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# Presuming Competence:

## Among All Children in Thailand and Myanmar

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## Table of Contents:

<b>Introduction:</b> .....	3
<b>Methodology:</b> .....	4
A. Aims .....	4
B. Audience .....	4
C. Site and Participants .....	5
D. Data Collection Tools.....	6
E. Documentation Strategy.....	7
F. Obstacles and Limitations .....	9
<b>Research Findings:</b> .....	11
1. Government .....	11
2. Cultural Complexities.....	14
3. Environmental Context .....	17
4. Attitudes.....	19
5. Resources/Accessibility .....	24
6. Accessibility .....	28
7. Adolescent/Adult Life .....	30
8. Barriers of Independent Living .....	31
<b>Discussion:</b> .....	33
<b>Summary:</b> .....	36
<b>Recommendations:</b> .....	37
<b>Acknowledgements:</b> .....	38

## Introduction:

It is estimated that around 15% of the global population has some form of disability.<sup>1</sup> The United Nations states that individuals with disability make up the world's greatest minority group. A deeper and more conscious awareness and understanding of the needs and challenges faced for this population is necessary in all areas of the world. Thailand and Myanmar are two developing countries where there is little information or knowledge on the lives of people with a disability. This research aims to contribute further information about the complexities of this situation especially among children.

I would like to begin this report with a story of the first day and first interview of this research project. This was a pivotal moment, one that set the tone for the following months in the field collecting data. I was in Yangon, at a scheduled interview with an organization working to support people with disability. I was asked if I would be interested to talk to any of the employee's for a more personal account of the situation in Myanmar. I was nervous and anxious as I tried to remind myself to be calm and focused.

*She walked in the room. She was shorter than me, with a youthful spunky style and straight black hair. I was conscious not to fall back on routine and reach for a handshake, as she had no arms to extend back to me. We sat down. She was so confident and sure of herself. Her arms ended right below the shoulder and one of her legs was shorter than the other. When she first sat down for the interview, I introduced myself and she offered hers in return, but because so many Myanmar names are difficult to pronounce, I instinctually asked her if she would be willing to write it down since I was unsure on pronunciation. Without waiting for a response I extended my notebook and pen her way only to feel my insides drop as I realized what I had done. I just asked a woman with no arms to write her name for me. I could feel my body tighten at the thought that I may have offended this woman. As I was about to apologize for my misstep, she smiled and replied, "Of course!" Her friend jumped in and grabbed the notebook, pen and placed it on the chair next to her. The woman then took up the pen between her toes and began to write her name.*

This interaction reminded me of the importance of presuming competence, and that having a disability is not synonymous with incapable or incompetent. What does it mean to have a disability? There are several definitions of the term "disability". According to Merriam-Webster's Dictionary,

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<sup>1</sup> "Possible Definition of "Disability": Discussion Text Suggested by the Chair." *UNenable*. United Nations, 2005. Retrieved on January 18, 2014 from <http://www.un.org/disabilities/default.asp?id=18>.

the term disability is defined as, “a condition (such as an illness or an injury) that damages or limits a person's physical or mental abilities.”<sup>2</sup>

This research chooses to support the United Nation’s definition of disability stating that, “disability resides in the society not in the individual.”<sup>3</sup> This definition highlights the major role society plays in defining what it means to be person who has a disability. By focusing on several different aspects of society it can be further understood how children with disabilities are impacted. This woman whom I first encountered in this research project is considered to have a disability, but this does not mean she herself does not have ability. She revealed that it is her environment and others, who limit her, not the fact that she is missing limbs.

## **Methodology:**

### **A. Aims**

This research project aimed to provide an overall understanding of the lives of children with developmental disabilities in Myanmar and from Myanmar living in Thailand. This research documented the current opportunities and challenges that are faced for children with disability (CWD), their families and what current resources are available within these countries to support this population. Through recorded conversations with service providers, community members, and families of children with developmental disabilities, this research provides a more holistic view of the situation and its complexities. This research ultimately aims to pin-point the most pressing issues in order to advocate and support this population in a sustainable and empowering way. In understanding the context and aspirations of children with disabilities, it is hoped that we can gather ideas on how to best to support their efforts and promote equality for all.

### **B. Audience**

This research has been undertaken for The John P. Hussman Foundation (JPHF), to inform their grant making in support of children of Myanmar with disabilities within the country and those

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<sup>2</sup> "Definition of Disability." *Merriam-Webster*. Merriam-Webster, 2004. Retrieved January 2014 from <http://www.merriam-webster.com/dictionary/disability>.

<sup>3</sup> "UN Enable - Possible Definition of Disability - Discussion Text." *UN News Center*. UN, 2005. Retrieved January 2014 from <http://www.un.org/esa/socdev/enable/faqs.htm>.

displaced in Thailand. This research also intends to inform other organizations interested in understanding the social and cultural dynamics surrounding CWD in Thailand and Myanmar in order to provide more holistic assistance from external sources. The JPHF has provided funding and advocacy for Autism awareness and Autism research in the United States and has supported foundations like, Autism Society America and Hussman Institute for Autism. Currently, JPHF supports locally based community organizations focused on formal and informal education in Thailand and Myanmar. This research encourages conversation about opportunities for and engagement between individuals concerned for the common welfare and equality for all people living with disabilities, especially children and youth.

### **C. Site and Participants**

This research was conducted among marginalized populations within Thailand and Myanmar. This usually implies, but is not limited to, rural communities and urban slums where access to basic needs is difficult to obtain. This study prioritized communities where The JPHF had already been engaged.

The researcher spent two weeks in Myanmar meeting with people and services supporting children with disabilities and another three weeks in Thailand over a two-month period. In Myanmar, interviews were based in the city of Yangon. In Thailand, interviews were conducted in the southern areas of Chumphon, Phang Nga, and Ranong province. The focus in Thailand was with organizations and community groups supported by JPHF.

This research included participants from four categories:

1. Family of CWD
2. Individuals representing an established organization or providing direct services that support people with disabilities
3. Random sampling of members of the Thai and Myanmar community including teachers
4. Individuals with a developmental disability

Data collection was conducted between November 1, 2014 and January 31, 2015. A total of 22 interviews were conducted including four group discussions or activities, and approximately 20 direct or participatory observations.

## D. Data Collection Tools

This research used a number qualitative data collection tools to provide triangulation of findings. Primary data collection was complimented with known research (secondary data) to provide a deeper understanding and context. This research was not intended to calculate percentages or determine the extent of these issues, but instead to understand the experiences, perspectives and situations for children and their families facing day-to-day challenges. In order to understand disability in Thailand and Myanmar it is important to consider the circumstances, perspectives, and beliefs that surround it. The environment and the community in which children are raised are revealing to the societal perspectives towards the concept of disability. No one knows better about their situation then the people and families directly impacted by this challenge. This research collected a range of perspectives by participating in six types of data collection in order to gain a more holistic view of the situation.

**Secondary Data:** Secondary research was conducted during all stages of this study. This data informed the research on the situation of disability in different parts of the world and provided a link and reference to what resources and initiatives were already available. Secondary data on people with disabilities helped aid in more detailed and well-developed research.

**Direct Observations (DO):** Direct observations were collected early in the study so that the researcher gained an awareness of the area, language, and dynamics before engaging in conversations. It was important to record these observations in order to develop an understanding of the landscape, people, and broader environment. This included walking through places where people congregate (i.e. a market, near food vendors, schools, health centers, government buildings, etc.). This gave the researcher some initial ideas to the situation, questions to consider and strategies for engaging ethically.

**Participatory Observation (PO):** The researcher had informal conversations with those in the area. This was not considered an interview, as no personal information was gathered. It did, however, provide a way to gain basic knowledge of the community and its people. These observations made by the researcher were crucial, as it provided insight on common thoughts, perceptions, and attitudes towards people with disabilities. These observations were also important in understanding the language people in Thailand and Myanmar use when discussing the concept of disability.

**In-Depth Interviews (IDI):** These interviews were the most important aspect of this study, as they

give a detailed account of individual experiences and opinions on the subject of disability. These accounts shared the depth of realities and challenges faced by children with a disability in Thailand and Myanmar and their families.

