

# Contents

| List of Acronyms   | 3    |
|--|------|
| Glossary   | 4    |
| 1. Acknowledgements  | 5    |
| 2. Executive summary   | 6    |
| 3. Introduction  | 8    |
| 4. Research objectives   | 10   |
| 5. Research methodology  | 10   |
| 5.1 Target groups  | 10   |
| 5.2 Data collection  | 11   |
| 5.3 Confidentiality  | 12   |
| 5.4 Community participation  | 13   |
| 5.5 Research limitations   | 13   |
| 6. Study locations   | 13   |
| 7. Analysis  | 14   |
| 7.1 Services of disabled people's organizations (DPOs)   | 15   |
| 7.2 Challenges at the family level   | 16   |
| 7.3 Challenges with health promotion and protection  | 17   |
| 7.4 Challenges with education, independent living, vocational training and livelihoods provision | ı.18 |
| 7.5 Challenges for community-based rehabilitation (CBR)  | 21   |
| 7.6 Challenges for information channels on disability services                                   | 22   |
| 7.7 Challenges for funding   | 22   |
| 8. Case stories  | 23   |
| Case Study 1: Education, mobility and physical access  | 23   |
| Case Story 2: Rehabilitation and family support  | 24   |
| Case Story 3: Sociability and the need for education.  | 24   |
| Case Story 4: Adaptive education   | 25   |
| Case Story 5: Lack of public understanding creates social barriers                               | 25   |
| 9. Conclusion  | 26   |
| 10 Recommendations   | 27   |

| 10.1 Developing training programs on disability   | 27 |
|---|----|
| 10.2 Increasing skills and raising awareness of teachers to work effectively with PWDs        | 27 |
| 10.3 Implementing disability diagnosis systems and health promotion programs in every communi | ty |
| 2   | 28 |
| 10.4 Developing common strategies of co-operation to create disability-friendly environments2 | 28 |
| 10.5 Developing networking spaces in the community  | 28 |
| 10.6 Developing information and resource centres  | 29 |
| 10.7 Strengthening and developing sustainability of DPOs                                      | 29 |
| 10.8 Initiating vocational training for PWDs  | 30 |
| 10.9 Supporting livelihood investment funds   | 30 |
| 10.10 Supporting human resource development for the employees of DPOs                         | 30 |
| 10.11 Mobilising mass media to promote disability   | 31 |
| 10.12 Establishing educational institutions on and for disability                             | 31 |
| 10.13 Challenges to protection of PWDs  | 32 |
| Annex A   | 33 |
| References  | 34 |
| Biography of the researcher   | 35 |

# **List of Acronyms**

AEP Adaptive Education Program

CBO Community Based Organization

CBR Community Based Rehabilitation

CRPD Convention on Rights of Persons with Disabilities

DPO Disabled People"s Organization

DSW Department of Social Welfare

GO Government Organization

ID Intellectual Disability

INGO International Non-Government Organization

NGO Non-Government Organization

PWD Person with Disabilities

SHG Self Help Group

TLMI The Leprosy Mission International

#### Glossary

Adaptive Education Program (AEP)

Adaptive Education Programs (AEP) provide special support services to students who have difficulty functioning in the standard curriculum due to an identified learning disability or a significant learning discrepancy. Students who qualify on the basis of psycho-educational test results and personal interviews, and who are accepted into the AEP, enroll in a Learning Strategies Class. This class combines a learning strategies/tutorial approach to developing learning and study skills which can be applied in all other curriculum areas to enhance academic performance there, as well as in real life situations.

Autism

Present from early childhood, autism is a developmental condition characterized by great difficulty in communicating and forming relationships with other people, and in using language and abstract concepts. The cause of autism in children is unknown, but the researchers generally believe that it stems from a problem in the central nervous system, not in the way parents have treated the child or in others aspects of the environment.

Institution

Any venue offering long-term residential and non-residential services for PWDs, including basic and adaptive education, and livelihoods provision.

Intellectual disability

Intellectual disability is a disability which is characterized by significant limitations both in intellectual functioning (reasoning, learning, problem solving) and in adaptive behavior, which covers a range of everyday social and practical skills. Intellectual disability forms a subset within the large universe of developmental disability, but the boundaries are often blurred as many individuals fall into both categories to differing degrees and for different reasons.

Job coaching

A range of job-finding skills workshops including CV development, application form completion, interview practice, etc.

Livelihood(s) provision

A combination of provision of vocational training and start-up capital to start own small business.

Medical schemes

Medical schemes provide some free medical costs including some operation costs, food during hospital stays and medicines.

Shelter workshop

A workshop where PWDs can produce handicrafts that are then sold through the workshop, which identifies a market for the products.

Special education

Special education is instruction that is specially designed to meet the unique needs of children which result from having a disability, so that they may learn the information and skills that other children are learning.

#### 1. Acknowledgements

Firstly I would like to acknowledge and thank those who gave their time and assistance to help further this research. I would also like to thank the people who participated and gave up their time in the interview sessions and focus group discussions. I would especially like to thank those who were kind enough to allow me to conduct private sessions.

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Finally, I would like to thank Internships Asia and Hussman Foundation for kindly providing a small grant to support this research study.

#### 2. Executive summary

This predominantly qualitative research on disability and development in Myanmar was conducted between August 2011 and February 2012, in three commercial centres of Yangon, Mandalay and Taunggyi. Stakeholders of service providers, persons with disabilities (PWDs) and families of disabled people were interviewed in order to discover the needs and challenges that they face. Discoveries were made concerning independent living and adaptive education, vocational training and livelihoods challenges, community-based rehabilitation, organisational and human resource capacity, and information channels, networking and cooperation between organisations.

The study found that PWDS, especially those with intellectually disabilities, need training for independent living, adaptive special education, motor development programs and behaviour modification programs in special institutions. Effective services and programs are necessary in all of these areas of need.

The second priority is the need for basic and advanced vocational training programs for both disabled people and their families. A variety of programs need to be followed up by job coaching programs and job placements in both the government and private sectors. The service providers should especially analyse the existing range of adaptive vocational trainings available and the current market demand for establishing vocational training in a wider range of subjects.

Livelihood challenges of PWDs and their families are another serious factor. It was found that there are only a few supporting organizations providing livelihood programs for PWDs and their families, but they do not have enough funding to support and promote livelihood programs fully in the community. Limited funding resources and low donor interest in disability are some of the reasons that have affected the struggle of service providers to initiate livelihood programs in Myanmar. There is also limited organisational and human resources capacity building available to disabled people"s organizations. The poor quality of financial support and resources has resulted in organizations facing an acute shortage of adequately skilled personnel and consultants, to not only generate funds but also to effectively meet the needs of people with disabilities and their families.

Another challenge to dealing with disabilities is a lack of information channels and media portals in Myanmar that might raise awareness and provide a function for advertising and connecting with a wider range of stakeholders. The study found that the networking and cooperation between stakeholders including international non-government organisations, local non-government organisations, government organisations and disabled people"s organisations in Myanmar is weak. Additionally, the government does not offer any guidance or encouragement for the growth of networking space for stakeholders to collectively support disability. It is also vital that PWDs are able to access information and services just like any other citizens, so there needs to be increased development of communication methods to reach people with all kinds of disabilities, for example, sign language-supported media and

television programmes. It must be remembered the great influence media has on people in society. It can advertise, promote public awareness and provide methods to share essential information and different perspectives, making it an ideal inclusion tool.

