

# SITUATION ANALYSIS of CHILDREN with DISABILITIES in Myanmar 2016



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Contact:

UNICEF MYANMAR 23-A, Inya Myaing Road Shwe Daung Gya Ward 2, Bahan Township, Myanmar yangon@unicef.org

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Illustration: Khine Zar Mon

Design and Layout: Yar Zar Ye Ni

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This report is dedicated to all the children in Myanmar.

## **Study Team**

Paula Frederica Hunt	Team leader
Pinaki Joddar	Quantitative expert
San Tun Aung	Qualitative expert
Sanjay Tripathi	Situation analysis and quality assurance expert

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## **ACRONYMS**

ATEO	Assistant Township Education Officer
CBR	Community-based rehabilitation
CDD	Child Development Department
CEDAW	Convention on the Elimination of All Forms of Discrimination Against Women
CFD	Child functioning and disability
CI	Confidence interval
CRC	Convention on the Rights of the Child
CSO	Central statistical organisation
CWD	Children with disabilities
CWOD	Children without disabilities
DBE	Department of Basic Education
DPO	Disabled people's organisation
DSW	Department of Social Welfare
DTEO	Deputy Township Education Officer
ECCD	Early childhood care and development
ECD	Early childhood development
ECDC	Eden Centre for Disabled Children
ECI	Early childhood intervention
EU	European Union
FGD	Focus group discussion
FSU	Final sampling units
НН	Household
HI	Handicap International
IBR	Institution-based rehabilitation
ICF	International classification of functioning, disability and health
ICF-CY	International classification of functioning, disability and health - children and youth Version
ICRC	International Committee of the Red Cross
IE	Inclusive education
IHLCA	Integrated Household Living Conditions Assessment
IIC	Intellectually-impaired children
IQ	Intelligence quotient
KII	Key informant interview
LMF	Leprosy Mission Foundation
MC	Medical care
MICS	Multiple indicator cluster surveys
MILI	Myanmar Independent Living Initiative
MIMU	Myanmar Information Management Unit
MLRC	Myanmar Literacy Resource Centre
MoE	Ministry of Education
МоН	Ministry of Health
MoRA	Ministry of Religious Affairs

Myanmar survey research
Ministry of Social Welfare, Relief and Resettlement
Non-governmental organisation
Public health
Probability proportionate to size
Primary sampling unit
Regional extension centre
Request for proposal
Rural and sub-rural health centre
Situational analysis
Standard of living
Township education officer
Terms of reference
UNESCO Institute for Statistics
United Nations
United Nations Convention on the Rights of Persons with Disability
United Nations Educational, Scientific and Cultural Organisation
United Nations Children's Fund
United States dollar
Volunteer Service Overseas
Water and sanitation hygiene
Washington Group on Disability Statistics
Washington Group Extended Set of Questions on Child Disability
Washington Group Extended Set of Questions on Functioning

## PREFACE

Children with disabilities in Myanmar are one of the most marginalized and excluded groups of children and often remain invisible to the mainstream population and relevant officials.

The 2014 Census reveals that there are approximately 17.2 Million children in total in Myanmar. 1.35% of these, 232,021 children, are children with disabilities.

However, the individual stories that lie behind these numbers are little understood. While numerous Government departments and organizations regularly produce statistics on children and women in the areas of their respective responsibility, quantitative and qualitative data related to children with disabilities is still scarce, incomplete and its quality questionable.

The situation analysis of children with disabilities in Myanmar is therefore a timely and very relevant resource that provides important evidence necessary to identify and address the needs of children with disabilities, and ultimately to contribute to the achievement of the 2030 Agenda for Sustainable Development and its vision of disability-inclusive development for all. By providing analysis and information on the challenges and barriers faced by children with disabilities in their daily lives and communities and in accessing social services, this report sets out the key areas where action is urgently required to ensure their social inclusion and full participation in society. Therefore, I encourage all stakeholders to study the report, consider its recommendations, and support national efforts to enhance the realisation of rights for children with disabilities.

The situation analysis was developed by the Department of Social Welfare, Ministry of Social Welfare Relief and Resettlement, in collaboration with UNICEF Myanmar. It is the first result of an ongoing discussion with a range of stakeholders to realize the rights of children with disabilities, and ensure their inclusion and participation in Myanmar society.

I am deeply grateful to UNICEF and development partners of the Myanmar Quality Basic Education Programme (QBEP), Australia, Denmark, DFID, EU and Norway, for their strong technical and financial support for this study. I would also like to express my sincere thanks to concerned officials from various ministries and Disabled Persons Organizations who provided valuable inputs in preparing this report. Without their interest, support and involvement, the situation analysis of children with disabilities in Myanmar would not have been possible.

All children with disabilities have the right to achieve their full potential and enjoy the opportunities open to other children. I hope that this report will contribute to inform programmes that improve the situation of children with disabilities in Myanmar, and ultimately help to achieve a socially inclusive future in the country.

Dr. Win Myat Aye Union Minister of Social Welfare, Relief and Resettlement

### FOREWORD

This situation analysis is the first ever study in Myanmar to provide a systematic understanding of the experiences of children with disabilities and their families, informed by robust, qualitative evidence.

Children with disabilities have the same rights as all children. Given the same opportunities to flourish as any other child, they have the potential to lead fulfilling, dignified lives and to contribute to the social, cultural, and economic vitality of their communities. Yet surviving and thriving can be especially difficult for children with disabilities. Across the world, they face challenges as a result of their impairments and the many barriers that society casts in their way.

According to the World Health Organization's Report on Disability, approximately one billion people in the world are living with a disability, with at least 1 in 10 being children and 80% living in developing countries. They are often likely to be among the poorest members of the population, to have limited access to education, and to be at greater risk of violence. Their disabilities also often exclude them from receiving proper humanitarian assistance in emergencies.

To address these disparities, a country needs relevant and high quality data to guide policy formulation and implementation Myanmar is no exception. To deliver on their commitments under the Convention on the Rights of Persons with Disabilities (CRPD), which Myanmar signed in 2011, policy makers require solid evidence on which to base their decisions.

This Situation Analysis of Children with Disabilities in Myanmar aims to bridge this information gap. It analyses the current situation of children with disabilities in relation to realizing their rights and accessing basic services, as well as their life experiences in their communities. It focuses on identifying the barriers created by society that prevent children with disabilities from enjoying their human rights. This includes identifying negative attitudes; environmental and communication barriers; gaps in policies or their effective implementation. The report also reveals that children with disabilities in Myanmar are less likely to access services in health or education; rarely have their voices heard in society; and face daily discrimination as objects of pity. It also highlights how inadequate policies and legislation contribute to the challenges these children face.

This study is the result of a close collaboration between the Department of Social Welfare, Ministry of Social Welfare Relief and Resettlement and UNICEF. It also benefited from the generous financial support of Development Partners Australia, Denmark, EU, Norway and the UK under the Myanmar Quality Basic Education Programme (QBEP), for which we would like to express our deepest thanks.