**Participatory Rapid Assessment (PRA):** This is a method of collecting data that provided insight and engagement without depending on verbal expressions and common language. This was particularly important when communicating with individuals with a disability. Some individuals that the researcher engaged with verbal communication was not an option, in which case Participatory Rapid Assessment (PRA) methods was used as a tool for expression. These creative methods may included drawing and writing. There are many ways to conduct PRA, and this study sought to use methods that furthered the insight of the situation in a positive way.

**Focus Group Discussions (FGD):** Once the researcher engaged the community through observations. The researcher attempted to organize and sometimes requested a focus group discussion on disability with the consent of each individual. These discussions were conducted between small groups of people and were recorded when possible. These discussions were important because they helped triangulate the direct and participatory observations by recording concrete evidence of people's general feelings, experiences, ideas, and provided an opportunity to document dynamics among the participants to capture attitudes and behavior.

This study focused primarily on the first four data collections tools presented above, the PRA and FGD were introduced only as opportunities arose. It was understood that given the short time of this research project these latter tools were not always possible to employ.

## **E. Documentation Strategy**

All effort was made to record the data as accurately as possible. To accomplish this, the researcher used three notebooks to keep the data and maintain organization. The first notebook was used to document the research process. It contained the researcher's ideas, thoughts, as well as background information, and contacts. The second notebook was used for the actual data collected. These pages were kept completely anonymous to ensure security for the interviewee. The final book contained the codes for the data collected and the background information for all data. The notebook with all the coded information was never carried with the researcher or kept together with the other two notebooks to ensure confidentiality. When possible and with the consent of the interviewee a recorder or video camera was used to back up all written data. This allowed the researcher to record the data most accurately. The researcher used a translator when necessary in order to conduct and

engage in conversations with the local community. These translators were informed in advance about the subject of the research and intended approach with the researcher. The researcher was assured that the translator understood and engaged in the interviews appropriately and ethically.

**Ethical Considerations:** There were three core aspects to ensure ethical standards throughout the research: Consent, Confidentiality, and Security.

**Consent:** All interviewees were aware of their rights and reminded by the researcher of this before and after the interview. These rights included, awareness of research objectives, agreement to participate and choice of what to share with the ability to remove any unwanted information.

Awareness: There was complete transparency of the aims and objectives of this research project to all participants in this study prior to any data collection. All participants were encouraged to ask questions or share any concerns during this time and again at the conclusion of the data collection.

Agreement: Before the data collection took place, the researcher asked each participant whether they were willing. They were assured that there was no pressure from the researcher if the participants did not want to take part in any or all of this study.

Information: The researcher reminded each participant that they could opt out of any question if they did not wish to answer. The researcher periodically checked in with the participant by asking them if they felt comfortable, and again reiterated that they should only discuss what they feel comfortable to share.

At the end of the data collection exercise, the researcher also asked the individual if there was anything they would like add or remove from what they shared. This was a final time for the participant to make sure the content with the interaction and information collected was freely of their consent. The researcher is confident that all data was collected voluntarily and did not use any data that was not fully approved by the participants of this study.

**Confidentiality:** It was the responsibility of the researcher to ensure that each participant remained anonymous if they desired. The researcher asked each person prior to participating in the study, if they would like use an alias in order to remain anonymous. No address, phone number, or identifiable information was included in the research data findings. It was also explained to each participant that the exchange was meant to gain understanding and in no way would be used to identify or expose any individual or organization.

**Security:** As noted above, the researcher used separate notebooks for quantitative background data and another notebook for the qualitative information. These notebooks were never kept together to ensure that no data was identifiable even if one or the other notebook was misplaced. The data code created was able to connect the data in the two notebooks and the key for this code was kept in the third notebook. All recorded data in the notebook was scanned regularly to ensure that if a notebook is lost, the information was backed up and not completely lost. Passwords on the computer and locks on suitcases secured data throughout the study.

**Analysis and Dissemination Strategy:** When all the data was collected, the researcher began to organize the information electronically. All interviews were transcribed as accurately as possible into English. If a translator was used it was recorded when possible so that the researcher could take time to double check the interpretation. If recording was not possible the translator and researcher discussed the interview immediately afterwards to ensure all data was recorded as accurately as possible. Once the information was transcribed the researcher used a software program to organize all the data. All quantitative data such as the sex, age, religious background, etc. of each participant was entered in an Excel spreadsheet.

This data was analyzed, written and submitted to the JPHF as a resource for further understanding the situation of children with disabilities in Thailand and Myanmar and to identify some key areas of support that could be provided by organizations like The JPHF.

Although this study was supported by The JPHF, it also hoped that the data collected in this research will be provided back to the community. This could come in the form of a translated version of the research paper or a short advocacy film (or other possible forms of communication that emerge from this study for the participants) in support of the empowerment and rights for people with disabilities.

## **F. Obstacles and Limitations**

During this study, there were numerous obstacles and limitations. The main challenges faced by the researcher were:

**Time Management:** The key to the success of research relied on the organization and time management of the researcher. This was a challenging area to maintain throughout the study. Also, when interviewing participants, it required time to build a relationship, which would require more

time to collect the data.

**Language Limitations:** An obstacle that was the most challenging was the language barrier. The researcher was born in Thailand, lived there for 12 years and speaks Thai. The researcher's conversational Thai made it possible for her to conduct the interviews on her own. Since she has lived abroad for many years it was challenging initially to conduct the interviews, she informed the participants of this challenge and confirmed if they would be willing to elaborate or discuss anything she may not understand. All participants were helpful and patient through this process. The researcher does not speak Burmese and needed a translator for many interviews conducted in Myanmar. It took time to find and discuss with a translator about the research. The interviews were therefore, longer to conduct and transcribe.

**Culture:** In Thailand and Myanmar, elders are respected, the researcher being a young woman, faced challenges gaining credibility in the community. Conducting interviews took time to instill the trust of those older than her. People in these countries do not discuss delicate matters openly to strangers. It took more time to develop relationships with the participants being interviewed.

**Travel:** People were not always easy to locate. Since some of the people may not be legal, finding people who want to talk was sometimes challenging. Travel took time, and it was not possible to conduct interviews everyday.

**Access to information:** It was discovered that in Myanmar almost all of the private organizations and the only government aid in supporting children with disabilities were based in Yangon. Because of this, my time was spent primarily in Yangon as it took time to build a relationship.

**Transcribing:** Since most of the interviews were conducted in Burmese and Thai, it took a great deal longer to transcribe the interviews into English and the language barrier made it a more complex process.

**Protests in Thailand:** During the time that the interviews were conducted, Thailand was going through a series of protests against the current government. These protests have lasted several months and are still occurring. Transportation, travel, ability to meet individuals was limited as the protests overwhelmed most of Thailand.

These obstacles are not negative to this research. They are ones to be aware of and address throughout the process, adapting and moving through them creatively and honestly only better

served this study.

## Research Findings:

The discussions of the past few months were eye opening to the incredible strength and courage of families and organizations working hard to support equal rights for all children. The core findings of this research, relies on the documented thoughts and experiences of the individuals interviewed. The following themes emerged as the core influential factors that impact the lives of children with a disability in Thailand and Myanmar: government, culture, environment, attitudes, available resources, accessibility, adolescence into adulthood and improvements people hope for. The findings here are based on the experiences and perspectives of those who participated in the study as well as the observations of the researcher.

### 1. Government

The government of a country can contribute to the societal acceptable norms, attitudes, perceptions, and ideas. When trying to understand the lives of any vulnerable population in Thailand or Myanmar, the government's awareness and policies towards these individuals largely defines the broader social context. Therefore, given that there are few laws protecting the rights of people with disability and the implementation of these laws is extremely poor, challenges of those with a disability and go largely ignored.

Myanmar has been strictly controlled by a military dictatorship since 1962. Since the 2010, general elections the military has slowly begun relaxing their tight control, yet many challenges still remain to be addressed throughout the country. A combination of policy change from within the government and advocacy for the equal rights of all citizens will be a major factor in providing support and services.