Only a few institutions are available for people with hearing and visual impairments, and physical and intellectual disabilities, and cannot provide skills and knowledge training for the families of disabled people to better meet the needs of their disabled family members. There has been no nationwide initiation of community-based rehabilitation. As a result, families have difficulty accessing information, services and home-based intervention programs, which contributes towards a lack of awareness about how to assist and deal with disability-related challenges in their families and in society. Community-based rehabilitation is a valuable model of intervention as it provides awareness, protection and empowerment to people with disabilities and their families in society. Thus it is important that community-based rehabilitation programs are available for families and PWDs, as these can be an ideal program model to provide the necessary information and services to effectively support disability in society.

Health and rehabilitation services are one of many major factors that can determine mobility challenges and improve PWDs" life-skills and integration into society. Thus, health services need to promote and support effective health schemes and occupational training throughout the different regions of Myanmar.

Communication between PWDs and society is a major concern, as without sufficient knowledge of the needs and problems of PWDs it is impossible to provide services, programs and policies that can support and find solutions to those needs. Lack of communication causes ambiguity, and creates loosely-supported and implemented strategies, techniques and policies. Therefore, more research would increase the existing data pool, which in turn could become a foundation for defining and creating service goals and strategies that can develop stronger support for all aspects of disability in Myanmar.

Finally, whilst the challenges facing the development of the country as a whole are recognised, not just for people with disability, so to is the need for PWDs" purposeful inclusion throughout the development processes.

An analogy given by an interviewed mother of children with intellectual disabilities, comparing their lives with boats: "The lives of children with intellectual disability are like boats without an oar; they can propel or steer to nowhere, they can float along the stream or flow with the tide. If they are faced with large waves, they can "t help but sink. Only if they" re tied to other boats with oars can they be steered to shore."

# 3. Introduction

Myanmar has a population of 48.3 million people, of which 66% reside in rural areas (UNFPA, 2011). Disability and development in Myanmar is greatly under-researched. The First Myanmar National Disability Survey was conducted by the Department of Social Welfare (DSW) and The Leprosy Mission International (TLMI) between 2008-2009 (DSW and TLMI, 2010). According to this survey, a total of 2.3% of Myanmar"s population have some form of disability. Of this, 68.2% are persons with physical impairment, 13.3% are persons with visual impairment, 10.4% are persons with hearing impairment and 8.1% have some form of intellectual disability.

This research on disability and development in Myanmar was conducted using predominantly qualitative methods, between August 2011 and February 2012. Service providers, persons with disabilities (PWDs) and families of disabled people were interviewed in the commercial centres of Yangon, Mandalay and Taunggyi, in order to discover the needs and challenges that they face in their daily lives. This study discovers that, as there are currently only limited services provided in the community for disabled persons, certainly disability will become a great challenge for the whole country in the future. Hence, there is great demand for more social research on disability.

In Myanmar, someone with disabilities might face discrimination on many levels, within their families and communities, at the regional level and also at the national level. Most disabled people suffer from some discrimination or/and exclusion, but the degree and severity often depends on the nature of their impairment and their varying personal situations. Disabled children and women are particularly vulnerable.

A further problem impacting upon the lives of people with disability is that there is hardly any partnership, co-operation or information sharing between international non-governmental organizations (INGOs), non-governmental organizations (NGOs), government organizations (GOs) and community-based organizations (CBOs) in Myanmar. This results in service providers and organizations being ill-equipped to support the disabled, having under-developed conceptualizations on disability. The lack of information sharing leaves organizations with inadequate knowledge to support the necessary foundation of community-based rehabilitation (CBR) programs and projects across all of the different regions of the country.

Myanmar is presently going through a critical social and political transition, and is leaning towards a democratic Myanmar that is seeking to improve the country socially and economically. The Government of the Republic of the Union of Myanmar, newly elected in October 2010, has already initiated ensuring the rights of people with disabilities, at the national level through to the international

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<sup>&</sup>lt;sup>1</sup> The proportion of disability amongst the world"s population is 15% (WHO, 2011.) However, criteria to measure disability in Myanmar differs to the usual international criteria. It includes persons with functional impairment due to a range of disabling conditions, regardless of age, but specifically does not include persons with limited function as a result of chronic diseases such as heart disease, HIV/AIDS, depression or general age-related debility.

level.<sup>2</sup> The Myanmar government signed the Bali Declaration on Inclusive Development for People with Disabilities<sup>3</sup> on November 17, 2011, and the Convention for Rights of Person with Disabilities (CRPD) on December 7, 2011. Yet, until now, there is a lack of research and recommendations to establish an inclusive development program for those with disabilities in Myanmar.

In addition, there has been no sufficient case study on equal rights and full participation of disabled people from which one may make reference. It is important that the public and the government become aware of the social implications of disability and that they gain knowledge of the capacity and effects of different rehabilitation services for PWDs in Myanmar. Before we even begin to build the foundations of these services, service providers must have firm understanding of the best strategies to approach disability in Myanmar, and there must be familiarity with appropriate methodologies to use to support the needs and challenges of PWDs and their families.

Therefore, the goal of this research is to inform families of people with disability and service providers of the needs and situation of PWDs to enable them to offer better support and more adequate services. Some of the questions that the research aims to answer are: How are disabled persons and their families coping in their communities? What are the greatest challenges that they face? What are their short and long-term needs? A further aim of the study is to provide a clearer picture of the situation of people with disability in Myanmar today. It was discovered that as a result of a combination of the lack of research, and limited co-operation and information sharing between different organizations, there is little accurate information on most disability services. Therefore, some organizations have been supporting the same activities, causing duplication of services and support. In some cases, the same organizations have been visiting the same locations, collecting the same data and even promising the same support to PWDs without any continuation. Consequently, many PWDs and their family members lose faith with these service providers.

<sup>&</sup>lt;sup>2</sup> Mechanisms to secure education for PWDs were enacted by previous governments, but implementation was hindered by economic and social constraints. For example, Myanmar''s Basic Education Law of 1973, amended in 1989, states main objectives as including ,to enable every citizen...to become a physical or mental worker well equipped with a basic education, good health and moral character" (UNESCO, 2011). Article 20 of Myanmar''s Child Law, enacted in July 1993 as a mechanism through which to implement the rights of the child recognized in the Convention on the Rights of the Child (acceded to in 1991), states that "every child shall have the opportunity of acquiring education" and that "the Ministry of Education shall...make arrangements for children who are unable for various reasons to attend State schools, to become literate." Article 18 further stipulates that a mentally or physically disabled child (a) has the right to acquire basic education (primary level) or vocational education at the special schools established by the Department of Social Welfare or by a voluntary social worker or by a non-governmental organization; and (b) has the right to obtain special care and assistance from the State. (UNESCO, 2011.) Finally, Section 32 (A) of the 2008 Constitution of the Union of Myanmar states that "the State has the responsibility to take care of mothers and children, orphans, children of deceased military personnel, elderly people and persons with disabilities." The Department of Social Welfare has the primary responsibility to fulfill this mandate. (UOM, 2008.)

<sup>&</sup>lt;sup>3</sup> The full title of the Bali Declaration is the "Bali Declaration on the Enhancement of the Role and Participation of the Persons with Disabilities in ASEAN Community".

I believe that this research is a major instrument that will shine a light on the lives, challenges and needs of PWDs and their families, on the expectations placed on PWDs by their families and in the community, and on the challenges and needs of service providers.