UNICEF hopes that the information available in this publication will be used by policy makers, development partners and Disabled Persons Organisations to promote the realization of the rights of all children with disabilities. The document should also help guide mainstreaming of disability across all of our policies and programmes, both in development and humanitarian action, to improve the quality and inclusivity of social services provided.

This Situation Analysis is thus an attempt to make visible what is otherwise kept invisible – the plight of children living with disabilities. In this way, the analysis can inform positive responses to disability in Myanmar, and strengthen our joint commitment to the rights of these children, and their inclusion and participation in the lives of their communities,– as a matter of principle, equity, and for the benefit of all.

Bertrand Bainvel UNICEF Myanmar Representative



## **EXECUTIVE SUMMARY**

This analysis of the situation of children with disabilities in Myanmar intends to provide a systematic evaluation of the experiences of children with disabilities and their families to establish a baseline against which policy responses can be set and progress can be measured. As the first ever analysis of this kind in Myanmar, its key objective is to increase knowledge and awareness among policy makers and key stakeholders about the situation and the rights of children with disabilities in Myanmar, including what rights and entitlements are not being fulfilled and what children themselves see as the most pressing needs. By providing a strong evidence base of this kind, it is expected to inform disability-inclusive legislative and policy reviews that will ensure the fulfilment of the human rights of children with disabilities in Myanmar.

Given opportunities to flourish as others might, children with disabilities have the potential to lead fulfilling lives and to contribute to the social, cultural, and economic vitality of their communities. Yet surviving and thriving can be especially difficult for children with disabilities. Across the world, children with disabilities confront challenges as a result of their impairments and the many barriers that society throws their way.

The situation analysis focuses on identifying the barriers created by society and the physical environment that prevent a child with disabilities from enjoying its human rights. This includes, for example, identifying negative attitudes, environmental and communication barriers, and gaps in policies or their effective implementation.

In this way, the analysis can inform responses to disability in Myanmar, including a commitment to these children's rights and their future, giving priority to the most disadvantaged as a matter of equity and for the benefit of all.

## Methodology

To gather information on the daily life of children with disabilities in Myanmar and the barriers they face, 2,547 households in 28 townships were surveyed (1,271 families who have children with disabilities, and for comparative purposes a further 1,276 families whose children do not have disabilities). In addition, 267 key informant interviews, and 60 focus discussion groups (with 8-10 persons per group) were undertaken. A further important case study on the prevalence of disability in Mon State examined data from 1,096 households (1,318 children) gathered in five townships (three in Mon State and one each in Yangon and Rakhine States) and nine additional key informant interviews with officials.

In its entirety, the situation analysis provides a good illustration of the lives of children with disabilities in Myanmar in 2015, but because the sample is not nationally representative, the findings should be taken with caution. However, taking into consideration the size of the sample, its geographic distribution, the use of both quantitative and qualitative data, and how little has been known about this topic to date, this study presents a good baseline for further inquiry.

Critically, the situation analysis took place shortly after the 2014 Population and Housing Census, which, for the first time, examined the prevalence of disability through a short set of questions aimed at measuring functional difficulties in four domains: seeing, hearing, walking and remembering. Results of the census indicated a prevalence rate of 4.6 per cent for the entire population and 1.3 per cent among children (ages 0-18 years), both of which are much lower rates than might normally be expected, 15 and 5 per cent respectively.<sup>1</sup>

<sup>1</sup> WHO and World Bank (2011) World Disability Report.

## **Key Findings**

#### **Defining disability**

Although Myanmar has approved a national law on the rights of the persons with disabilities, the definition of disability used in it is not explicit or widely understood. Other definitions/explanations of disability used by most stakeholders were also largely outdated and reflected a charity model not aligned with the CRPD's establishment of persons with disabilities as rights holders. In fact, disability is most often described as a physical impairment, a difficulty with communication, a "mental or learning" impairment, or "as having a low IQ," and in some cases derogatory terms were used.

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

#### **Daily lives**

Difficulties were reported in areas such as self-help and hygiene, eating, and changing clothes. Although many children with disabilities can do things independently, many require assistance. Some key findings emerging from this survey are:

67 per cent of the children with disabilities are out of the formal education system and do not attend school. This represents an exponentially higher percentage of children out of school than among children without disabilities, 11 per cent of whom do not attend school, according to the most recent national census.

An overwhelming 93 per cent of the 2- to 4-year-olds with disabilities have no exposure to school readiness programmes, while attendance of children with disabilities at monastic schools, vocational training centers and special schools was found to be negligible.

#### **Caregiving and living environment**

Family members – especially mothers – are the main caregivers for all children, including children with disabilities. Of the 75 parents/caregivers of children with disabilities interviewed, eight prepare everything the child might need throughout the day before going to work, or they leave the child with other family members who can help take care of it. No parent reported having hired help for this task. Almost half of the parents reported that taking care of their child does not impinge on other tasks, but more than 1 in 4 indicated that they did not have enough time for other household tasks because of the extra care required by their child with disabilities.

Despite the often critical role of assistive devices in ensuring the self-sufficiency of children with disabilities, almost all the parents/caregivers and the children with disabilities alike (99 per cent) reported never having received advice on the use of assistive devices to aid mobility, vision or hearing. Nonetheless, 10 per cent of the parents/caregivers had provided their children with assistive devices on their own initiative. Wheelchairs were the most commonly used assistive devices (36 out of 108 children had one), followed by crutches/ walking sticks (27 of the 108 children). Spectacles, braces and hearing aids were among other devices being used.

Critically, most parents who responded to questions related to potential environmental modifications said they had never felt a need to modify their physical environment or household structure to accommodate the requirements of their child with disabilities.

#### Community and social life

Perceptions regarding social interactions varied among stakeholders, with no differences for girls or boys with disabilities. Overall, 81 per cent of the children with disabilities reportedly faced the same treatment by the community, good or bad, as all other children. 79 per cent of the parents with children with disabilities

said they felt that community members were generally understanding and supportive, a sentiment reflected in almost equal proportion (73 per cent) by parents/caregivers of children without disabilities. Notably, however, 20 per cent of the children with disabilities were reportedly bullied by children, and 13 per cent were bullied by adults.

Community members largely agreed that all children, including children with disabilities, are entitled to have a happy life. Even so, only 11 per cent of the community members have observed children with disabilities participating in social life. This overall "invisibility" perpetuates the idea that only a very small proportion of the population has a disability and indicates the potential that children with disabilities encounter shame and discrimination.

While children with disabilities reportedly have friends in and around their homes and are encouraged to make new friends, only a third of them interact with friends regularly. Of those who do, many go to their friends' houses, or their friends come to visit them. Importantly, however, more than 1 in every 10 children with disabilities do not have friends – a much higher percentage than that of children without disabilities who do not have friends (1 in every 25).

More than half (44 out of 75) of the children with disabilities reportedly participate in social activities, although the scope of these activities is generally much narrower than that of children without disabilities, and they participate in a wide variety of events, including sports, games, fairs, school events, religious festivals, charities, wedding receptions and funeral rites, among others.