*In 2014, we are going to be fighting for the right for disabled people to vote. Currently it is the law that anyone with a physical or mental disability does not have the right to participate in any election. We are also trying to build a network to approach the government to have one seat in parliament for disabled. The government says that currently the disabled population is 2.2% but our research from other organizations and NGO's says it is really around 10%. But, the government doesn't know about Autism. We need to help create awareness of autism and other disabilities within Myanmar.*

**A Burmese father of child with Autism and a member of an organization supporting children with disability in Yangon, Myanmar**

*The government and us have to work very far to build more awareness, more knowledge and advocacy for the rights of those with disability.*

**A Burmese female member of an organization supporting persons with disabilities and their families in Yangon, Myanmar**

*Here we have no community support. The media doesn't understand. The government doesn't understand. No one really knows what autism is.*

**A Burmese mother of a child with Autism and a member of an organization supporting children with disability in Yangon, Myanmar**

Both Thailand and Myanmar are currently facing major political and social shifts. Due to the numerous challenges these countries face, disability rights is not always high on the agenda. Most of the current support networks for children with disability are funded by community-based organizations. These organizations are eager to continue approaching the government to discuss reforming their policies on disability rights and services.

*Here is not like the United States where businesses have to hire a certain number of people with disability. I do not see our country even in this category or thinking of these things for another 20+ years, we are not ready yet. We have so many problems, fighting for democracy, national unrest, ethnic autonomy, war, and so forth. There are many steps. We have to work on it.*

**A Burmese father of child with Autism and member of an organization supporting children with disability in Yangon, Myanmar**

*The school also invites all parents to talk. The government schools don't organize anything specific, we only do so privately. We are trying to work with the government. Tried and failed.*

**A Burmese female member of an organization supporting persons with disabilities and their families in Yangon, Myanmar**

*Our organization is also conducting workshops with other special school and private schools on what Autism is. The government has passed a law on inclusive education. We try to cooperate with government schools and government teachers. This is a process that is coming.*

**A Burmese father of child with Autism and a member of an organization supporting children with disability in Yangon, Myanmar**

*So my opinion is that the children whether they are rich or poor should receive the same services. So what we*

*are doing is the training courses for special teachers and then we invite government schools, charity organizations, private schools-the teachers, who all come attend the course. We don't have any regular training course, we have to do it only when there are experts coming from abroad or only when there are some people who will pay for it (often the experts) so it's not regular. The government sends their teachers so we train them all. This means government and private we train so that they receive the same training and can give service to the children. At the moment they are just sending the teachers, they are not funding these trainings.*

**A Burmese female member of an organization supporting persons with disabilities and their families in Yangon, Myanmar**

Laws protecting and supporting the rights of people with disability are few in both Thailand and Myanmar. Some of the existing laws are beneficial, yet the implementation of these laws needs improvement. The Inclusive Education Act has been accepted in Thailand.<sup>4</sup> According to the Government of Thailand all children have the right to standard education regardless of ethnicity, race, gender, or ability.<sup>5</sup> In writing, the law seems very beneficial, yet many children still face challenges accessing and attending school. Myanmar has signed up for the Dakar EFA but has yet to implement any laws protecting or supporting children with disability.<sup>6</sup>

*Currently the government has no policy, no regulation, and no benefits for people with disability. This is part of the reform and hopefully the government will support.*

**A Burmese male with partial hearing and a member of an organization in support of women with disability in the workplace in Yangon, Myanmar**

*Several organizations have chosen to work with those facing physical disabilities because the reality is that they are easier to work with. It is easier to get them in inclusive school because they have the social capacity. Mental and other disabilities need the support or special schools here. Some we should try to integrate into the*

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<sup>4</sup> "Inclusion of People with Disability in Thailand." Inclusion of People with Disabilities in Thailand (2009): International Labor Organization, June 2009. Retrieved January 2014 from [http://www.ilo.org/wcmsp5/groups/public/---ed\\_emp/---ifp\\_skills/documents/publication/wcms\\_112307.pdf](http://www.ilo.org/wcmsp5/groups/public/---ed_emp/---ifp_skills/documents/publication/wcms_112307.pdf).

<sup>5</sup> Piromya, Kasit. "Human Rights." Thailand's Policy on Persons With Disabilities. Thailand Government, n.d. Retrieved January 31, 2014 from <http://www.mfa.go.th/humanrights/statement/110-foreign-minister-emphasized-thailands-leading-role-in-promoting-human-rights-at-the-16th-regular-session-of-the-human-rights-council>.

<sup>6</sup> Senegal, 26-28 April 2000, and D. World Education Forum; The Dakar Framework for Action: Education for All: Meeting Our Collective Commitments (including Six Regional Frameworks for Action); 2000 (2000): n. pag. UNESDOC. UNESCO. Retrieved from [http://www.unesco.at/bildung/basisdokumente/dakar\\_aktionsplan.pdf](http://www.unesco.at/bildung/basisdokumente/dakar_aktionsplan.pdf).

*government system but some really need more support than the government can currently offer.*

**A Burmese male member of an organization supporting persons with disabilities and their families in Yangon, Myanmar**

*In Thailand the law is that every child has the opportunity for standard education, however the problem is for children with disability because it requires a more specialized education system. Things like communication and language are a few challenges that teachers would face.*

**A Thai male teacher at a migrant school in Ranong, Thailand**

*It is not enough to just have a medical point of view, because social dynamics are equally as important. We follow the UN guidelines when considering disabled people in Burma. The one thing when I think of CWD is their part in the education sector. The biggest thing for them is that they want to feel normal, like other kids. The government has a law that claims to promote a so-called inclusive education but the reality is very different. It is not only about children with disability (CWD) getting an education but it is about society and community, and their relationship with other kids, we are human and this is a human desire to fit and be part. This is where there is some conflict, because we need special schools also not just putting them in any school, any way. My opinion is that CWD should go to school. We should focus on encouraging them and building confidence. There are many steps that need to be taken in the community. It is not simple or fast change.*

**A Burmese male member of an organization supporting persons with disabilities and their families in Yangon, Myanmar**

There is clearly more attention that the government can and should give to the needs and rights of individuals with developmental disabilities. The government can influence a society's perceptions on a subject by their awareness and engagement with it.

## **2. Cultural Complexities**

Understanding the cultural dynamics within a country provides powerful insight into the lives of individual members. Countries like Thailand and Myanmar have tremendous social, ethnic, and economic diversity. Religion has always been influential in forming many of the societal thoughts and behaviors. The primary religion in Thailand and Myanmar is Buddhism. In this nontheistic religion the notion of reincarnation and karma play a significant role within its teachings. This impacts the way people are treated and perceived. By acknowledging these cultural complexities, a more holistic understanding is established about the functions of society in Thailand and Myanmar and how it pertains to the treatment, perceptions and policies on disability.

## Religious Complexities:

Religious teachings can inform behaviors and attitudes in individuals and communities. The concept of reincarnation and karma in Buddhism plays an impactful role in the way people consider disability. Reincarnation is the notion that when someone dies, they are reborn into the world again in some form. Karma is the principal that actions performed in this life will influence the future of the individual. Pity and sympathy is often the way individuals approach the concept of disability, as it is believed that someone who has a disability is paying for something bad that they did in the past life.

*I think in these rural areas there is some religious confusion. Some people have a different way of thinking than in the west. In Myanmar we believe when we die, we can be reborn. So if I die and three years later a baby is born they could think it is me reincarnated. This is our traditional thought. Even Thailand has this concept of reincarnation.*

**A focus group discussion comment by a Burmese male member of an organization in Yangon, Myanmar**

*Many parents think here that if you have a physical disability you are of low intelligence. This is a Buddhist country and most of our society, have mercy, but are not willing to send their kids to school. For an extremely poor family sending a child to school is very expensive, and many parents think it is a waste to send their disabled kid.*

**A Burmese male member of an organization supporting persons with disabilities and their families in Yangon, Myanmar**

*I take my son's disability as a lifelong challenge based on my religious belief. I believe that I have the karma to take care of him. He is suffering through his own karma, whatever reason his karma has put him in this position. He is here. This is my way of thinking. My karma is to look after him and his karma is to go through this. For example, I cannot have a clean house my child takes everything and spreads it around. When I come home from work I want a clean house I want to be able to relax and watch tv, but I CANNOT! But at the end of the day I realize if my Karma won't let me enjoy I cannot enjoy. Things are all right now. I think my son is a lovely child.*

**A focus group comment by a Burmese male member of an organization supporting persons with disabilities and their families in Yangon, Myanmar**

## Economic Complexities:

The economic diversity in Thailand and Myanmar is dramatic. Part of the population is financially stable, while the majority of the population lives largely “hand to mouth”. Families with economic support can provide more of the necessary care and stimulus for their children than families that have little savings or extra money.