#### 4. Research objectives

The purpose of this research is to discover "What kind of services are provided for people with disability in Myanmar, and how can the services be improved?" Research objectives are:

- 1) To investigate the types of services available for disabled persons and their families in 3 locations in Myanmar.
- 2) To investigate the challenges and needs of service providers, PWDs and families of PWDs in their communities.
- 3) To identify appropriate social and rehabilitation services for PWDs.

#### 5. Research methodology

Research data collection and analysis took place over 7 months, between August 2011 and February 2012. Many field-trip visits to Yangon, Mandalay and Taunggyi were conducted, and data collection methods of interview and focus group discussion were used. The study relied upon triangulation methodology between the three target groups (PWDs, their families and service providers), to examine and investigate the needs and challenges of PWDs. Collected data variables were coded and analyzed using Microsoft Excel, after being checked for data errors.

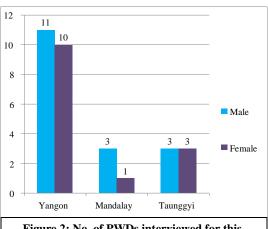
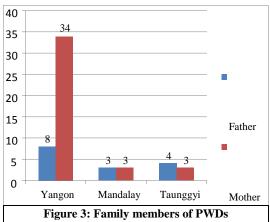


Figure 2: No. of PWDs interviewed for this research

#### 5.1 Target groups

31 people who have disabilities and 55 of their families were interviewed and participated in focus group discussions, and 29 organizations providing services for people with disability were also interviewed. Of the twenty-nine service providers, five were government institutions or organizations (GOs), seven were international non-government organizations (INGOs), and three were private organization and fourteen were



(national) non-government (NGO) Disabled Peoples" Organizations (DPOs).

Of the thirty-one people with disabilities who were interviewed, seventeen were male and fourteen were female. Eleven males and ten females were from Yangon, three males and one female were from Mandalay, and three males and three females were from Taunggyi. The interview included 42% are Intellectual disability, 39% are Physical Impairment, 10% are Visual Impairment, 6 % are Hearing Impairment and 3% are Children with Autism. In addition to analysis of interview data, this research includes the case stories of five interviewees.

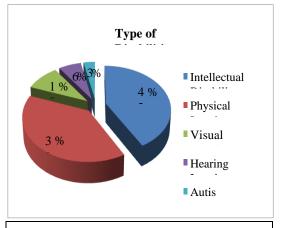


Figure 4: Type of Disabilities interviewed

#### 5.2 Data collection

In preparation for conducting the research in the 12 target areas on research objectives 1 and 2, the researcher and a networking consultant contacted DPOs and met with selected volunteers who would assist the researcher to conduct the survey. Guidance was given to the assistants, who were all family members of PWDs or community volunteers, on how to clearly inform PWDs and their family members of the survey and its aims. Meetings were arranged in interviewees" homes or in community venues. A great deal of care was taken to be gender sensitive, and also to actually include PWDs in

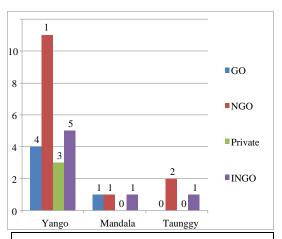


Figure 5: Service providers interviewed

in-depth interviews and focus group discussions, rather than just their family members and/or service providers.

The data was collected through the medium of in-depth interviews and focus group discussions that were guided by questionnaires with mainly open-ended questions. Three individual questionnaires were created and used for services providers, PWDs and the families of PWDs, which were pre-tested in Yangon with two DPOs, five PWDs and five families of PWDs.

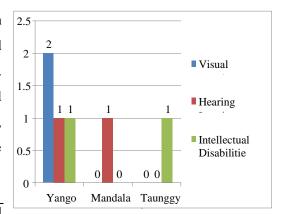


Figure 6: Type of Institution interviewed

#### Questionnaire categories were:

- 1) Demographic information, including the age and gender of PWDs, gender of interviewee (if not PWD) and region.
- 2) Medical history of the PWDs and their families, including pre-natal, natal and post-natal health issues.
- 3) Service provider information such as organization names, length and type of services provided to PWDs.
- 4) How families have been affected by disabilities and the impact upon their socio-economic situation.
- 5) The personal perspective and suggestions of PWDs and their families on the issue of disability in Myanmar.

Three focus group discussions, in which PWDs and their families shared their different experiences and perspectives, were conducted in Yangon, Mandalay and Taunggyi. The focus group meetings were conducted with four PWDs and twelve family members from Yangon, nine family members from Mandalay and eight family members from Taunggyi.

To answer research objective 3, the researcher drew on previous practical experience working in India with a DPO implementing CBR, and conducted a literature review on the use of CBR in Asian contexts.

#### **5.3** Confidentiality

Precautions were taken before beginning the interviewing process to ensure the safety of the interviewee. Before each interview the researcher explained the research content and the possible benefits the research might have on the disability sector in Myanmar to the interviewee. It was also explained that names and addresses of PWDs and their families, employment positions of service

provider employees, and any other details that were not relevant to the study, except any which were willingly expressed, would not be included. Where conversations of some respondents were recorded, this was done with their permission. For case stories, interviewee face-photos and real names have only been used with permission.

# **5.4 Community participation**

During the interview sessions in Mandalay and Taunggyi, family members and volunteers participated in the research process by accompanying the researcher on home visits to collect data and sometimes facilitated focus group discussions.

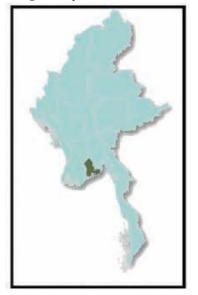
#### 5.5 Research limitations

The people with disability and their families who participated in this research were accessed via their involvement with service providers or self-help groups (SHGs). Therefore, as the majority of disabled people in Myanmar do not receive any support from service providers or SHGs, research respondents cannot be said to be representative of all people with disability in Myanmar.

When conducting this research, the researcher faced challenges to encourage PWDs and their families to articulate their challenges and needs, and to collect data from DPOs in the different areas. The PWDs and their families had not previously experienced participating in interviews or focus group discussions, and were unfamiliar with expressing their opinions about the issue of disability and their wants and needs, and they understand little of their rights in the community. Some DPOs are reluctant to share information on their programming and networking activities, and no existing data on PWDs and their needs could be shared by DPOs, as it is not systematically collected.

# 6. Study locations

Yangon city, also known as Rangoon, was Myanmar"s capital city between 1885 and 2006, and



currently still serves as the commercial capital of Myanmar and a hub for social interactions. The population of Yangon is over four million, and it continues to be the country slargest city and the center of economics, and business trading. Yangon hosts many national and international organizations operating in social development and the humanitarian aid sector. These include donor agencies, International Non-Government Organizations (INGOs), (national) Non-Government Organizations (NGOs) and many organisations providing services for PWDs, including various rehabilitation institutions. The proportion of people living with disability in Yangon Region is recorded at

Mandalay city is the Mandalay Region capital, and was founded as a royal national capital on 13 February 1857 by King Mindon, at the foot of Mandalay Hill. When it was founded, the royal city was officially named Yadanabon, meaning "The City of Gems". Presently, Mandalay is the second largest city and is situated on the east back of the Ayeyarwaddy River. The city has a population of over one million people, and remains the main commercial, educational and medical centre of upper Myanmar. 134,445

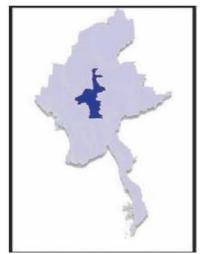
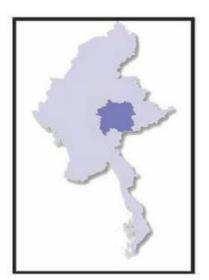


Figure 8: Mandalay Region

(1.76%) of Mandalay Region"s population have been recorded to have some form of disability. (DSW and TLMI, 2010.)