An overwhelming 89 per cent of the parents/caregivers "strongly disagreed" or "disagreed" with the idea that children with disabilities are a source of embarrassment. Even in households without children with disabilities, 62 per cent of the parents said they felt that there was no embarrassment associated with having a child with disability. Thus, it is possible that one of the reasons why children with disabilities are often not active participants in social life is due to their parents' fear for their safety (please see below).

Most parents/caregivers also reported receiving little assistance from the community, which is similar to results for parents of children without disabilities with regard to health, financial or routine services.

#### **Right to education**

Inclusive education – here understood as having schools that include all children, celebrate differences, support learning, and respond to individual needs – was initiated in 2010. However, there are still many barriers to children's participation in education, particularly for children with disabilities:

- Numerous children with disabilities are reported to have been denied enrolment in mainstream schools despite a recent study that found that social relationships in school are a major enabling factor for many children with disabilities who participate in everyday activities;
- Overall, 67 per cent of the children with disabilities were not in school, compared to a much lower

   but still high 19 per cent of the children without disabilities. Moreover, in 46 instances it was
   found that schools had refused admission to a child perceived as having a disability.
- Education attainment also declines as the child progresses in age, with only about 29 per cent of the children with disabilities in the 14- to 17-year-old cohort having completed secondary education. Most children, both with and without disabilities, start dropping out of school after completing primary education.
- Of special concern is the number of children with disabilities who have never had the opportunity to attend school. Further, 97 per cent of the parents/caregivers of children with disabilities aged 2-4 years reported their children had received "no education," but it is notable that even in the age group 5-9 years, 56 per cent of the parents/caregivers reported "no education."

Several of the township education officials (TEOs) interviewed do not appear to understand that placing children with disabilities into special schools and failing to ensure that teachers are supported in the

classroom so as to be able to adequately teach children with disabilities are fundamental breaches of the rights of children with disabilities.

- Among all the TEOs interviewed, a strong belief was found that special schools are better equipped to provide children with disabilities with education.
- According to the TEOs, some children with disabilities need additional support and special learning equipment, e.g. those who are hearing- or visually-impaired.

Some parents of children without disabilities do not like their children being friends with children with disabilities, and even some teachers do not want to have children with disabilities in their classrooms.

Of the 75 families of children with disabilities who were interviewed, only one-third (27) reported that their child with disabilities attended a mainstream school, while five others had enrolled in mainstream schools but no longer attended. Many of the parents/caregivers of children with disabilities said that the children found it discouraging to go to school for reasons such as not fitting in with classmates; teachers not being supportive; not doing as well in school as their classmates; failing some grades; and not being able to make friends like their classmates do.

32 per cent of the parents/caregivers of children with disabilities reported their children being mocked or bullied at school – by classmates and teachers alike – while only 11 per cent of the parents/caregivers of children without disabilities agreed with these statements.

#### **Right to health care**

Most of the parents/caregivers of children with disabilities (64 per cent) reported that they were the first persons to identify a disability, with doctors/psychologists a distant second (28 per cent). As expected, the wealthier the family, the more likely that disability/limitation is identified by a doctor/psychologist.

An important finding in the situation analysis is that doctors/psychologists generally identify disability/ limitation in children younger than age 2, and identification rates decrease as a child ages. This underscores the urgent need for expanded early identification services.

Many health professionals, particularly at the township and rural levels, do not have specific procedures for the identification of children with disabilities, including early detection and prevention services. Although some relevant training programmes are available, these have reportedly not been accessed by most of the professionals. Moreover, very few health professionals said they had any relevant documents, manuals, guidelines or audio-visual materials for support services for children with disabilities. Likewise, health service infrastructure suitable for children with disabilities is almost non-existent, particularly in remote areas.

More than half of the health professionals interviewed have a list of children with disabilities living in each township. They prepared it with the help of ward and village administrators, rural health centres, sub-rural health centres, or the township Department of Health. In almost all cases, however, the lists are not updated regularly, and issues of both usefulness and confidentiality exist. For the most part, lists are not linked with any other data collection systems.

The vast majority of the parents/caregivers of children with (87 per cent) and without (89 per cent) disabilities reported they rarely visited a health facility or medical practitioner, and only when required. This was the case despite the fact that nearly 1 in 3 children with disabilities reportedly require regular health check-ups, some as often as once a week. The distance to the health facility or the non-availability of quality, doctors were cited as the key reasons for not visiting a doctor. Of the parents/caregivers who sought health care for a child with disability, about half went to a private clinic, a finding that bears further investigation.

#### **Protective environment**

While most of the parents of children without disabilities believe their children are safe outside the home,

the parents of children with disabilities worry about their children's safety and protection from harassment, bullying and exploitation.

A strong majority (64 out of 75) of the parents said their child is not afraid of anything in/around their house, but 1 in 4 mentioned their child is afraid of people and dangers outside in their community. Concerns related to harassment and bullying when their child goes outside the home were particularly prevalent and account for some of the reasons why children with disabilities are not active participants in community life.

One-third (23 out of 75) of the parents said their children had been bullied or mocked by other children, and sometimes physically hurt. Nonetheless, it should be noted that only 2 of the 75 children with disabilities indicated not feeling safe outside the home, because "people don't respect one another on the streets."

#### **Other issues**

Overall, more than 1 in 4 children with disabilities (27 per cent) did not have a birth certificate. Data indicated a wide geographic variation, with only the Magway Region claiming 100 per cent registration of births. In particular, the cases of Tanintharyi, Rakhine and Kayin Regions are extremely concerning, with the rate of birth registration of children with disabilities at around 50 per cent, which is in clear violation of Articles 7 and 8 of the CRC and Article 12 of the CRPD.

Life aspirations of children with disabilities do not differ from those of children without disabilities. Parents of children with disabilities hope their children will become educated, and some said they would support their child's aspirations, no matter what they might be.

#### MON CASE STUDY

#### Methodology

This case study provides an example of data collection aligned with global standards in which childhood disability is understood through the lens of the social model of disability. Accordingly, it does not focus on an account of children with specific impairments, their level of severity, or medical diagnosis. Rather, it supports the work of the 2014 Census and continues to clarify what are acceptable concepts, language and definitions in accordance with the CRPD, providing a baseline for future work.

Primary data was collected using two age-specific child functioning and disability (CFD) modules, for ages 2-4 years and 5-17 years. These modules, adapted from the newly developed UNICEF/UN Washington Group on Disability Statistics CFD modules, provide information collected from primary caregivers of children, mostly mothers. The case study thus provides insight into the lives of children in various domains, the challenges they face, and the functional limitations they may experience. Taking this approach, it provides a holistic view of children and helps to identify the sub-populations/ populations of children ages 2 to 17 years who experience functional difficulties.

The figures presented below are weighted estimates for Mon State as a whole, prepared as a scientific and stratified sampling process.

#### **Findings**

- 1. Complete blindness was not found in Mon State, and the use of eyeglasses is very low.
- Although the total percentage of 5- to 17-year-olds who have difficulty in hearing is low, almost two-thirds of all the children who are in that category have severe hearing impairment.
- 3. More boys than girls (9.0 versus 7.6 per cent respectively) have difficulties in performing self-care activities.