*His parents are independent business people. They have a rubber farm, and some other businesses, he is a child from a rich family. He is lucky even though he has some difficulties. It is good that his parents have money, they also help a lot for the school.*

#### **A Thai female headmaster of a government school in Phang Nga, Thailand**

*Most of the parents at the school are day laborers hired for different jobs. Right now there is a lot of work at resorts and hotels. Many also work in the rubber plantations but they do not own the farms, they only work on them. There are families that own rubber farms, but very few. Of course, people who work on farms make far less than those who own them.*

#### **A Thai female working as a teacher in a government school in Phang Nga, Thailand**

Although there are new organizations established in Myanmar and Thailand supporting children with disability and their families, most individuals cannot afford these programs. It is a current challenge to find ways to provide care that is available not only to the wealthy.

*My interest to get involved in this group is not only for my child, but for the other parents and children with autism that are not as financially secure as I am. For the daycare center, was started by all parents who had the same dream for their children. Special schools are very expensive. So, we wanted to provide a special school for parents that cannot afford to send their children to these schools. We need more places like our daycare center that is free and available not only for parents who can pay.*

#### **A Shan female member of an organization supporting persons with disabilities and their families in Yangon, Myanmar**

*So now we do include parents, who previously could not afford to send their child with disability to school. The instructors here at the Myanmar Autism Association are trained and provide training to teachers and other volunteers. They come and play, watch the children and teach a few intervention methods for the parents at home to be able to go about their day. I read that there are groups interested to do work with children with disability, but here I don't see that very much yet.*

#### **A Burmese father of child with Autism and member of organization supporting children with disability in Yangon, Myanmar**

*For parents that are really poor, they can't send their children to a special school. After we started this program, we had parents immediately contacting us wanting to send their child here.*

**A Shan female and mother of a child with a disability and member of an organization in Yangon, Myanmar**

*Although most of the people that are part of the Myanmar Autism Association have money and can afford this care for our children. There are many families that are not in our position and we need to focus on supporting these parents and families.*

**A Burmese mother of a child with Autism and a member of an organization supporting children with disability in Yangon, Myanmar**

As all cultures are unique and have their own complexities, it is crucial to understand how cultural norms and expectations impact society and its individuals. Challenges faced for individuals with a developmental disability in one part of the world may be completely different in another.

### **3. Environmental Context**

There are many aspects to consider when determining the accessibility of an environment. There are many aspects to consider. The physical landscape can be a reflection of society's attitudes, perceptions or lack of their understanding towards disability. Public spaces and areas such as schools were mentioned as physical barriers for children with a developmental disability and their families.

The cost of private transportation is high, and most families cannot afford to use the services of a taxi or private driver on a regular basis. Public transportation is also not structured in a way that parents with children with disability can easily access.

*We face many challenges if you have a disability. I have one friend who uses the wheelchair and once we went together across town. The public transportation is poor already, many people stand cramped on the bus. How would anyone in a wheelchair manage? Especially alone. We stood on the side of the road for a long time, many buses slowed down when they saw people at the bus stop, but when they saw my friend they picked up speed and didn't stop for us. Finally we had to take a taxi because no bus would stop. I think they didn't stop because it would take too much time and it would be a complicated situation to have a wheelchair on the bus.*

**A Burmese male member of an organization supporting, individuals with physical disability in Yangon, Myanmar**

*Many parents of these deaf children are very poor and are not from Yangon but from surrounding villages, they cannot afford school and daily transportation. We have about 200 students that can stay here at the school, and currently all rooms are full. It is hard because if we say no to families or children, they have no other option and they most likely will not attend school.*

**A Burmese female principal at Christian school based in Yangon, Myanmar**

The roads in Myanmar and even Thailand are not in good condition. Although improving, walking or driving is not a casual act. It often takes intricate maneuvering on the sidewalks to avoid the uneven concrete and massive sewage holes. With the rapid influx of cars in Yangon, the streets are always crowded and traffic laws seem to not be followed consistently. Many individuals who have a disability cannot move independently and require a great deal of support.

*When I was a child I lived in Pyay near Yangon. My mother was a doctor and my father was an engineer. I was lucky because my parents were able to have a teacher come to the house. I was home schooled, but only in the morning Monday, Wednesday, and Friday. If I was to go to school, how would I get there?*

*Transportation is difficult. The roads are not accessible, it costs money, and without wheelchairs kids even 9-10 years old have to be carried on an adults hip like a baby.*

**A Burmese male member of an organization supporting persons with disabilities and their families in Yangon, Myanmar**

*My son understands his environment cannot accept him so he feels depressed. He becomes more isolated and more lonely.*

**A focus group comment by a Burmese female, mother of child with Autism and member of an organization in Yangon, Myanmar**

Most learning centers and schools have few or any altered facilities to support children with specific environmental needs. For example, children in wheelchairs must rely on peers and teachers for almost everything at school.

*At school, teachers and friends help him, for example like the bathroom. We help, but if he really has to go, he doesn't live far away and his mother will come if there is time. If it is not possible for his mom to come, the teachers will take him and say, "alright, open up your pants, and pee." We have been taking care of him since he was young, now he is in the 4<sup>th</sup> grade. We have to help him. Students need to know their role for him, we talk to them about needing to help him, moving around, picking up things and bringing things to him, his peers will help him with the things he needs. For children in a wheelchair like him, he doesn't get any exercise, he can eat like a normal person but he is fat. Very fat. It is good that his parents are both big so*

*that they can manage to carry him. The teachers barely can lift him now, before he was just a baby, and it was easy, now it is getting almost impossible.*

**A Thai female teacher in government school in Phang Nga, Thailand**

The physical environment in both Thailand and Myanmar are not accessible for all individuals. In fact many individuals with disabilities are extremely limited in their ability to move through society independently. This is a challenge that is urgently need of attention in both Thailand and Myanmar.

#### **4. Attitudes**

Negative attitudes towards children with disability can impact their lives in several ways. It can affect their self-esteem, how they are treated in their community as well as influence policy and the services they are provided. It is common for people with disability in Thailand and Myanmar to be confronted with many forms of discrimination at national policy level, in their communities, at school and even at home among their family members and relatives.

*In the world she has to face it. Some people will bully her. Some people will neglect her. She has to face it. If she doesn't learn to face this she will not know how to deal with it. At her home, she faces it from the neighbors. Her relatives are the same. She has so many problems she already faces and in addition, so much discrimination. Is it not enough for your daughter? She needs some place to build up her esteem that's why she came to this school. Discrimination is often her biggest problem.*

**A Burmese female member of an organization supporting persons with disabilities and their families in Yangon, Myanmar**

*Discrimination and disgrace is a big problem.*

**A Burmese male member of an organization supporting persons with disabilities and their families in Yangon, Myanmar**

Most participants stated that there was little access to information on disability, and there is a lack of awareness and understanding throughout Thailand and Myanmar towards people with disability. There are only a few organizations working to educate the public on disability.

People with a physical disability are much more accepted in society than a child other forms of developmental disability because it is much easier to see and understand. Also, those with a physical disability can still engage socially allowing them to engage in a more socially acceptable way.