**Taunggyi** city is the capital of the ethnic Shan State. Taunggyi"s population is estimated at about 210,000, making it the fifth largest city in Myanmar. The city lies on a wide shoulder that supports the Sintaung Hills of the Shan Plateau, and is populated by peoples of many ethnic races. In the southern area of Shan State, 34,664 (1.61%) people have been recorded with some form of disability. (DSW and TLMI, 2010.)

Figure 9: Shan State (south)

#### 7. Analysis

The research addresses the three research objectives such as:

**Research objective 1**, to investigate the types of services available in the community for disabled persons and their families in 3 locations in Myanmar, is answered by analysis point 5.1, "Services of disabled people"s organizations".

**Research objective 2**, to investigate the challenges and needs of services providers, PWDs and families of PWDs in their communities, is answered by analysis points 5.2, "Challenges at the family level"; 5.3, "Challenges with education, independent living, vocational training and livelihoods

provision"; 5.5, "Limited information channels on disability services"; 5.6, "Challenges for funding", and 5.7. "Challenges in protection of PWDs".

**Research objective 3**, to identify appropriate social and rehabilitation services for PWDs, is answered in analysis point 5.4, "Challenges for community-based rehabilitation".

# 7.1 Services of disabled people's organizations (DPOs)

The results of research objective one, to investigate the types of services available in the community for disabled persons and their families in three locations in Myanmar, are based on data collected by interviews with representatives from DPOs from seventeen NGOs, seven INGOs and five GOs based in Yangon, Mandalay and Taunggyi. Service provision, which was shown to be inequitably spread across the three locations, was revealed in four sectors of health, educational, livelihood and empowerment services.

The first type of service provision identified amongst the DPOs is in health services, provided by 62% of service providers. Health services provide assistive devices, referral (for assistive devices, vocational training, health, etc.), and physical rehabilitation and psychological support. Rehabilitation services and support include physiotherapy, health interventions (including nutrition and other health

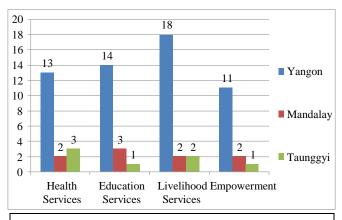


Figure 10: Number and types of services provided

education for mothers), occupational therapy, counseling, limited financially-supported medical schemes (including some operation costs, food during hospital stays and medicines), family and community disability awareness programs and community and national-level sports programs (including for the Special and Para-Olympics). Thirteen health services are provided in Yangon, whilst only two are provided in Mandalay and three in Taunggyi, which only have access to physical therapy (physical rehabilitation) and medical schemes.

The second type of service provision identified is educational services (62% of service providers provide educational services), which include institutional and inclusive education. Institutional special education (primary through to high school-level) for people with intellectual disabilities exists in Yangon only, and is provided by 2 government schools (one residential, one non-residential) under the Department of Social Welfare (DSW), 5 private schools and 5 NGOs. Inclusive education through mainstream schools, supported by NGOs and GOs with special education approaches for different

disabilities, educational grants and the creation of physical barrier-free environments, can be accessed in all three locations. Other educational services include the provision of special educational trainers for service providers, and quality programs on physiotherapy, occupational therapy and speech therapy, all of which are based in Yangon.

Two educational institutions for people with visual impairment and one for people with hearing impairments are available in Yangon through NGO and GO providers, and another service for people with hearing impairments is available through a GO provider in Mandalay. No services for people with hearing or visual impairments are available in Taunggyi.

The third type of service provision identified is livelihoods programs (provided by 59% of service providers), which includes basic vocational training and financial support to begin small businesses. Again, most (76%) of the learning institutions available for vocational training are based on Yangon. Different vocational training subjects are available, such as computers, electronics, tailoring, silkscreen printing, hairdressing and traditional Japanese massage. 35% of livelihoods provision organisations support PWDs with small loans to be used as start-up capital to initiate their own businesses or group businesses through self-help groups (SHGs).

SHGs are often initiated by DPOs through empowerment programs, the final type of service provision. As well as acting as a mechanism through which to transfer funds, SHGs can also be utilized to increase community peer-support networks. In this way, SHGs focus on strengthening the PWD"s place in the community and conducting referrals, and support the sharing of information and resources at the community level. SHGs primarily exist in peri-urban areas.

#### 7.2 Challenges at the family level

The research discovered many challenges and obstacles at the family level for someone with disability, and highlighted the challenges and problems that PWDs and their families might have to deal with when integrating in the community. Results are based on data collected by interviews taken with family members of PWDs.

The majority of families (69%) admitted difficulty in controlling the aggressive behavior and hyperactivity of their disabled child. In addition, 90% of families were worried about lifetime care for the disabled child, for example, the necessity of one family member having to care for the disabled child for the rest of his or her life. 71% families caring for PWDs are often prevented from participating fully in family and community activities and functions by the demands of care, and, in some cases, shame, as a result of lack of understanding regarding the cause of disability. Reduced participation in community activities often leads to further isolation and discrimination from the community.

Interviews showed that mothers have the main responsibility in society (73%) of caring for PWDs. As a result, mothers tend to be those most deeply affected by the depressive and/or aggressive behaviours displayed by the disabled person. Additionally, having a disabled child has forced many mothers to resign from their professions, jobs and businesses, as they do not have the time or energy to work when they are constantly caring for their child. Therefore, it is disproportionately the mother who loses her opportunities for investment in education, work and social participation.

Carers, including mothers, do not have access to knowledge about behaviour modification, early intervention and home-based intervention for PWDs, and as a result they are not able to train and deal with PWDs at home appropriately or effectively. In addition to this, the majority do not have access to information about communication techniques like sign language, nor services such as special education, physical education, training centres and institutions.

Parents of disabled children claim that their loss of employment and income adversely affects their child and family"s quality of life. If both parents are unable to work, their ability to save sufficiently for their family"s survival and future is greatly reduced. In turn, the education, health and livelihood of further siblings can be negatively affected, as, for example; school fees and fees necessary for transportation to school are very expensive for the average family, even if both parents can work.

Worries by most parents about their disabled child"s future is expressed when they say, "Where will we take our child [to be looked after] when we die?" Families are not trained how to impart daily living and vocational skills to their disabled children, or do they know how to teach their disabled children to live life independently or how to generate income.

#### 7.3 Challenges with health promotion and protection

Myanmar hasn't developed a medical disability diagnosis system on which doctors are trained to base diagnosis of disability within the pre-natal, natal and post-natal periods. As a result, pre-natal, natal and post-natal medical checks are unable to systematically diagnose disability. One mother of four children living in Taunggyi said that doctors told her during each annual visit to the clinic that her daughter, who the researcher believes has Down's syndrome, will be fine and will develop like any other typical child. At birth, the girl weighed at over 7 lb. but she did not develop as expected like other children. As the mother had previous experiences with other children, she knew the girl was definitely different so visited many doctors in Taunggyi and Yangon. Doctors prescribed many pills to take every day and always said she will be fine. Also as a consequence of the lack of a diagnosis system, society holds many different beliefs about disability and its causes. As an example of the different beliefs held and the lack of understanding of the causes, one family member expressed that "At first, we were very poor; but our [disabled] daughter came from her past life, bringing with her all

her good luck and property. After we had this child, we started to earn a good income and succeed in our business."<sup>4</sup>

The research indicates that most mothers from urban areas are able to access health education and intervention programs. Thus they can attend healthcare centres and make regular medical check-ups. However mothers from the rural areas around the 3 locations researched were shown to have difficulties in accessing healthcare and health education programs.