- 4. A total of 1.9 per cent of the children in Mon State have difficulty being understood by family members, with 3.0 per cent facing difficulty being understood by people outside the household. In both cases, the percentages are higher for girls.
- 5. Very young boys have more difficulty than girls with emotions. However, in the older age group (5-17), girls are much more vulnerable to feelings of anxiety and depression.
- 6. While few children aged 5-17 have difficulty controlling their behaviour, difficulties are experienced by girls in particular in focusing on their favourite activities, accepting changes in routine, and making friends.

### **Recommendations**

The overarching recommendation for all stakeholders is to enhance inter-ministerial cooperation and coordination among various sectors (public and private alike), an essential practice (CRPD Articles 32, 33, 34 and 37) to develop legislation and services that are disability inclusive; to provide much-needed information regarding the rights and responsibilities of both the duty bearers and the rights holders; and to ensure a transparent, all-encompassing system for monitoring and evaluation.

Parliament is recommended to re-examine relevant legislation through the social model of disability lens, and ensure that laws, any subsequent amendment(s), and associated bylaws are aligned with, and respectful of, international commitments. Parliament should also consider signature and ratification of the CRPD's Optional Protocol to ensure children with disabilities have the mechanisms by which complaints can be lodged and penalty actions can be applied against those who violate their rights.

Parliament should increase awareness and sensitisation of parliamentarians by promoting the exchange of information about international experiences and best practices with regard to mainstreaming disability and issues relevant to children with disabilities;

Parliament should work with the National Committee for Disability – once it is established – to: (1) develop, with line ministry endorsement, a "vision" for social inclusion in which children with disabilities are seen as rights bearers; (2) assess gaps and overlaps of mandates, as well as service delivery, across all government agencies; and (3) complete, with the active participation of the DPOs, CSOs and persons with disabilities, the first monitoring report to the UN CRPD Committee. Parliament should also require regular reports from ministries as well as the National Committee for Disability on their activities related to inclusive and effective service provision for persons with disabilities/children with disabilities.

Parliament should allocate financial resources to implement legislation, policies and the National Action Plan on Disability as per the recommendations of the National Committee for Disability. Moreover, it could provide incentives to the line ministries and the private sector to improve infrastructure and service provision for children with disabilities. It could also examine options to lower the cost of goods and services that are critical for children with disabilities, e.g. through the provision of budgetary subsidies.

The government of Myanmar through the President's Office should develop clear reporting lines and ensure a clear assignment of roles and responsibilities at all administrative levels and across all ministries. It should also formally adopt the social model of disability in planning and programming at all administrative levels.

The government of Myanmar should form a National Committee for Disability (as per CRPD commitment) with a clear mandate for the promotion of the rights to social inclusion of persons with disabilities, and with the resources to fulfil its coordination and monitoring mandate. The National Committee for Disability should receive support from the government of Myanmar (among all other stakeholders) in the development of a national action plan.

The government of Myanmar should allocate funds to address the increasing social assistance needs of

households that face multiple vulnerabilities, including through the implementation of the 2014 National Social Protection Strategic Plan.

The government of Myanmar should revise existing practices of data collection, from procedural, privacy and discriminatory standpoints, and develop new guidelines regulating data gathering, data sharing, and confidentiality issues. It should provide transparent and disaggregated budgetary data related to existing and/ or planned policies and programmes for children with disabilities, and it should coordinate the expansion of statistical information systems, in collaboration with CSOs and DPOs, to inform programming and budgeting.

The government of Myanmar should develop quality benchmarks and protocols for all goods and service providers in line with international standards, and it should also develop a coordinated training agenda and curricula for staff in line with international disability protocol standards.

The Ministry of Social Welfare, Relief and Resettlement (MoSWRR), through the Department of Social Welfare (DSW), should establish township support groups (TSGs) to include children and adolescents with disabilities, and to establish appropriate mechanisms to ensure opportunities for the inclusive participation of children with disabilities in community and social activities.

The MoSWRR (DSW) should expand the role and capacities of the DSW social workers involved in the case management system to ensure that they reach all children, including children with disabilities, everywhere in the country and make sure that children with disabilities and their families can access the services to which they are entitled. The DSW should also establish a mechanism for case managers to identify and report all forms of abuse/neglect of children with disabilities given their specific vulnerabilities.

The MoSWRR (DSW), in close partnership with the Ministry of Education and the Ministry of Health, should develop national guidelines and systems for the early identification and registration of persons with disabilities that are in accordance with the UNCRPD and use protocols compliant with the International Classification of Functioning (ICF). The system should be compatible with e-platform technologies and gather data in real-time to inform evidence-based planning and resource allocation as well as the monitoring of expenditures.

The MoSWRR (DSW), in close partnership with the MoE and the MoH, should, using standardised protocols, extend school health programmes to screen school-age children for the development of functional limitations.

The MoSWRR (DSW) should continue and expand its Violence Prevention Project to educate professionals and the general public on the rights of children with disabilities, and it should establish a system by which children with disabilities can report, anonymously, on instances of abuse/neglect, ensuring children's reports are taken seriously and followed through.

The Ministry of Education (MoE) should ensure that the right to inclusive education is fully realised by further amending the most recent "Law Amending the National Education Law," and it should also ensure that the amendment and its bylaw(s) are aligned with SDG4, CRPD, and the Incheon strategy to ensure that children with disabilities are welcome in schools and that their learning is supported in ways that are individualized.

The MoE should invest in the capacity development of teachers and education professionals to help foster an inclusive education system. Teachers and education professionals must also be trained to identify the need for the support of specialized professionals.

The MoE should ensure that data on children with disabilities is incorporated into the EMIS system, and it should include level of impairment, the setting where education takes place, and the support services needed and provided.

The MoE should ensure that the nationwide out-of-school children initiative encourages higher attendance rates in mainstream schools in Myanmar and targets children with disabilities.

The Ministry of Health (MoH) should lead in developing a nationwide child development strategy that is disability inclusive and includes professionals from various disciplines, parents, and the children themselves.

The MoH should improve the capacity of all health care professionals to ensure non-discriminatory practices and adequate referral to specialists when needed. In close partnership with the MoIPL, the MoH should ensure that all children are registered at birth.

The MoH should provide adequate community-based rehabilitation for all citizens, including children with disabilities, in accordance with Article 25 of the CRPD.

The Ministry of Planning and Finance (MoPF) should examine options for the sustainable financing of goods and services (e.g. subsidies to service providers) that enable children with disabilities to fully realise their potential.

Development partners should support (1) Parliament and the GoM/National Committee for Disability in their effort to develop the capacity for better coordination and leadership across all sectors, fulfil their mandate, and ensure compliance with CRPD; (2) the National Committee for Disability's specific efforts related to the National Action Plan on disability, the strengthening of the capacities of stakeholders to develop appropriate knowledge about the rights of children with disabilities through training, exposure to knowledge, and best practices; (3) the MoSWRR (DSW) in implementing communication for development campaigns and training to address misconceptions with regard to children with disabilities; and (4) all the stakeholders in their efforts to address violence, abuse and neglect, particularly those related to anonymous reporting of complaints.