*A child with autism looks like a normal child. There is no physical distinction that they have a disability. When I go with my child into the community, my son does things like kiss me in the middle of the road. Now my child is 16 years old. For most people this is strange behavior, there are eyes that look at us filled with questions. There are a few people who understand, but many who do not. I feel shunned and neglected from the community. Most people cannot understand children with autism. Therefore, most people, when they see my son for the first time, assume their own stereotypes, they make their own ideas about my child, like, “a child with autism will destroy everything.”*

**A focus group discussion comment by a Burmese mother of child with Autism, member of an organization supporting children with disability in Yangon, Myanmar**

*Physically you do not see that they (autistic children) are disabled. In some places people call these people mentally ill or a “mental child.” Also some people just cannot accept a child’s disability if they cannot see it.*

**A focus group comment by a Burmese male working for organization supporting persons with disabilities and their families in Yangon, Myanmar**

*It seems everyone has attitudes though. People say you shouldn’t marry a disabled girl and have a family because it costs a lot more money and takes so much time. Money and resources are a huge concern for the men it seems. People in society think that it is best to have disabled people marry each other. This is the attitude. I am married now for three years and I hear these attitudes frequently.*

**A Burmese female with physical handicaps who is a University Graduate in Yangon, Myanmar**

Some parents of children with a disability feel pressure from these attitudes in society that lead to discouragement and shame, making them hesitant to reach out for help and support from the community.

*This school was established in 1920 and Mary Chapman had an interest in people with disabilities in Myanmar. She wanted to start communication and discussions on the situation. Many people in this country are superstitious of disabled people. Parents tend to hide their children because they feel that it is their fault and also the community sees it that way.*

**A Burmese female principal at Christian school in Yangon, Myanmar**

*Parents sometime have a sense of denial. They don’t want to admit that their children are disabled. They don’t want to admit because of peer pressure, and then of course you don’t want your child to be disabled, right? You want to have a normal child and if you don’t have ... how should I say, your expectation are not perfect. Lets say usually the father has much expectation of their children. And sometimes there is only one*

*child, so they want that child to be very good, something like that, and when they know they cannot achieve it then they are really disappointed. The children then absorb all this and also determines how the children themselves feel.*

**A Burmese female member of an organization supporting persons with disabilities and their families in Yangon, Myanmar**

*Some parents are ashamed to have their kids in public, we have a very famous Myanmar celebrity who has a child with autism but they do not say anything and no one really talks about it.*

**A Burmese male with a child with Autism and a member of an organization supporting children with disability in Yangon, Myanmar**

*Most parents think that they have to send their children to the government school, because normal kids go to these schools.*

**A Burmese female member of an organization supporting persons with disabilities and their families in Yangon, Myanmar**

Many parents have had encounters with relatives who have formed attitudes and placed stereotypes on them and their child. Relative's attitudes towards their child were described as not wanting to be associated or involved and making little effort to support or understand.

*As for my son, there is no situation or environment that can accept my son's behavior. So my son cannot enter into the society. Everywhere, even in our relative's homes. When he was young everyone could accept his behavior and the situation. But after time, now he is 12, they don't accept him. They don't know what autism is.*

**A focus group comment by a Burmese mother of child with Autism and member of an organization supporting children with disability in Yangon, Myanmar**

*My immediate family, his uncle and aunts and grandparents, they love him but nowadays everyone has their own life, I do not see any of them volunteering their time to be with my child. No one will take one hour to train my kid or even spend a bit of time with him.*

**A focus group comment by a Burmese male working for organization based in Yangon supporting persons with disabilities and their families in Yangon, Myanmar**

*People say because I am a disabled person having children is not recommended. My parents say that I should not. My husband's family has not said yes or no, they do not say anything yet. They feel pity I think for me. I think I can care for a child. I have experience from my brother's child, and blood is thicker than water, my*

*family will come and support me if I have a child.*

**A Burmese female with physical handicaps who is a University Graduate in Yangon, Myanmar**

*I have explained my son's situation so many, many, times, and they can understand. What I mean is that they can accept what I say but they do not accept my son's behavior. My son doesn't even have to do anything anymore. When they see my son at the door. They close their windows, and blinds and hide their things, my son hasn't done anything yet, but they are afraid that my son will destroy their place. I see their fearful behavior towards my son so I never take him there. I do not want to blame them, but I don't want their pity. I don't want to feel it.*

**A focus group comment by a Burmese mother of child with Autism and member of an organization supporting children with disability in Yangon, Myanmar**

There is often the attitude towards intellectual disabilities that any bad behaviors and actions of a child is a direct reflection of how he or she was raised. That the reason they act the way they do is because of their parents. This attitude affects parents negatively as they struggle with self-blame already.

*When my son does something he isn't supposed to or he does something unacceptable by others, they always turn to me and say, "What is your son doing?" and "It is your fault. As a mother, as a father, you are very bad. The child is following your behavior." So they look down very on you very much. I feel depressed. Now I cannot take him anywhere, even to a relative's house.*

**A focus group discussion comment by a Burmese mother of child with Autism and member of an organization supporting children with disability in Yangon, Myanmar**

*Recently my brother came from Canada, we had a family gathering, and I can see that many family members do not know what is autism. They look at my child and think, maybe something is off and he is a little mad. A lot of people will look and have no idea what is going on, they think it is so strange and weird. They of course don't ask me anything. If they don't ask I am not going to go around explaining, trying to defend myself. No, so I say look, I don't care, I love my child and I am all right.*

**A focus group comment by a Burmese male working for organization supporting persons with disabilities and their families in Yangon, Myanmar**

Teacher's attitudes towards their students can impact a child's self-esteem and self-perceptions. If a child with a disability is faced with discrimination at school from teachers it can impact the child in a monumental way. Many teachers show an attitude of not having high expectations for children with

a developmental disability.

*I knew that my child was not an ordinary child. When I tried to enroll him in kindergarten most of the schools didn't accept my child, because he runs all the time and he is very hyperactive.*

**A Shan female member of an organization supporting persons with disabilities and their families in Yangon, Myanmar**

*So you have to talk to the principal, 'so my child cannot manage the time to finish within the boundary, so ok sometimes she needs extra help, but she is ok to do the test, she knows the information.' But they don't give her a chance and they always give her, FAIL, FAIL, FAIL, all the marks are fail. And also, teachers and principals say things like, 'ah children like this will not be good for the reputation of our schooling, our reputation will be ruined' because they want to make the government exam, they cannot understand.*

**A Burmese female member of an organization supporting persons with disabilities and their families in Yangon, Myanmar**

*When it comes to learning we need to understand better teaching techniques. Now this boy can write the alphabet by following the dots, he can even write a few letters on his own. Like this morning I wrote a letter and asked him if he knew which one it was, and he did. He can also point to letters for you. He is now 11 years old in the fourth grade. He doesn't learn the same material as his peers, because we have to follow his capabilities. If we try to have him learn material that is out of his capacity he won't be able to. We teach him at another rate.*

**A Thai female teacher in a government school in Phang Nga, Thailand**

*There is another girl in the 5<sup>th</sup> grade. She has difficulty learning in school. All the students though move forward, we don't keep them back a grade. Everyone must pass each year, regardless of their capacity.*

**A Thai female headmaster at a government school in Phang Nga, Thailand**

Many children in school have not discussed the topic of disability before. With no guided support, students are not sure how to engage children who have a disability. Without a discussion, misunderstandings and fear of the unfamiliar can have a negative impact on the social lives of children with a developmental disability.

*He has some friends. No one really pays attention to his challenges. School peers will play with him, but at home no one really plays with him.*

**A Thai female teacher in a government school in Phang Nga, Thailand**

*There are not many problems among the students. He is the smartest one in his class. He is ten years old in the 4<sup>th</sup> grade but can do work at the 6<sup>th</sup> grade level. He is very smart. So there are some students who are jealous of him. If we mix any of the classes like fourth and sixth and none of the older students can answer the question, he usually always can. He knows so much because at lunch time he is in his wheelchair, he didn't play with any of the other students, he reads and reads, meaning he works hard to study in class. He probably plays at home. He is like a normal kid, but doesn't play with children at school. He doesn't really make an effort to make friends, he could though, he is smart and could teach his peers everything.*

**A Thai female headmaster of a government school in Phang Nga, Thailand**

*Yes, at break children sometimes invite her to play gadood yaang (jump rope), and they seem to get along. It is just difficult because the children do not want her to hurt them but she also cannot seem to help it. They do not understand why she does what she does and that makes interacting hard.*

**A 17 year-old Burmese female teacher at a migrant school in Ranong, Thailand.**

Attitudes towards any individual or group can be a potent poison that can heavily impact in a negative way. These attitudes carried among relatives, teachers and students towards the notion of disability are important to consider when trying to understand the daily lives of children with developmental disability and their families.