31% of families of children with intellectual disabilities and autism state a lack of adequately-trained medical doctors who can understand the nature of their child satisfactorily. For example, children with intellectual disabilities and autism have a tendency to refuse injections and taking prescribed medicines. One mother said, "I am very scared that my child will eventually get a fever. The doctors really want to treat him, but he really dislikes taking his medicine and he cannot control his aggressive behavior." <sup>5</sup>

Finally, protective services for PWDs in Myanmar are not well developed, neither within the service sector nor at the level of the medical and legal professions.

Female PWDs can be vulnerable to sexual attack. However, because implementation of law in Myanmar needs to be strengthened, people who commit violence towards PWDs are not always arrested and charged. Additionally, families claim that they often cannot afford to pursue cases through the legal system. In order to protect female PWDs, families often resort to extreme measures which will prevent pregnancy. One mother said, "When our daughter was 12 we decided to send her to a private orphanage/day-care centre for academic learning. Then one night she told us that she had experienced a serious act of violence that day at the centre. However, we had previously arranged for her to have an operation to remove her uterus."

### 7.4 Challenges with education, independent living, vocational training and livelihoods provision

Service providers state that education is of the utmost importance for PWDs in creating the foundations for social skills, academic skills, economical skills, independent living and vocational training. Yet, the research discovered that there are few educational institutions for the disabled in Myanmar able to offer components of this range of education, those that do exist being located in Yangon. Additionally, the national education system is not, on the whole, inclusive for disabled students, and presents many difficulties and obstacles to those PWDs who attempt to access mainstream education. Consequently, the majority of PWDs in other areas of country, where the only other alternatives are limited adaptive

<sup>&</sup>lt;sup>4</sup> Interviewed mother from Mandalay (February 2012).

<sup>&</sup>lt;sup>5</sup> Interviewed mother from Yangon (December 2012).

(special) community education, have little access to either formal or informal education. But even where PWDs have geographical access to institutions and special schools, many families who believe in the value of education (51%) for PWDs still cannot access it as they are unable to support the expensive school fees, accommodation, and transportation fees. In fact, the high expense of most special schools means that many PWDs rarely attend higher education, which is contributed to by a scarcity of scholarships. Consequently, the education of many children with disability depends on their family's economic status.

Yet, through being able to access schooling, PWDs gain not only education, but also the opportunity to socialize and make friends with those of a similar age, and a comfortable space to interact with others whilst practicing important life-skills. The leader of Unity Self Advocacy Group of Intellectual Disabilities said, "I would love to be able to meet with friends. If I stay at home, I feel lonely and bored, as I have nothing to do. Without any peer group activities or interactions with my community, I find staying home meaningless for my life. However, I am enjoying being with friends in school and this has become my life and my world."

Many PWDs perceive the necessity of a wide range of education, both basic and adaptive, including vocational training, in order to support independent living skills and long-term learning. (87% desire vocational training for their short and long-term life improvements.) Yet, some feel that when they become adults, they do not have the skills required or the social abilities to relate to others in the community. 49% of family members state PWD"s need for independent living skills and life-long training, and 51% want their child to attend adaptive vocational trainings for independent living. Additionally, many family members believe that if PWDs can achieve this independence, then pressure on family carers would reduce, allowing the carers to focus on providing for the family financially.

However, although PWDs and their families recognize some PWDs as slow learners and perceive the value of education, and especially educational institutions, in maintaining skills through life-long education, they express fears of the long-term effects of increased isolation from society that institutionalization, residential and non-residential, brings. On the part of the families, these include fears of PWD's reduced confidence to communicate with others and further lowered self esteem, which could result in increased difficulties to gain basic vocational training which would further impact upon their isolation from the community. Many PWDs themselves state that they would prefer not to become residential students, with 31% desiring instead to gain the skills to reduce their dependence on their families and to live independently in society, able to make decisions about their own life and eventually having a personal income that will support them and increase their self-esteem. People with mild intellectual disabilities also explained that they want to be able to communicate with their peers and to be part of the community. Yet, a lack of peer workshops or shelter workshops for

PWDs will continue to make institutions attractive not just to child orphan PWDs and PWDs with moderate or severe disability, but to adult PWDs with mild disability, with or without families.

Vocational training service providers in Yangon target not only PWDs, but other groups such as people living with HIV/AIDS (PLHIV) and street children, and consequently, competition for market access is high. PWDs report that vocational training provided in institutions tends to rely on basic or outdated techniques, and is therefore be inadequate. 9% of vocational training institutions report that there are limited job opportunities for those with disabilities.

In order to provide relevant livelihood support for PWDs, PWDs state the need for selected vocational training subjects to be based on market analysis, training for which also needs to be integrated into the program to provide PWDs with skills to conduct market analysis independently, which will allow them to initiate their own businesses with start-up capital provided by the service provider. (39% of PWDs claim a need for livelihoods programs to enable them to earn their own incomes and participate equally in economic life. Service providers shared the same view, many stating that PWDs also require job opportunities to give them independence in the community and that they need livelihood support for long-term survival.) Job coaching programs should also be available through the institution for VT graduates, and, where there are limited job opportunities, shelter workshops (where PWDs can produce handicrafts which are then sold through the workshops) need to be initiated. Vocational training needs to be preceded by pre-vocational training, to enable PWDs to gain functional skills (including basic literacy, numeracy and financial management, to prepare them for vocational training), social and life skills, and independent-living skills.

Families of PWDs unable to benefit from livelihoods provision, such as those with intellectual disability and other moderate or severe disability, expressed a need for access to indirect livelihood support to reduce financial pressure to the families, enabling them to better support their disabled family member.

However, the majority of service providers were found to be having great difficulties in livelihoods provision, as there is a lack of advanced vocational skills programs, funding and human resources are low and networking between various vocational training providers in Myanmar is weak.

#### 7.5 Challenges for community-based rehabilitation (CBR)

The World Health Organization (WHO) promotes community-based rehabilitation (CBR) as an inclusive, participatory strategy to improve access to rehabilitation services for PWDs in low-income and middle-income countries (WHO 2010).<sup>6</sup> WHO, on its CBR website, describes the strategy as such:

"Community-based rehabilitation (CBR) focuses on enhancing the quality of life for people with disabilities and their families, meeting basic needs and ensuring inclusion and participation. CBR was initiated in the mid-1980s but has evolved to become a multisectoral strategy that empowers persons with disabilities to access and benefit from education, employment, health and social services. CBR is implemented through the combined efforts of people with disabilities, their families, organisations and communities, relevant government and non-governmental health, education, vocational, social and other services." (WHO, 2012)

Interviews with service providers highlighted that the majority are aware of concepts of CBR, but few provide the full complement of services of health, education, livelihood, social and empowerment, tending to focus just on health and education. (See Annex A for a matrix produced by the World Health Organisation of integral components of community-based rehabilitation.)

One director of an INGO who is implementing a CBR project in a rural area in Shan State said, "The value of CBR is that it is a good strategy to include PWDs and their families in implementing services, empowering and promoting their rights, ability, willingness and minds to be independent in society. However, there are few CBR programs in Myanmar and we still need more ways to apply the professional skills that staff of service providers have qualified for inside and outside the country. If there are many CBR programs for the disabled in Myanmar, then a higher percentage of PWDs will find accessing information and rehabilitation services in their community easier and faster".