Development partners should also support children with disabilities in participating freely in community events and support them in making their voices heard through innovative mechanisms, including working with the private sector, e.g. mobile operators and helplines.

Development partners should continue to advocate social inclusion measures that lead to the efficient allocation of resources, including subsidies/incentives for the supply of essential services.

Development partners should support the GoM as it works with the private sector to set up real-time, centralised data gathering mechanisms, employing the widespread use of cell phones, smartphones and other ICTs.

Advocate inclusive education as the foundation for the social inclusion of children with disabilities, and make all forms of discrimination and bullying unlawful.

Development partners could explore options for collaboration with private sector providers for good quality goods and services at affordable prices.

Civil Society Organisations (CSOs), including NGOs and DPOs should organize events and activities to promote the vision that children with disabilities have the same rights as other children and are capable members of society who have a positive contribution to make. Through these activities, they should develop children's capacity to participate meaningfully in different forums and provide space for them to freely express their views and influence decision making in matters that concern them.

Moreover, CSOs should:

- Carry out anti-bullying campaigns and sensitisation activities related to the rights of children with disabilities;
- Develop partnerships with professional networks and introduce educational materials about disability and inclusion in a participatory way;
- Engage in and report on monitoring and evaluation activities that provide clear feedback on inclusive service provision and inclusive data gathering mechanisms to all line ministries (via the National Committee for Disability);
- Ensure that persons with disabilities, including children, contribute to the development of the standards and guidelines for the provision of goods and services for children with disabilities.

## SECTION I CONTEXT



## 1. Context of the situation analysis

#### 1.1 Country information

The Republic of the Union of Myanmar<sup>2</sup> is the largest country in Southeast Asia, featuring many natural resources, e.g. agriculture, hydrological systems, petroleum, natural gas, coal, mineral resources, and marine life. However, it also faces numerous development constraints, such as frequent monsoons and mountain ranges that make communications, transportation and rural development difficult (The Republic of the Union of Myanmar, 2014). With a low population density and fertile land, however, it has significant growth potential arising from its rich natural resource endowment, especially with regard to agriculture (The World Bank, 2014). The ongoing triple transition in the country – from a military regime to democratic governance, from a centrally-directed to a market-driven economy, and from a protracted period of conflict to peace in border areas – has begun to show positive results.

Particularly following the 2010 elections, an ambitious economic, political and governance reform programme was developed by the government for a wide variety of sectors. These changes have positively affected the economy, which registered a growth rate of 8.5 per cent in real terms in 2014-2015.<sup>3</sup> The gross domestic product (GDP) for the fiscal year 2015-2016 is likewise expected to grow by 8.3 per cent.<sup>4</sup> Nevertheless, Myanmar remains one of the poorest countries in the East Asia and Pacific Region<sup>5</sup>. Available national statistics encompass only those citizens who are able to access services, thus constraining accurate data on poverty. However, poverty rates are expected to be high, according to the Integrated Household Living Conditions Survey in Myanmar (IHLCA Project Technical Unit, 2011). Rural poverty stands at 29 per cent, nearly twice that found in urban areas (15 per cent). In addition, 56.6 per cent of the urban population lives in slums, with children among this group particularly at risk of poor development (The Republic of the Union of Myanmar, 2014).

National elections in November 2015 ushered in a new administration that took office on 1 April 2016 and is led by the National League for Democracy (NLD). The NLD manifesto highlights the guarantee of basic human rights as an explicit goal and includes pledges to promote education and health care services for persons with disabilities<sup>6</sup>.

However, the transition remains in its early days and Myanmar must still address high levels of poverty,

<sup>2 &#</sup>x27;The Republic of the Union of Myanmar' will be referred as 'Myanmar' in this document

<sup>3</sup> World Bank.

<sup>4</sup> Asian Development Bank, Asian Development Outlook 2015.

<sup>5</sup> Ministry of National Planning and Economic Development and UNICEF, 2012; World Bank, 2013; World Bank, 2014

<sup>6</sup> National League for Democracy, 2015 Election Manifesto, authorised translation

low per-capita income, very large numbers of undernourished children, and the poor condition of social and physical infrastructure, e.g. drinking water, roads, electricity, telecommunication, and the Internet. At the same time, policymakers in Myanmar and international development partners are struggling with evidencebased decision making in several critical areas because of the lack of data noted above. An important case in point is identifying the situation of children with disabilities in Myanamr. In many countries, studies show that children with disabilities and their families continuously experience barriers to the enjoyment of their basic human rights and social inclusion,<sup>7</sup> with their abilities overlooked, their capacities underestimated, their voices unheard, and their needs given low priority. In this context, UNICEF Myanmar and the Department of Social Welfare at the Ministry of Social Welfare, Relief and Resettlement conducted this situation analysis (SitAn) in 2015 to better determine the current situation of these children.<sup>8</sup>

Critically, this situation analysis took place shortly after the 2014 Population and Housing Census, which for the first time surveyed for disability prevalence with a short set of questions aimed at measuring functional difficulties in four domains: seeing, hearing, walking and remembering. Results of the census indicated a prevalence rate of 4.6 per cent for the entire population and 1.3 per cent for children prevalence (ages 0 -18 years) – both of which are much lower rates that those that normally would be expected, 15 and 5 per cent respectively.<sup>9</sup>

Overall, while Myanmar signed and ratified the United Nations Convention on the Rights of Persons with Disabilities (CRPD) in 2012, a national plan for implementation is still being developed. Nonetheless, a number of laws and bylaws aimed at guiding a disability-inclusive normative framework have been drafted. This SitAn was conducted to aid in the preparation of the CRPD national plan, and to support existing social protection and child development strategies in Myanmar.

#### 1.2 Laws and policies

#### A. International commitments

Among the relevant international commitments ratified by Myanmar are<sup>10</sup> the Universal Declaration on the Eradication of Hunger and Malnutrition (1974); the Convention on the Rights of the Child (CRC, 1991); the Convention on the Elimination of all Forms of Discrimination Against Women (CEDAW); the Convention on the Rights of Persons with Disabilities (2011), but not its Optional Protocol; the Bali Declaration on the Enhancement of the Role and Participation of the Persons with Disabilities in ASEAN Community, ASEAN Decade of Persons with Disabilities (2011-2020); and the Incheon Strategy to "Make the Right Real" for Persons with Disabilities in Asia and the Pacific (2013-2022). Myanmar also adheres to the declaration of A World Fit for Children (2002); the Dakar Framework for Action for Attaining Education for All (2000); the Incheon Declaration/Education 2030: Toward Inclusive and Equitable Quality Education and Lifelong Learning for All (2015); and the Sustainable Development Goals (2015).

#### B. National legal and policy frameworks

As can be expected in a national context such as Myanmar's, a considerable proportion of legal and policy frameworks are under revision. However, with the post-2010 reform, numerous new laws are being enacted, particularly the Law on the Rights of Persons with Disabilities, developed to ensure national compliance with the international commitment to the CRPD; the National Building Code; and the National Education Law. While many examples could be given, four pieces of legislation/policy will be reviewed in some detail as most relevant for the SitAn.