## **5. Resources/Accessibility**

Identifying the resources available for children with a disability provides a glimpse into the kinds of support systems established to care for the needs of these children. The accessibility to resources is another area that should be acknowledged because if there are resources, but few people can access them, they render the resource less effective or useful to the community.

The current resources provided for children with developmental disability in Thailand and Myanmar is limited. Although there are few services provided, some aspects of what is presently available is beneficial to those living with a disability. There is a rise in organizations working towards equal rights for people with disability. There are dedicated and passionate people working with heart to engage these challenges. Schools specializing in working with children with severe disabilities are becoming more available, though most families cannot afford to send their children. Figuring out what resources are available is important, but it is also crucial to focus on identifying the gaps. What is not available? What needs are identified and not currently met? The lack of funding is a major barrier for many of these community-based organizations supporting people living with disability.

*If I can say honestly, parents fund most of this organization, we get no corporate or external funding, we have not gotten to that level. There are businesses that are interested to support our cause for their own desires for their own face, not with our interest in mind. These local disability organizations are managing, the cost of rental is high, good teachers are expensive and hard to keep. We can't move forward very much, just try to maintain.*

**A focus group comment by a Burmese male member of an organization supporting persons with disabilities and their families in Yangon, Myanmar**

*We all volunteer at this association, in fact we are also the only funders. We put money into this group. We are always contributing to our cause.*

**A focus group comment by a Burmese mother of child with Autism and member of an organization supporting children with disability in Yangon, Myanmar**

*We really want to establish some space. We had to move from our last office because the rent was too expensive. We have moved here, but it is too small to have an adequate program. We need a better place that is not temporary. We need a fixed place where we can invest in the necessary accommodations.*

**A Shan female member of an organization supporting persons with disabilities and their families in Yangon, Myanmar**

*We have three teachers here to cover six grade levels. I ask you, how do we make it work? We do not get any funding for the school, only the teacher's salary, if we want to get something to use for the school or build anything, it is on the teachers to supply it, no one else. I do not go ask others to give, because I also see the community members are having difficulty. They also do not have a lot of money, so I don't go ask them to invest in this school. We have to make do with what we have.*

**A Thai female teacher at a government school based in Phang Nga, Thailand**

*For parents who cannot afford tuition, we allow their children to attend for free. For other parents, when they start to attend they can afford to pay, but sometimes after one year, they have used up all their extra savings and can no longer afford it. For this situation, if they cannot pay, we cannot say you have to give it to us. So, what we do instead is, let it be, including transportation and including teaching costs, we have to give them free. This school depends on the salary (of parents), so it is difficult, we are running it and losing money. We cannot make profit, so we loss more, but we have to keep on going. We cannot make a profit, but we cannot stop this school. So we just keep on going like that. Parents also have to work and they are busy. We cannot blame them like, 'your so busy you don't make time for your child.' They have to earn some money for their child and for themselves. This is big difficulty for us.*

**A Burmese female member of an organization supporting persons with disabilities**

### **and their families in Yangon, Myanmar**

*We do awareness workshops once every two months. This is when we can talk and share information about the challenges and successes of living with disability. We also try to discuss things like behavioral therapy. There is always a financial burden because we just began this organization as a small group of parents and do not have any major funding.*

### **A Burmese father of child with Autism and a member of an organization supporting children with disability in Yangon, Myanmar**

Learning centers rely on donor funding to operate and public schools in Thailand and Myanmar receive very little money from the government. This can lead to lack of space for classrooms, few teachers and limited resources. The ability to make needed adjustments for children with a disability depends entirely on the teachers and the parents contributions.

*A problem is that now in Myanmar, 'normal' children don't even have enough for school. Schools themselves are really struggling. Therefore, they feel taking on a child with a disability is too much. So, what can we do?*

### **A Burmese male member of an organization supporting persons with disabilities and their families in Yangon, Myanmar**

*Even private schools cannot understand the needs of a child with a disability. Government schools are over loaded with one classroom holding over 60 students under one teacher. How can a child with a disability manage? How can a teacher give extra attention to one student. For the government school the teachers have to go and wait at the gate, to see how many students that day. She does not only do lesson plans, but does other work for the school. When one class has over 60 students per classroom, the teacher cannot give time to develop an individual education plan.*

### **A Burmese female member of an organization supporting persons with disabilities and their families in Yangon, Myanmar**

*I would like to see more children with disability in school. It is better than just being at home. It is more difficult for a child with a mental disability because there are too many students to one teacher.*

### **A male from Myanmar teaching at a migrant school in Ranong, Thailand**

There are few people trained or aware of how to support children with a developmental disability. The necessity for various training is urgently needed. Currently there is no degree to study developmental disability at any University in Myanmar. In Thailand however, there are options for receiving a degree in this field and Universities like Chiang Mai University has hosted organizations

and students from Myanmar to come for trainings and courses they have held.

*One thing I want you to know about Myanmar is that we have so many necessary things we need like early intervention. We have no psychologist. No child psychiatrist. We have nothing, so everything will be beneficial for us.*

**A Burmese mother of a child with Autism and a member of an organization supporting children with disability based in Yangon, Myanmar**

*The teacher cannot understand the child's situation, how to teach, how to support, thing's like that. It is very difficult.*

**A Burmese female member of an organization supporting persons with disabilities and their families in Yangon, Myanmar**

*Let's talk about Thai children first. The Education department addresses special education needs, and children with disability can enter school. In the District of Ranong there are about three special schools, helping 'special children.' But, this is only for Thai children, if we talk about children from Myanmar, its difficult. I don't know any child from Myanmar with a learning disability who has been allowed to enter a Thai school or even a migrant learning center. Although, I don't know if there are even any children with a disability in the migrant schools, I think that these places would accept all children. However, some children need special care and trained teachers. These migrant schools are extremely limited. For a child with a disability, the way they learn is unique, and they require learning strategies that fit their abilities.*

**A male from Myanmar teaching at a migrant school in Ranong, Thailand**

*Another thing we plan is to mainstream another four children to the government school. However, while we negotiated for these children we also accepted another four children from the government school into our school. The teachers at the government school just cannot understand the child's situation and how to teach to support them. It is very difficult.*

**A Burmese female member of an organization supporting persons with disabilities and their families in Yangon, Myanmar**

There are resources that are currently available, however it is clear that there is much more needed. With the availability of support networks, it is crucial to consider who is able to access these resources. Even finding grants or support for the smallest things such as obtaining a wheel chair or making a school or home accessible is challenging. Myanmar as a country has been isolated from the world, much of the basic care available and expected for children in other countries does not exist here because of the lack of information and support.

## 6. Accessibility

The cities of Yangon and Bangkok are very different from other parts of these countries. What is available in the urban areas may not be in the rural areas. There are not many “special schools” available to support those who need particular care. The few such schools in Myanmar are located in Yangon. In Myanmar there is only one school for special needs that is funded by the government, this is not enough to support the children and families that need affordable care and support. There are extremely limited options and major challenges to accessing available resources, especially outside the capital cities.