A further challenge impacting upon the quality of services provided to PWDs is that service providers lack human resource knowledge capacity about disabilities. 40% of service providers state that their staff members are not professionally trained to implement community rehabilitation and social services, and that most staff members struggle by with only experience as their learning tool. As a result, DPOs find it difficult to establish projects in new areas. To address the knowledge gaps in this sector, academic curricula and courses must be developed for university-level students wanting to study disability-related studies in Myanmar.

<sup>&</sup>lt;sup>6</sup> CBR is currently being promoted as a rehabilitation strategy for PWDs in Cambodia, Thailand, Vietnam, Malaysia, Laos, India, Bangladesh and Sri Lanka.

The research shows that, in the 3 field study locations, there is only one institution providing training about rehabilitation techniques to family members, in Yangon<sup>7</sup>. Family members of PWDs state that they want to learn the correct skills, knowledge and techniques to assist their children at home through home based interventions. This is especially vital for parents struggling alone as there is hardly any training or assistance for them. Again, to address this gap, service providers need to provide advanced training programs about rehabilitation techniques including special education training, speech therapy, and occupational therapy.

#### 7.6 Challenges for information channels on disability services

Interviews with both PWDs and their families revealed 37% believe rehabilitation services are implemented by non-government organizations and another 37% are unaware of any providers of rehabilitation services for PWDs in Myanmar. 13% believe that INGOs implement rehabilitation services in their community and only another 13% were aware that GOs implement rehabilitation services for PWDs in Yangon.

Many PWDs and their families depend on TV programs to provide them with information concerning disability. However, as only 49% of the national population has access to national-grid electricity (MNPED et al, 2011), it can be surmised that similar proportions have access to TV, and that, as a result, the majority of the population is denied access to this information channel. Moreover, as Myanmar TV currently has no sign language channels, access to this information is prevented for people with hearing impairments.

A country director from an INGO said, "There are a lack of [TV] channels and [information] portals that can give education and awareness information about disability. People with disability are isolated from the community, and in turn society also does not understand or have awareness about their different behaviors and situations, their ways of thinking and communicating, and their needs. As long as we can access media, it can be an important channel and tool for information, where we can evaluate and brainstorm different strategies to change the perception of society [on disability]."

#### 7.7 Challenges for funding

Many DPOs are struggling to secure funding from donor agencies and INGOs. They are hindered by a lack of information about these funding resources, funding policies of donor agencies and experience to complete funding applications. The lack of funding for disability projects has a direct effect on the sustainability of DPOs in the community. If they do not have enough funding, the organization may

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<sup>&</sup>lt;sup>7</sup> Eden Centre, Yangon.

cease its operations. Even if they are strongly dedicated to supporting disability and development, without funding it is impossible to run a service.

Additionally, DPOs have little or no access to capacity building training such as proposal writing, project cycle management, fundraising, sustainability and disability leadership training that could support them to effectively implement projects for PWDs.

#### 8. Case stories

#### Case Study 1: Education, mobility and physical access

Daw Than New Aung suffered poliomyelitis when she was 3 months old. Her mother resigned from her job as a tutor to take care of her daughter until she passed her matriculation exams. Although her parents worried about her, Daw Than New Aung had ambitions to go to university and gained a place at the Yangon Economic University. She graduated in 1978.

She shares her experiences attending university, "When I started studying in Yangon, I never expected to be able to live without my family. Even so, I tried to stay at a hostel of the university. On my first day of class I had no friends, but my classmates supported me to get to the classes, looked after and took care of me, loved me and became my friends." After she graduated, she couldn't get a chance to work in the private or government sector. But she took classes of LCCI (UK) training, and after passing all 3 levels, she set up a LCCI training centre in Taunggyi.

Daw Than New Aung came face to face with many problems whilst living in Yangon; one was the physical challenge of accessibility. She gave one example, "When I visited Bogyoke market, I couldn't go to the shops up-stairs as I was in a wheelchair. My sister, who accompanied me, couldn't help me as she wasn't strong enough, and no one offered us any help."

The same thing happened when she went to the pagoda. She couldn't go up the steps leading to the stupa. While many people stood around just looking at her, two western tourists helped her up the steps. She shares her disappointment about the situation and comments, "Most of my own society needs to know they must assist people with disability... I had a vacation in Singapore, and visited many places without difficulties. When I was at the airport to take a flight coming back, the Myanmar airline even asked for a medical certificate... Awareness on disabilities needs to raised within the public and business sectors."

#### Case Story 2: Rehabilitation and family support

Maung Hla Swe is a twenty-two year old male with intellectual disability who lives in Mandalay with his brother in their relatives" house. He also has a sister, but their parents passed away when he was young. He had no experience of family life, and the relatives didn"t know how to deal with his behaviour and found it very hard to control. In 2010, he began attending a school for the hearing impaired in Mandalay, giving his family more time to go to work during the day.

The school for the hearing impaired provides special education, social activities, and activities of daily living (ADL) skills. Although his family didn't expect the school to be able to improve his aggressive behaviour, his self-control, and consequently his social life, improved.

During his time at the school, his uncle supported him with his school bus fare and food. His relatives think that Maung Hla Swe will need life-long care, if possible in a residential institution. If an institution can provide this sort of life-long care, then his brother would be able to work independently and have a healthy social life whilst knowing that Maung Hla Swe was living in a safe environment.

#### Case Story 3: Sociability and the need for education

Maung San Htwe is a 23-yeaer old male with an intellectual disability who lives in Yangon. He often plays football with his friends on Insein's sport centre field.

He explained his improved situation, "My family allows me to go out on my own now. I have friends and I"ve met many people who love me." He feels he should and wants to get a job, he commented, "Sometimes my family needs more income for survival. I can"t support them, and I also don"t have enough money to go to the football field." He continued, "So, for that reason sometimes, I also don"t want to stay with my family all the time." He explained that wants to live with his friends and supporters who will be patient and understanding towards him.

He said, "I really want to go to school but there are no school which will accept me. Sometimes the reason they give is that I can"t speak well but that is because no one has taught me how to speak. So I end up spending most of my time at home. When I see kids going to school, I envy them. However my family don"t care about me, sometimes they told me that they have no money or there is no school for me. My unhappy days will never end."

#### Case Story 4: Adaptive education

Maung Minn Swe Htet is a 22-year old male who lives in Yangon. When he was only days old he contracted kernicterus, a neurological condition which causes brain damage, and started have seizures after 2 days. He was admitted into a baby unit in a hospital for a month. As he got older, he developed an intellectual disability.

When he joined preschool at 5 years old, Maung Minn Swe Htet was very hyperactive and played a lot. But he found lessons difficult and couldn't learn how to write or follow lessons. He had a poor memory, so poor that he couldn't remember simple things like where he put his pencils or shoes. His family decided to send him to a mainstream school until grade three (8 years old). He became depressed that he couldn't complete his schoolwork like other children, so in 1998 his parents, referred by a family doctor, sent him to the School for Disabled Children (SDC) where he learned slowly and had some improvements in his academic and social life, and became independent to some extent. Although he was still hyperactive, there were some positive changes in his behaviour. He started receiving vocational training and gaining chances to participate in community activities through learning adaptive life skills and modifying his behaviour. His parents suggested that poorer families should be supported for their livelihood. They said, "If we had had any financial difficulties, we would never have been able to send him to school or let him participate in school trips or activities. Then he wouldn't have developed or improved as much as he has right now."