#### **Rights of Persons with Disabilities Law**

Although Myanmar signed and ratified the CRPD in 2011, the national legal framework to enact it - the

<sup>7</sup> UNICEF, 2007. Promoting the Rights of Children with Disabilities, Innocenti Digest No. 13

<sup>8</sup> To be published in first quarter of 2016

<sup>9</sup> WHO and World Bank (2011) World Disability Report

<sup>10</sup> The Republic of the Union of Myanmar, 2014

Law on the Rights of Persons with Disabilities – was promulgated only in June 2015. In all, the notion of a legal framework for disability is relatively open, varying from country to country. Even so, some aspects of the CRPD remain essential to its spirit, mission and obligations, regardless of location, and must be present within each national framework, e.g. assigning responsibility for implementation of the law, defining "disability" and "persons with disabilities," and aligning with the general principles and specific rights of the convention. In this regard, the currently available English translation of Myanmar's Law on the Rights of Persons with Disabilities – the translation used for this situation analysis - does not fully comply with the CRPD. To underscore this, three elements of the law require further review.

First, the law is not a clear statement of the government's commitment to the rights of persons with disabilities. Instead, it simply establishes the National Committee on the Rights of Persons with Disabilities as a coordinating mechanism for the implementation and monitoring of the convention. Although critical, this committee is not yet functional. This sets the conditions for the perpetuation of the still prevalent charity model (see below) with regard to persons with disabilities, effectively preventing them from fully enjoying their rights. Second, the terms "disability" and "persons with disabilities," as described in the English translation of the law, do not convey the idea that disability is an evolving concept or that it results from environmental or attitudinal barriers that hinder participation. Both ideas are essential to the CRPD. Instead, the national law, developed jointly by development partners, disabled people's organizations and the government of Myanmar, maintains that the existence of a medical condition is the principal element of "disability,"<sup>11</sup> placing the onus on the persons with disability themselves. Likewise, the definition of "persons with disabilities" is restricted only to those in specific categories.<sup>12</sup>

Lastly, while some of the general principles and specific rights of the CRPD are included in the law, these are not always explicit. For example, no mention is made of the right that a person with disabilities has to live independently and to make his/her own choices. Similarly, there is no mention of the right that a person with disabilities has to full and effective participation and inclusion in society, and there is no mention of issues related to equality of opportunity, accessibility, gender equality or children. Under duties and responsibilities of the National Committee, the law provides the legal basis for the provision of Braille and sign language for persons with a visual or hearing impairment<sup>13</sup>, but no mention is given of using augmentative communications or other alternative methods of communication. In a further illustration of issues involving the law, the National Committee is tasked with "open[ing] special private schools, special private vocational schools, and private rehabilitation centres, providing the needed guidelines and support,"<sup>14</sup> in direct contravention of Articles 24 and 26 of the CRPD.

#### **National Social Protection Strategy Plan**

The second relevant government initiative is the National Social Protection Strategy Plan, developed in 2014 with the aim to "prevent and alleviate economic and social vulnerabilities, promote access to essential services and infrastructure and economic opportunity, and facilitate the ability to better manage and cope with shocks that arise from humanitarian emergencies and/or sudden loss of income."<sup>15</sup> The plan intends to be child sensitive and holistic, recognizing the positive impact of investments made early in life. In its assessment of the situation of persons with disabilities in Myanmar, it further acknowledges that "people with disabilities lack access to specific rehabilitation services, mainstream education, training for independent living, vocational training programmes, protected job opportunities, opportunities for social inclusion, and income security."<sup>16</sup>

<sup>11</sup> National Law on Rights of Persons with Disabilities, Chapter 1, Paragraph 2a

<sup>12</sup> Retrieved from http://www.un.org/disabilities/default.asp?id=151#sqc5, 28 December 2015: "Disability refers to not being able to fully participate in society due to physical, mental, or any other form of hindrances.".

<sup>13</sup> Unofficial translation of the Law on the Rights of Persons with Disabilities: unpublished, Chapter 3, Paragraphs 7 h) and i),

<sup>14</sup> Ibid, Chapetr 3, Paragraph 7 t), Chapter 5 and Chapter 14

<sup>15</sup> The Republic of the Union of Myanmar (2014), unofficial translation of the draft National Social Protection Straetegy Plan for Myanmar

<sup>16</sup> ibid

The plan goes on to outline a full protection spectrum that ensures the rights of all children with disabilities up to age 18; supports the family until the child is age 18; envisions the development of workshops and centres "to take care for life for adult/elderly persons with disabilities;" and provides job facilities "for those who complete vocational training and are capable of work." However, these four lines of social protection are not congruent with the core commitments of the CRPD in that they do not respect the full potential and individuality of persons with disabilities and again perpetuate a charity model of development.

At the same time, the plan's core intervention for persons with disabilities is limited to a cash allowance for those certified as having a disability. It also states that "the goal is to support the well-being of all those with disabilities, and to support their access to services that promote all-round development and their best interests, especially during childhood."<sup>17</sup> As noted throughout this SitAn, however, many basic services do not exist in all parts of Myanmar, and those that do are largely not available to persons with disabilities or are of poor quality. Moreover, as illustrated below, while poverty is certainly a factor for many families when choosing among services, the two main determinants remain the proximity of the services to an individual's home and their perceived quality.

#### **ECCD Policy**

The recently developed Early Childhood Care and Development Policy 2014 is unprecedented in Myanmar and is expected to have a major impact. Led by the MoSWRR in collaboration with other relevant ministries, the policy focuses on child and family development initiatives related to child development, nutrition and health, education, and the protection of all children aged 0 to 8 years. According to the policy, care is to be provided in holistic, high-quality and developmentally appropriate ways established through multisectoral coordination, while also being culturally and linguistically appropriate.

The policy is all-encompassing and disability-inclusive. Among many topics, it addresses conception; antenatal and postnatal education; health and nutrition care; parent education; early care and development; and health and nutrition care for children ages 0-3 years. Critically, it includes early childhood interventions for children with developmental delays, atypical behaviour, malnutrition, disabilities or chronic illnesses<sup>18</sup>. In addition to outlining legal, social and child protection services, it focuses on universal, affordable and inclusive preschool services as well as compulsory and inclusive kindergarten for children age 5 years, followed by inclusive primary schooling. In all, the policy highlights the need for pre- and in-service training, accountability and quality assurance, and advocacy and communication. In turn, this provides a positive model of disability inclusion that policymakers should be encouraged to follow.

#### **National Education Law**

The 2014 National Education Law and its 2015 amendment were designed to reform an out-of-date education system and represent one of many positive steps toward social cohesion taken by the government.

In fact, in the amendment it is explicitly mentioned that persons with disabilities should have an "equal opportunity" (rather than the "right") to an education, teacher education programmes should "produce teachers who can teach people with disabilities using appropriate teaching methods," and persons with disabilities should not face barriers to entering the teaching profession.