*At the government level there is only one school and a charity center let's say, the rest are all private schools. So rich families can go to these private schools and those who cannot afford can go to the government schools or try to get into the charity center.*

### **A Burmese female member of an organization supporting persons with disabilities and their families in Yangon, Myanmar**

*It is very sad for me to see that only in downtown Yangon and Mandalay people are aware of autism or even other disabilities and the only resources are in these two places, in the rural area there is nothing. When I have gone to the rural areas, I do not find much of anything for people living with a disability. For example, when I go to the Patheingyi area, I don't see many children with autism.*

### **A Burmese father of child with Autism and a member of an organization supporting children with disability in Yangon, Myanmar**

*Myanmar Autism Association is now three years old. There is a lot happening in the Yangon area, but the rest of Myanmar is not getting a lot of attention or support.*

### **A Shan female member of an organization supporting persons with disabilities and their families in Yangon, Myanmar**

*We try to raise awareness of autism through pamphlets and the television. We try to promote understanding and when they heard about it they come over. For children who live outside the city it is quite difficult because the service is not available so if they want the services they have to stay in Yangon. For parents to come stay in Yangon is very difficult, if they have families or relatives or something like that they can do it, but if not then they just come for lets say, 20 courses to train with us. For two weeks or one month something like that. Go back, carry on with the children then come back again later. It is very expensive and many parents need to work.*

**A Burmese female member of an organization supporting persons with disabilities and their families in Yangon, Myanmar**

*Not many women in Myanmar know any formal sign language. It is difficult because there are not many schools or places where you can learn it.*

**A Burmese male with partial hearing, founded organization in support of women with disability in the workplace in Yangon, Myanmar**

*One woman I know divorced with her husband and there is not person to take care of her son when she had to work. So, she sent her child to the mental hospital. Although she knew her son didn't need to be in a place like that, there was not place or people to take care of him. Therefore, she sent him to the mental hospital.*

**A Shan female member of an organization supporting persons with disabilities and their families in Yangon, Myanmar**

Those who live in the city of Yangon have access to information and resources that people in the rural areas do not. Many organizations are concerned about how to bring awareness and discuss disability with those who do not have internet or other modern communication.

*We work with mostly women, but we have two deaf men working in the factory. Most women with disability are not receiving any information, so we want to advertise for new 'women with disability' workers. We advertise through newspaper, pamphlet, online, and fax. The newspaper is for all of Myanmar, but still the distribution is limited. It is difficult because not everyone has internet access.*

**A Burmese male with partial hearing, founder of organization in support of women with disability in the workplace in Yangon, Myanmar**

*The first time we used media as our main tool to educate the community about autism.*

**A Burmese mother of a child with Autism and member of an organization supporting children with disability in Yangon, Myanmar**

*I especially want to know about PECS (Picture Exchange Communications Systems). I heard there was a new system that came out in the United States and has come to Asia, but it doesn't include Myanmar. It's a program for autistic children. I heard this new system has reached Thailand. But, it is not here in Myanmar. In the time of the internet age we can't access this information, because our country doesn't have good connection with the developed countries.*

**A Burmese mother of a child with Autism and member of an organization in Yangon, Myanmar**

*We have been advocating as much as we can. We have a ten-minute awareness clip that was broadcasted on TV and skynet. We also do a magazine article and talks on the radio. We need to reach as many people as we can outside of the city as well.*

**A Burmese father of child with Autism and member of an organization supporting children with disability in Yangon, Myanmar**

A current major concern for many individuals working in support of children with a disability is how to make these resources accessible to all. The current available resources are limited to families with the financial backing, which is only a small portion of the population in both Thailand and Myanmar.

## **7. Adolescent/Adult Life**

Throughout this research a frequent concern was raised about the options for children with disability as they enter adolescence and adulthood. This transition and developing future options is challenging, particularly for children with a disability. If children with a disability have the opportunity to receive education, how do they apply it in a job so that can contribute to their independence in society? Concerns for what comes next weighs heavily on families who have children with a developmental disability.

Adolescent years are universally challenging. The transition from being a child to being an adult and an active member of society is a major step in any individual's life. Many parents of a child with disability find these challenges as well as ones that are unique to the realities of the disability itself.

*When my child was young I do not think he realized he was different, but as children become older and once they hit adolescents they begin to realize themselves and their environment. This is when he began to notice the isolation, that he was different and not the same.*

**A Burmese mother of a child with Autism and member of an organization supporting children with disability in Yangon, Myanmar**

*Services are currently primarily offered in the city of Yangon. There is nothing outside of this city and Mandalay. We are concerned with the next step, which is vocational training, what happens to the children after they finish school?*

**A Burmese father of child with Autism and a member of an organization supporting children with disability in Yangon, Myanmar**

*I do not think the training procedure's here have come down to practical level. We have interventions for a young child with a disability. But, when the child gets to 13-14 years old, then that's when the problem starts. There are very few services or resources and a lot of new challenges.*

**A Burmese father of child with Autism and a member of an organization supporting children with disability in Yangon, Myanmar**

The notion of independence and being a contributing member of society is important for many people with a disability and their families. Even to be partially independent is something that is not easily gained in Myanmar and Thailand. There are many people in these countries looking for jobs, and many people refuse employment to individuals with a disability because they do not presume the competence of these individuals. Instead most employers are concerned that individuals with any sort of disability are not capable of working.

*I do not have many expectations for my child's future, I only want one thing. When I pass away I want my child to be able to be in the community and learn from people. I want my child to be independent enough to know what is dangerous and what is safe.*

**A Burmese mother of a child with Autism and a member of an organization supporting children with disability in Yangon, Myanmar**

*It is best to have interventions or diagnosis as early as possible. Children engaged before the age of 12 will learn more long term skills than if they were engaged afterwards. We want to help raise the children at our program to work towards independence and not be totally dependent forever.*

**A Burmese father of child with Autism and a member of an organization supporting children with disability in Yangon, Myanmar**

*We have passed so many difficulties together, but now our association is targeting a plan on how to train autistic adolescents. We have no resources, especially human, and materials, not everyone can have access to this. Our group is really trying to target this group currently. How can we get them to a point of self-control, self-consciousness and strong self-esteem?*

**A Burmese Mother of a child with Autism and a member of an organization supporting children with disability in Yangon, Myanmar**

## **8. Barriers of Independent Living**

Job opportunities are rare among individuals with a disability in Thailand and Myanmar. The

common attitude is that anyone with a disability is not capable of working, even when the person considered to be “disabled” does not feel incapable. Some organizations are making an effort to support individuals with a disability to find access to working and making an income but very few establishments are willing to hire these individuals.

*When I was younger I injured my eye while woodworking. A small piece of wood entered and blinded me. I had always dreamed to work at the government level, I wanted to help bring change to my country. However once I was blinded in one of my eyes I learned that anyone who is not “complete” cannot work in the government, because I was missing one eye, I am not able to work there. I never felt like I had a disability, at first I was shy and embarrassed but later my friends understood and supported me.*

**A young male member of an organization supporting individuals with disability based in Yangon, Myanmar**

*Some ways people with disabilities can currently access jobs in garment making, haircutting/ styling, handicrafts, and massage, although most prefer to have someone with a visual disability for massage.*

**A Burmese male member of an organization supporting persons with disabilities and their families in Yangon, Myanmar**

For many parents who have children with a developmental disability, the most common concern expressed was what will happen to their child when they pass away.

*When I was less aware of what autism was I believed that after 3-4 years of training my child would get better. My doctor told me very pragmatically that I should not spend all my time on high expectations, go day by day and just love them. As a parent of course we need secondary plans for the day when we are not around. I think for any parent who has money, they are thinking and planning for this. We also need some information on how do we set up a trust fund and a home for people with autism. When my son is 30 years old and I am not around, how do we set up a trust fund and make sure he is taken care of. We want to ensure that he can live a happy and full life. I think all parents have this feeling.*

**A Burmese father of child with Autism and a member of an organization supporting children with disability based in Yangon, Myanmar**

*When I realized my son had autism, I knew that I was young and could help him when he was young. My fear is what will happen when I pass away? I am lucky because my daughter is very understanding and has a aid that when I pass away her brother will go live with her, but this is my worry most of the time.*

**A Shan female member of an organization supporting persons with disabilities and their families in Yangon, Myanmar**

*One of the biggest concerns for parents is what happens to their child when they die? Who will take care of them? This home would be a safe place where children or adults with autism could come when their parents died. It is very difficult for parents with an autistic child because here in Myanmar both parents need to work and maybe even the child to make enough money to survive. This makes it very difficult for the parents because usually one has to take care of the child while only one parent works. It requires a lot of time and money.*

**A Burmese father of child with Autism and a member of an organization supporting children with disability in Yangon, Myanmar**

All children get older. As many parents stated, it is much easier and society is more accepting of a child with a disability than an adult. The transition into adulthood is challenging and complicated for many individuals and their family. The ability to be independent and take care of oneself is highly valued among parents and individuals with a developmental disability.