#### Case Story 5: Lack of public understanding creates social barriers

Kyaw Kyaw was born in Mon State and is a program director of a resource centre for people with hearing impairments. He and his 7 siblings are all deaf. They had to struggle a lot to survive, and they faced even more difficulties financially and socially than other families.

Kyaw Kyaw completed primary through high school education in mainstream school. He then went on to study civil engineering at a government technology institution. He found the work and learning was more difficult for him than his classmates as he couldn't hear the teaching properly. He said, "I doubled my efforts and I was able to graduate with a Diploma in Civil Engineering in 2000."

Although he succeeded in education, he said he faced a lot of other challenges in the working world, "As disabled people are still not included in the government"s social and occupational policies, we can"t utilise our abilities in society and the working world as much as we"re able to."

Discrimination against disabled people is still present in society. For example, deaf people have been prohibited from opening bank accounts by bank managers who believe that deaf people are unable to

take care of their own affairs, and are then affected by a policy from the Ministry of Statistics which states that those who are unable to take care of their own affairs are not allowed to open a bank account. "We don"t have a mental illness, nor are we people who can"t live independently," he said, "we only have trouble communicating."

He added that most disabled people are drowning in poverty. "To improve the condition of disabled people, including deaf people, and to escape from the circle of poverty and disability, policy makers need to understand and undertake a new attitude towards disability, and disabled people also need to be allowed to participate in the policy making processes."

#### 9. Conclusion

This participatory study concludes that whilst a wide range of organisations in Myanmar are attempting to understand the challenges faced by, and are providing for; people with disability living in the country, there are many gaps in the understanding and awareness of disability in Myanmar. Particularly, understanding as to what is and what is not classed as disability and a lack of qualified people and knowledge of supporting and accommodating disability in society, is delaying the development of a strong foundation on which to build an inclusive society.

The survey found that the majority of service provision for people with disability in Myanmar is based in the Yangon area, and is therefore greatly inaccessible to people with disability living outside of the city, especially in rural areas. Service provision in Myanmar tends to view people with disability through a narrow lens, as beneficiaries and receivers of services, rather than as employees and participants in strategy development and implementation. Additionally, whilst many service providers are aware of community-based rehabilitation as an effective approach for improving the lives of people with disability, none provide the full compliment of services.

Inadequate educational provision creates the greatest hurdle to inclusion in society for people with disabilities. The majority of people with disability and their families who were surveyed desire to see nationwide, inclusive educational programs in mainstream government schools.

Finally, a lack of networking amongst organisations and international parties greatly hinders the work of organisations working with people with disability, and the building of bridges between PWDs, families and service providers is necessary to improve communication, information sharing and collaboration between people affected by or supporting disability.

#### 10. Recommendations

In order to improve the situation for those with disabilities in Myanmar, the researcher has proposed a list of recommendations for implementation within government organisations, international nongovernment organizations, community based organizations.

#### 10.1 Developing training programs on disability

Family members of PWDs should have more access to information and training on how to engage with disability. Most families of PWDs are eager to be involved and tackle the challenges, both through home-based and community-based methods. Possible topics of training might be:

- 1) Early intervention training
- 2) Care-giver training
- 3) Behaviour modification training
- 4) Home-based education training
- 5) Basic sanitation and personal hygiene training
- 6) Daily activities and living training
- 7) Civic education amongst PWD communities

The different trainings related to these topics should target all stakeholders, including parents, teachers and doctors, to successfully increase society awareness of disabilities and to create an inclusive society.

#### 10.2 Increasing skills and raising awareness of teachers to work effectively with PWDs

Firstly, awareness-raising programs and skills development programs should be developed to be utilised within existing and newly-created special education schools. At the same time mainstream schoolteachers should receive training on the value of special-needs education, concepts of inclusive education, and disability awareness. The different training programs should introduce special curriculums and teaching techniques on how to teach disabled children in mainstream schools and in special classes in institutions.

Inclusive education systems and integrated class programs should be implemented and expanded within the public schools. There needs to be mutual cooperation between the government institutions and non-government institutions toward holistic development of all sectors focusing on disability.

# 10.3 Implementing disability diagnosis systems and health promotion programs in every community

There is no universally accepted system for disability diagnosis, however, both national and international approaches to classification exist and are practiced in many countries in Asia. Singapore and Thailand have particularly strong systems for diagnosis and training of medical personnel. Myanmar Department of Health should identify appropriate components of disability diagnosis systems from neighbouring countries and secure assistance from the World Health Organisation (WHO) to develop and implement a national, country-wide system in Myanmar.

Every mother, in both urban and rural locations, should have access to health checks and education during the pre-natal, natal and post-natal periods. Additionally healthcare providers need to receive more specialised training on maternity care, as well as on children with disabilities. Mothers and caregivers need awareness training on hygiene and medical care, health promotion training and homebased intervention training.

#### 10.4 Developing common strategies of co-operation to create disability-friendly environments

The value of community-based rehabilitation is the creation of disability-friendly environments in which beneficiaries can easily access effective services and information in the community. To successfully achieve the creation of disability-friendly environments, the role of CBR needs to be promoted in communities in both rural and urban areas.

Strategies to increase CBR put PWDs in the driving seat. As the essence of community-based rehabilitation is to not only to raise awareness of disability, but to move beyond service provision for PWDs to increase their participation in strategy development and service implementation, and to ensure service provision meets needs, participation, and therefore empowerment of PWDs, can be achieved through their employment in DPOs.

People with disability can also empower themselves through a common method of becoming agents of change in civil society. With a willingness to work for their own communities to assist and support other PWDs in their development and achievements, to grasp the opportunities and achieve goals which everyone has the right to, PWDs can increase their own civic education and that of others, with and without disability alike.

### 10.5 Developing networking spaces in the community

Networking spaces for people with disabilities, which can create good communication links between both family and PWD community institutions, and national and international institutions, for experience sharing and learning, need to be initiated throughout the country by PWDs, their families and supporters? Networking strategies should be developed by consensus, and networks could be used

to explore a variety of disability-related research and topics, act as a forum for advocacy and as a means to develop cooperation between national policy makers and different sectors on disability issues.

This program could explore the following issue areas:

- (1) Securing the rights of persons with disabilities in Myanmar.
- (2) Improving the educational situation of persons with disabilities in Myanmar.
- (3) Ensuring that national policies for disability in Myanmar are effective.
- (4) Increasing the current level of knowledge and experience of disabilities among policy makers.

#### 10.6 Developing information and resource centres

Information sharing is the most important variable in improving communication on disability. If information-sharing channels don"t exist then it is difficult to communicate national plans, conduct advocacy and share achievements of DPOs. Barriers are created to identifying existing service provision and gaps and duplication.

An information resource centre could store records of DPOs and their activities, and initiate networking activities and coordination among GOs, INGOs, NGOs and SHGs. This would encourage agencies to share information about activities, developments and achievements, and donor and partner information, and would support agencies and DPOs to inclusively improve disability service provision and strengthen organisational development. Additionally, DPOs need to regularly access data to strengthen program implementation, and an information centre could initiate, collect and update data and records of training programs that reflect the needs of PWDs and DPOs, and lists of volunteer consultants. Self-access learning centres such as this would support DPOs and PWD individuals to learn and strengthen project implementation.