Equally important, for the first time in Myanmar, the law mentions the possibility of employing persons with disabilities as teachers.

At the same time, specific language found in the law continues to highlight the challenges that children with disabilities face while trying to achieve the right to an education in Myanmar, despite a constitutional guarantee that every citizen has the right to an education and "shall be given basic education, which the Union prescribes by law as compulsory."

<sup>17</sup> ibid

<sup>18</sup> DSW, with technical support from UNICEF and the Leprosy Mission Myanmar, is supporting the implemention of this component through the piloting of international tools to develop an early childhood intervention system. It is expected that the system, once operational, will yield further data on children with disabilities.

Key issues remain since the education of children with disabilities traditionally was deemed the responsibility of special schools that were not necessarily under the Ministry of Education. The law defines "special education" programmes as "the establishment of schools which have special programmes to teach disabled children."<sup>19</sup> In a clear attempt to align the legislation with efforts to mainstream disability, the term "inclusive education" was added to the law in the 2015 amendment and was defined as "a programme that creates opportunity for persons who lack access to education, including disabled persons, to learn through formal or non-formal education."<sup>20</sup>

However, as the forthcoming General Comment on Article 24 of the CRPD will specify, to be truly inclusive and in compliance with the convention, national legislation will be obliged to define inclusive education according to certain minimum standards and to ensure clarity of implementation. Therefore, it will be necessary for the Myanmar law to remove references to "special education" or the setting up of special schools for persons with disabilities. This likewise will need to be applied to the 2015 amendment, which continues to equate inclusive education with "special education."

On an encouraging note, the amendment, in keeping with the definition of "persons with disabilities" proposed by the CRPD, proposes a much broader approach to learner diversity than the original law itself, mentioning "gifted or disabled persons, and those with learning difficulties." For the first time, it also highlights second-chance education for those students who drop out – a particularly important first step to ensuring that children with disabilities who have not transitioned from primary to secondary school, or who have never attended school, have an opportunity to complete basic education.

Lastly, the law makes parents and guardians largely responsible for ensuring the enrolment of school-aged children and their completion of compulsory education. At the same time, it takes an important step to address social responsibility – and perhaps to prompt community leaders to engage all children and youth in community life – by also emphasizing that "all members of a neighbourhood or village shall participate to ensure that the children in their community"<sup>21</sup> complete their education. Even so, other barriers and bottlenecks that restrict access to education for children with disabilities will need to be addressed concurrently.

#### 1.3 Defining disability

UNICEF and all United Nations agencies conceptualize disability through the lens of human rights. Since the global adoption of the CRPD in 2006, UNICEF has worldwide explicitly clarified that the convention does not propose additional rights for children with disabilities. Rather, it emphasizes "that children with disabilities should have full enjoyment of all human rights and fundamental freedoms on an equal basis with other children, (...) recalling obligations to that end undertaken by state parties to the Convention on the Rights of the Child." According to the CRC, children with disabilities are "children first" – a human right that extends to all children. Nonetheless, a fundamental question needs to be considered: What is disability? This is examined below.

<sup>19</sup> Ministry of Education (2014) Unofficial translation of the National Education Law: unpublished, Chapter 1, x)

<sup>20</sup> Law ammending the National Education Law, unofficial translation, 2015 Paragraph 2, c),

<sup>21</sup> Ibid, Chapter 8, Paragraph 48

#### What is disability?<sup>22</sup>

Article 1 of the CRPD describes persons with disabilities as "those who have long-term physical, mental, intellectual or sensory impairments, which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others." This definition results from substantial evolution in the way in which disability is understood. Three main models have been used in this regard:

- The charity model, which is the most outdated, conceptualizes disability as a punishment or tragedy, usually with the intervention of a deity. Under this model, the individual is seen as needy and pitiful, and can only find salvation or well-being through the mercy, love and care of others.
- The medical model, arguably still the most common around the world, conceptualizes disability as a physiological condition of the individual, a condition, illness or disease that needs to be treated and cured with the assistance of health professionals.
- The most recent model, the social model, developed from an increased understanding of barriers that prevent the participation of persons with disabilities. It maintains that disability results from interactions by an individual with specific physical, intellectual, sensory or mental health impairments and the surrounding social and cultural environment. Disability is therefore understood as a socio-political construct, with the attitudinal, environmental and institutional barriers that inherently exist within any society systematically excluding and discriminating against people with disabilities. However, as a construct, it can be challenged and changed.

The social model is the only one of these models in line with a human rights-based approach to disability. It is also consistent with the World Health Organization's International Classification of Functioning, Disability and Health (ICF), which conceptualizes a person's level of functioning as a dynamic interaction between her/his health conditions, environmental factors and personal factors. The ICF further defines functioning and disability as multidimensional concepts relating to:

- People's body functions and structures;
- · People's activities, and the life areas in which they participate; and
- Factors in the environment that affect these experiences.

In turn, these approaches acknowledge the importance of context and environment in enabling or disabling individuals from participating effectively within society.

<sup>22</sup> For more information, see: http://www.inclusive-education.org/sites/default/files/uploads/booklets/IE\_Webinar\_Booklet\_2.pdf

## SECTION II METHODS AND TOOLS



## 2. Objectives, design, methodology and limitations

#### 2.1 Objectives of the situation analysis

The SitAn was conducted with two broad objectives: (1) to gather evidence on the situation of children with disabilities in Myanmar, specifically with respect to the availability and accessibility of services, together with an assessment of barriers leading to their social exclusion and (2), to estimate the prevalence of disability among children in select townships to inform planners at the local level. Within these broad objectives, the SitAn focused on the following (see Box 2.1 below):

#### Box 2.1: Two SitAn objectives

#### **Objective 1 – Situation analysis of children with disabilities**

- Ease of access, quality of services received, and experience and perception regarding important social services such as education, health and social welfare.
- Participation and extent of inclusion of children with disabilities in the local community.
- Nature of the protective environment at home, at service delivery points like schools, and in communities, including attitudes of service providers and communities toward children with disabilities.
- Procedures for identification of disabilities and referral to health facilities, as well as availability of protocols for prevention, treatment and follow-up of identified cases at the health service level.
- Ability and readiness of the Myanmar education system (formal and non-formal schools, monastic education providers, and early childhood development centres) for the inclusion of children with disabilities.
- Provision of community-based rehabilitation (CBR) services and recommendations for scaling up.

#### **Objective 2 – Estimation of the prevalence of disability among children**

• Estimate the prevalence of disability among children in Mon State and compare with two UNICEF education focus townships (Hlaing Thar Ya in Yangon and Myebon in Rakhine) based on a household survey utilising the Washington Group updated module for measuring child functioning and disability (CFD).

Based on assessments under the first objective, the SitAn intends to provide an in-depth analysis of the barriers affecting the social inclusion of children with disabilities in light of four key determinants: enabling environment, supply-side factors, demand-side factors, and issues related to quality of services. The second objective then aims to produce an estimate of the prevalence of disability among children in Mon State as evidence for strengthened local-level planning and an example for other regions/states in Myanmar.