**Discussion:**

It took a good deal of discussion among parents, teachers, program directors, people with disability, and community members to consider how someone from abroad, could help promote the equality and rights of people with disability. Although many needs in both Thailand and Myanmar were discussed, the core ideas that emerged were:

1. Support of Existing Education Programs
2. Support for teacher and specialist training to work towards inclusive education
3. Support directly to families with children with disability, and for awareness raising among the general public
4. Support in providing employment options for individuals with disability

1. Support of Existing Education Programs

There are already programs established in Myanmar that are actively working to advocate for the rights of people with disability. The way that a international donor could help, is be to support efforts already being made, backing up the individuals and organizations currently established to help them create greater change.

*The biggest issues are finances and education. If I were to support funding I think that money is big. Many*

*families are very poor and it is hard to put children in school. I would help families funding for school – school uniforms, book costs, anything like this. It would be most effective to help poor families.*

**A Burmese female with physical handicaps who is a University Graduate in Yangon, Myanmar**

*If I could have any donation or support I would want to train and support teachers, because then at the very least we could teach the children.*

**A Thai female teacher at a government school based in Phang Nga, Thailand**

*If any parents can help pay they do, but if they cannot we do not charge. There is not enough current space at the daycare for all the children to attend each day. Now they rotate every other day and can only come for half day. Some children only can come once a week. If we had more room we would be able to work with more children and provide better assistance.*

**A focus group discussion mother of child with Autism and a member of an organization supporting children with disability in Yangon, Myanmar**

*In order for us to be successful we need not only the motivation and awareness of parents we really need some funding to support our long term plans. We all want different things in the future. We all have our own ideas. I rather have a home and our own place. Then we can develop it, we can invite people and it can grow. Some people will say training, training, training, that's also needed. Property or training in a structured manner. There are trainings and events here, but I don't know how many of those are ever translated into action, real action. People are aware this is needed, but implementation also needs its own resources.*

**A Burmese father of child with Autism and a member of an organization supporting children with disability in Yangon, Myanmar**

*Also we need more special education schools like us. All kids have the right to learn. Parents think that inclusive education means they have to go to the government school, and their child will be included, like that. So we need to explain to them that there is not just inclusive education, you can get education at home, at centers, at private, whatever it is, your child can get education, that's inclusive education, they should know. Then with support children may be able to transfer to government schools and succeed.*

**A Burmese female member of an organization supporting persons with disabilities and their families in Yangon, Myanmar**

2. Support for teacher and specialist training to work towards inclusive education

There is a shortage of trained individuals qualified to work with children with disabilities, especially

as those with developmental disabilities. Many hoped someday to have trained individuals come to Myanmar to hold workshops and share ideas about what has been successful in developing the potential of those with a disability. This way there would be more qualified trainers who could continue to train others over time. Involving teachers from all schools not only “special schools” to be part of the training will help open a discussion and bring awareness to the needs and challenges faced for children with a disability.

*We need trainings for our volunteer teachers. To finance this is difficult but we need more of it. They are working with the Shwe Minn Thar Foundation to open a new center in Mandalay, for vocational training, we have to network together and help one another. We have some concept notes for classes/ teacher’s salary and a letter of proposal. We really want to talk to teachers, we want them to know and understand what autism is and how to see the signs and how to work with a child who is autistic. The ministry of Education says that there is education for all under the inclusive education act, but this is not happening.*

**A Burmese father of child with Autism and a member of an organization supporting children with disability in Yangon, Myanmar**

*I think in order to support children with disability we need to look into the issue more deeply. We have to go into the community and schools to learn what is going on and build awareness. We need to do research first. We need to understand the situation more thoroughly. We also need special teachers or training, I am not sure about Myanmar, but Thailand also does not have many education opportunities for children with disability except for the few special schools in Ranong.*

**A Thai male teacher from Myanmar working at a migrant school in Ranong, Thailand**

*We have a waiting list for our training programs. There are not sufficient teachers. We need teacher trainings. We need more people in this field. If children do not make it into a school like ours or other special school then they are at home.*

**A Burmese father of child with Autism and a member of an organization supporting children with disability in Yangon, Myanmar**

*I also want to train my teachers. I want to send our teachers to be train and then to learn how to train others. Singapore is offering some training and other countries also. But the problem is to attend these trainings it is too expensive, we cannot get any more knowledge without this. There is nothing offered here in Myanmar.*

**A Burmese female member of an organization supporting persons with disabilities and their families in Yangon, Myanmar**

### 3. Support directly to families with children with disability, and for awareness raising among the general public

Many believe that focusing on supporting parents and families is the most important aspect to consider. They are the foundation and bridge between their child and the community. Most importantly they care and are deeply invested in developing their child's competencies.

*Most families feel disappointed when they find their child has autism. We need a parenting program that also provides an ongoing peer-program. This is really needed for parents who have children with autism.*

**A Shan female member of an organization supporting persons with disabilities and their families in Yangon, Myanmar**

*It's not about just having good teachers, but it is important for me to know and be educated as well. If we want our children to have a sustainable life, first the parents must have the knowledge to link and create the network for our children. We came together so that we can improve the lives of our children.*

**A Burmese mother of a child with Autism and a member of an organization supporting children with disability in Yangon, Myanmar**

### 4. Support in providing employment options for individuals with disability

Work opportunities for an individual with disability are exceedingly limited. There is an organization named The Deaf Resource Center that is currently working with factories to have women who are deaf employed. These efforts have been positive as this organization has successfully engaged some garment factories in the country, however attitudes as well as laws must be changed in order for individuals with disability to find work.

These recommendations for support should be highly considered, as they come from individuals who are deeply rooted in the issues and acutely aware of the needs and challenges faced for children with disability.

### **Summary:**

To repeat on of the UN's definition for disability, "disability resides in the society not in the individual". It is clear that there are many complexities to consider when discussing the situation for children with developmental disabilities in Thailand and Myanmar. This research hopes to add to the existing data on these challenges faced for children with developmental disabilities in these

countries. To bring a more holistic understanding of the situation for children with developmental disabilities to The Hussman Foundation, and to promote awareness and understanding to the complex dynamics faced for these individuals. There is still much more to learn in this field, and more research is necessary in order to further understand the situation.

### **Recommendations:**

As stated earlier in the findings section, recommendations directly from the participants have already been shared. The following recommendations are from the researcher, who noted and observed the situation throughout the data collecting on the ways The Hussman Foundation could support children with developmental disabilities in Thailand and Myanmar.

#### 1. Understand and respect the cultural complexities:

There are 136 distinct ethnic groups in Myanmar, which are separated into 8 major national ethnic races. These different groups in Myanmar speak different languages and can have drastically varying cultures and way of life. This ethnic diversity makes the country of Myanmar culturally complex and challenging to understand. Thailand also has different cultures within the country, as the north and south and middle all have their own dialect and traditions. There may be many social factors that influence the lives of children with developmental disabilities and it important to take time to understand and respect the different ways of thinking and being in the world.

#### 2. Listen to the local people they know the situation most intimately:

A local will understand the dynamics in a society much more instinctually than any outsider. This is their life. They will have insight that someone coming in will not have. It is also empowering to individuals to be part of deciding how to establish change than being told what to do.

#### 3. Sustainability and Training:

Currently in Myanmar there are very limited options for receiving trainings on how to work with children with developmental disabilities. There are few trained individuals, leaving few options for families. A way to train and bring awareness to more people would be to have a “training for trainers” course. This would allow individuals to learn how to train other individuals, so that more information and services could be available. There is only one government special school in Myanmar, which is not enough to support every child with a developmental disability. To provide

practical information or tools for established groups and special schools that would allow them to be more equipped to offer care would also be beneficial.

Both Thailand and Myanmar would benefit from more documented data on the situation for people with disability. With a simple training, individuals could go and conduct their own research that could be added to what has already been established. There is always a need for more data especially in countries like Thailand and Myanmar that are very diverse culturally and economically.

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