာ သင့်စိတ်ထဲမှာ ဖြေကြားရ၊ ဆွေးနွေးရခက်ခဲလာတဲ့အခြေအနေတွေ ဖြစ်လာခဲ့ရင် ထိုမေးခွန်းများကို ကျော်ပြီး အခြားမေးခွန်းများဆွေးနွေးနိုင်ပါတယ်။ သင့်ရဲ့ခံစားချက်များ ပြောပြရင်းနဲ့ စိတ်ထိခိုက်မှုခံစားရတယ်ဆိုရင် ကျွန်ုပ်ကို ပြောပြစေချင်ပါတယ်။ ဒါမှ လိုအပ်သလိုဝိုင်းဝန်းဖြေရှင်းနိုင်မှာ ဖြစ်ပါတယ်။ လိုအပ်ရင် နှစ်သိမ့်ဆွေးနွေးရာမှာ ကျွမ်းကျင်တဲ့ ဒေါ်တင်မြက ဝိုင်းဝန်းနှစ်သိမ့်ပေးမှာဖြစ်ပါတယ်။ ယခုသုတေသနမှာ ပါဝင်ကူညီသူများကို မထိခိုက်စေမယ့် ကာကွယ်မှုများလုပ်ထားမှုနဲ့ ပါတ်သက်ပြီး ကျွန်မအနေနဲ့ တာဝန်ယူပါတယ်။ ဒါ့အပြင် နိုင်ငံတော် ကော်မီတီက ခွင့်ပြုချက်ရယူထားပြီးလည်းဖြစ်ပါတယ်။

ဖြန့်ဝေခြင်း။ ။ ဤသုတေသနတွေ့ရှိချက်များကို လူမှုဝန်ထမ်းဦးစီးဌာန၊ လူမှုဝန်ထမ်း၊ ကယ်ဆယ်ရေးနဲ့ ပြန်လည်နေရာ ချထားရေးဦးစီးဌာန၊ ကျန်းမာရေးဦးစီးဌာန၊ ကျန်းမာရေးသုတေသနဌာန၊ ပြည်သူ့ကျန်းမာရေးတက္ကသိုလ်၊ JICA, UNDP, UNICEF, UNESCO အပါအဝင် အဖွဲ့အစည်းများ၊ သုတေသနမှာပါဝင်ခဲ့တဲ့ အော်တစ်ဇင် သင်တန်းစင်တာများ၊ ကျောင်းများသို့ ဖြန့်ဝေသွားမှာဖြစ်ပါတယ်။ သုတေသနတွေ့ရှိချက် အသေးစိတ်အချက်အလက်များကို သိလိုပါက အောက်ဖော်ပြပါ လိပ်စာကို ဆက်သွယ်မေးမြန်းနိုင်ပါတယ်။

သဘောတူလက်ခံခြင်းနဲ့ အဆက်အသွယ်။ ။ မရှင်းလင်းသည်များရှိရင် ကျေးဇူးပြုပြီးမေးစေလိုပါတယ်။ အခုလောက်ဆိုရင် သုတေသနမှာပါဝင်ခြင်းနဲ့ ပါတ်သက်ပြီးအတော် သိရှိနားလည်ပြီးထင်ပါတယ်။ ပါဝင်ကူညီနိုင်မယ်ဆိုရင် အီးမေးဖြင့် လက်ခံသဘောတူကြောင်း ပို့ပေးစေလိုပါတယ်။ အီးမေးသုံးစွဲ အဆင်မပြေရင် အောက်တွင် လက်မှတ်ထိုးပေးစေလိုပါတယ်။ နောက်ပိုင်းမရှင်းလင်းသည်များ သိချင်တာများရှိရင် အောက်ဖော်ပြပါလိပ်စာကို မေးမြန်းနိုင်ပါတယ်။

သုတေသနတွင်ပါဝင်ကူညီသူအမည် မေးမြန်းသူအမည်
လက်မှတ် လက်မှတ်
နေ့စွဲ နေ့စွဲ

ဆက်သွယ်ရန်

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