# 10.7 Strengthening and developing sustainability of DPOs

Sustainability plays an important role in the achievement of DPO goals in Myanmar. According to the research, the sustainability of DPOs is hindered by weak organisational development. To strengthen this, different DPOs should work together to learn from each other so operational and implementing processes, and donors and INGOs should desire to fund DPOs, CBOs and SHGs for organisational development and to implement various activities in different regions.

The donor agencies and INGOs should form programs that empower DPOs and SHGs in different regions in Myanmar. They should increase the capacity of a wider range of grassroots organisations and develop the talents of disabled people. All organizations need to generate a cooperative spirit that

will help them move forward towards inclusive development for PWDs. DPOs should mobilise PWDs to set up and develop more organisations in different regions to create more widespread help and access.

The donor agencies must increase their awareness and understanding of the challenges facing the different services providers of DPOs, CBOs and SHGs, especially regarding lack of networking. The agencies should be able to support networking and referrals between DPOs and families so that those with disabilities can receive rapid response and effective treatment. Different partners in the disability sector must share information and work together to find solutions to the various problems that can arise when dealing with disability.

#### 10.8 Initiating vocational training for PWDs

DPOs must increase the number and evaluate the relevance of their vocational training programs for PWDs. PWDs need access to relevant, up-to-date vocational training programs and market analysis techniques. A variety of different vocational training programs that reflect the needs of people with different types of disabilities need to be developed. To ensure that participants are able to secure incomes on which they can survive, and successful integration into society, courses need to be developed from basic through to advanced levels, and must include mobility training. These training programs must be supported with financial support for assistive teaching devices, teaching aids and materials. Post-training support is also necessary, such as job coaching programs, job opportunity seminars to which employers are invited, information sharing about job placements and employer advocacy campaigns.

#### 10.9 Supporting livelihood investment funds

Livelihood support is crucial to initiating and creating job opportunities for PWDs. However, disabilities that are moderate-to-severe can result in a lack of adequate physical and/or mental functionality that can disqualify people from receiving essential livelihood support. In cases such as these, DPOs need to implement equity strategies, to expand beyond provision of livelihood support directly to the person with disability, to supporting them indirectly, through provision to their families.

As well as different vocational training programs and market analysis training, PWDs need income management and business sustainability training. Donor agencies, INGOs and individual donors need to support small livelihood grants and management training through DPOs, CBOs and SHGs.

#### 10.10 Supporting human resource development for the employees of DPOs

There is a need to develop the skills and abilities of DPO human resources and encourage individual improvement, awareness and knowledge. DPOs should network with different institutions and raise their awareness of methods used by INGOs, NGOs and training centres, nationally and internationally,

so they can apply different methods of human resource development to develop a new generation of qualified and educated staff, and raised awareness.

DPOs require funding to support employees to gain national and regional capacity development in their specialist areas. Capacity development provision needs to be extended to provide follow-up progress monitoring, assessment of program effectiveness and any further necessary assistance.

Cooperation is needed between government institutions, INGOs, donor agencies and DPOs on human resource development to create a resourceful team of policy makers and trainers on topics of community-based rehabilitation, inclusive development and disability and development.

#### 10.11 Mobilising mass media to promote disability

The media is an effective channel of communication that can raise awareness and educate the public about disabilities, and advertise different DPO services available in Myanmar. The media needs to be mobilised to advertise service availability and raise awareness through featuring articles on disability and the challenges PWDs encounter.

#### 10.12 Establishing educational institutions on and for disability

The government should promote high quality academic and educational support for those working with people with special needs and disabilities who might need extra assistance with occupational or speech therapy. The department of social welfare must initiate a pilot program for short-term, regular trainings on special education, occupational therapy and speech therapy, supported by research of the situation of PWDs in Myanmar. The DPOs in target locations should have opportunity to access professional development on different approaches to a variety of disabilities.

Many more institutions for learning and education for PWDs should be established by INGOs, DPOs, GOs and CBOs, with a focus on delivering education and rehabilitation services for PWDs equally across all urban and rural areas of Myanmar. Those with disabilities should have a chance to access basic education, prevocational, vocational and life skills, for the improvement of their futures.

The government should create institutions that are free of charge for people with all kinds of disabilities. The institutions should organize full-day learning and recreation session for PWDs and should arrange transportation to ensure inclusion and access. The organizations should nurture an environment for PWDS that is safe and friendly, that is a place where they can sufficiently and comfortably learn different life skills and vocational training. Inclusive of all this, the organisations should provide job-coaching programs, job placement help and shelter workshops.

Additionally, residential institutions are needed in locations other than Yangon for those with severe disabilities and for orphans with disabilities. Residential care needs to be prioritised as a main issue by all organisations including the government, INGOs, CBOs, DPOs and SHGs, to find a solution to the

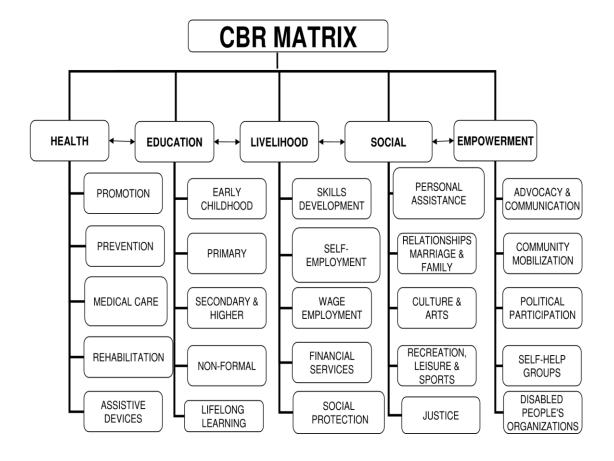
needs of PWD family members. Moreover, the government must take responsibility for care of disabled people who are without family members and who cannot take care of themselves, and ensure that their basic needs such as accommodation, food, clothing, medical treatment, living allowance, vocational skill development, occupational fund and advice are provided.

# 10.13 Challenges to protection of PWDs

The Myanmar government has responsibility to develop strong and significant policies and legislation for social justice, rehabilitation, and equity of opportunities for social and economic inclusion of people with disabilities. To uphold the Convention on the Rights of Persons with Disabilities (CRPD), signed by the government in December 2011, stronger laws and legislation are needed to recognize the rights and protect people with disabilities from discrimination and exploitation. To strengthen implementation of the CRPD, the capacity of service providers needs to be increased to provide access to civil rights education programs, legislation awareness-raising programs and subsidised legal aid systems, to ensure protection from abuse of people with disability.

Annex A

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# Biography of the researcher



Salai Vanni Bawi is the son of U Thang Pu and Daw Ani Phai. He grew up in Matupi Township in Southern Chin State in Myanmar. He attended primary and high school in Matupi and graduated from Dagon University with a BA in Laws in 2005. Between 2001 to 2009, he worked for the Department of Social Welfare as a social worker at School for Disabled Children in

Yangon. In 2009, through Internships Asia, he attended a six-month internship program at Leonard Cheshire Disability, South Asia Regional Office in Bangalore, India. During this internship, he mainly studied about community-based rehabilitation programmes for people with intellectual disability and multiple disabilities. In 2010, he studied post graduate training on Community Development and Civic Empowerment at Chiang Mai University in Thailand.

He is a supporter of the Unity Self Advocacy Group of Intellectual Disabilities in Yangon and is now currently working to support the Family Support Network for Intellectual Disabilities in Yangon. Salai Vanni Bawi is due to take up a program of Master of Arts in International Development Studies at Chulalongkorn University, Thailand, in October 2012.