#### 2.2 Design of the situation analysis

In line with its two objectives, the SitAn adopted a twofold research design:

## 2.2.1 Research design under Objective 1: Situation analysis of children with disabilities

Considering what is known about disability in the East Asia and Pacific region, as well as the little available national data from existing literature, it was assumed that Myanmar used a medical and/or charity model of disability. It was further considered that using traditional research methods and assumptions would not serve the purposes of this SitAn and would, in fact, perpetuate existing misconceptions about disability.

Therefore, this study was prepared on the basis of the global UNICEF Guidelines for Disability Analyses, with the research design under Objective 1 anchored by three pillars (Box 2.2):

#### Box 2.2: Research design for Objective 1

#### (1) Approach to the study:

Throughout the SitAn, disability is understood through the lens of the social model of disability rather than the medical or charity models. Because there is no official definition of disability in Myanmar – and because different stakeholders use different terminology, depending on their own understanding of disability – this study attempts to clarify and provide a standard model of acceptable language aligned with the CRPD, thus offering a baseline for future work. To illustrate stakeholders' responses or literature findings, exact translations have been used (in quotation marks and italics) to exemplify the current understanding of disability in Myanmar. However, this does not indicate agreement by UNICEF Myanmar or the research team with such statements.

#### (2) Parameters for the study:

In keeping with UNICEF's Guidelines for Disability Analyses, five key components guided the study:

- **Human rights-based approach**: The SitAn has reviewed Myanmar's efforts toward the implementation of the rights of children with disabilities as embodied in the CRC, Convention for the Elimination of All Forms of Discrimination Against Women (CEDAW) and the CRPD.
- **Equity**: To reach the most marginalized, the study attempted to include children with disabilities from different genders, with different types/severity/causes of disability, different ethnicities, and different geographic locations (e.g. rural/urban and townships). This was intended to ensure scrutiny of the availability of and accessibility to various services from diverse perspectives, as well as to assess all types of barriers faced by children with disabilities.
- **Social model**: The SitAn identified the attitudinal, environmental and institutional barriers (e.g., household economic conditions, communication barriers, and gaps in policies or their implementation) that limit/prevent children with disabilities in Myanmar from enjoying their full human rights in line with the CRC, the CEDAW and the CRPD.

- Inclusive development approach: Engagement and consultation with all stakeholders - specifically, children with disabilities, their families and disabled people's organisations (DPOs) - formed an integral part of this study, with the aim of promoting ownership and ensuring all voices are heard when setting priorities, planning, and during implementation and monitoring. However, it is also important to note various constraints in ensuring a participatory approach to the study, as has been done elsewhere.
- Life cycle approach: This SitAn takes into consideration children with disabilities across different age groups, as well as their dreams and aspirations for adult life. While several adults with disabilities were interviewed, it was only as key informants and not with the aim to gather data regarding their progress throughout the life cycle. To better understand the life cycle of persons with disabilities in Myanmar, a longitudinal study should be conducted.

#### (3) Process and means of analysis:

Data gathering was conducted by means of quantitative and qualitative methods, while analysis was completed by triangulating it according to the five parameters noted above. Data were collected through household surveys, key informant interviews (KIIs), focus group discussions (FGDs), and desk review from: (1) children with disabilities; (2) children without disabilities; (3) their parents and caregivers; (4) service providers at the grassroots level (education, health and social welfare); (5) community members; (6) policymakers (government officials at the national level); (7) DPOs; and (8) other development partners.

#### 2.2.2 Research design under Objective 2: Estimation of the prevalence of disability

The estimation of prevalence was carried out using quantitative data collected through a household survey in the selected townships (see Annexes 1, 2 and 3). However, supportive qualitative information also was collected through KIIs with local government officials/public service providers (health, education and social protection). The household survey was conducted through a scientific sampling process using a questionnaire prepared on the basis of the Extended Set of Questions on Child Disability (WG ES-C) and the Extended Set of Questions on Functioning (WG ES-F), which were proposed at the 13th annual meeting of the Washington Group (2013) and later revised.

#### 2.3 Methodology and activities under the situation analysis

Box 2.3: Phases of the SitAn			
Phase I: Study inception	Phase II: Desk review and fieldwork	Phase III: Analysis and validation	Phase IV: Report and dissemination
<ul> <li>Stakeholder mapping</li> <li>Sampling plan and strategy for identification and contacting stakeholders</li> <li>Research tools</li> <li>Quick desk review and draft analysis</li> </ul>	<ul> <li>Desk review</li> <li>Consultation with national level stakeholders</li> <li>Draft outline of the SitAn report after finalisation of the analysis plan</li> <li>Conducting of fieldwork</li> <li>Data entry, data</li> </ul>	<ul> <li>Conducting of analysis as per the plan</li> <li>Validation of findings with key stakeholders (e.g. DPOs)</li> </ul>	<ul> <li>Drafting, discussion with UNICEF and the DSW, and finalisation of the SitAn report</li> <li>Dissemination through a national conference</li> </ul>

- plan
- validation and cleaning

With regard to the methodological framework, broad activities under each of four phases are indicated Box 2.3. Activities conducted under Phase I are interrelated and common to both objectives. A detailed account of the sampling plans for each objective can be found in Annex 4.

### 2.4 Constraints

As may be expected when researching a relatively new field of study, preparation of the tools and methodology was lengthy. Most existing tools to measure and study disability are no longer acceptable and/or appropriate since the introduction of the UNCRPD, necessitating numerous discussions of the aims and methods of the study.

In turn, because little reliable and comparable data are available related to children with disabilities, both globally and locally, the choice of tools for data gathering for this SitAn became obvious given UNICEF's leadership in the field. UNICEF, in collaboration with the Washington Group on Disability Statistics, has been developing and testing data collection tools to be used with censuses and household surveys around the world. Under these, the CDM modules noted above are aligned with the social model of disability and the CRPD and focus on the presence/extent of functional difficulties rather than on the causes of those difficulties, e.g. body function, structure or conditions.

While there has been a great deal of interest on the part of the international community regarding these tools, they have not yet actually been published, which might represent a potential constraint. Nonetheless, the choice was made to utilise an innovative data collection method that is aligned with the social model of disability. At the same time, parents and caregivers of children were the main interlocutors in the research, and many children were not seen during household visits. Often, interviews occurred during the day, when children were at school.

Lastly, it was decided that a prevalence case study would be more useful if it provided an estimation for one state, not three separate townships as originally envisaged. Thus, it was decided to focus on Mon State, with the townships in Rakhine and Yangon States kept as control elements.

## SECTION III FINDINGS



## 3. General information: Children with disabilities

#### **KEY FINDINGS**

- 1. Boys account for 55 per cent of the children with disabilities in the study; 56 per cent of children with disabilities were found in urban areas; and the incidence of disability among childen is higher among the poorest.
- 2. Although Myanmar has been a signatory of the CRPD since 2011, and the law on the rights of the persons with disabilities includes a specific definition, no explicit or widely understood definition of disability (or associated common terminology) exists in the country.
- 3. Parents described 30 types of disabilities caused by physical impairments, but none associated with an environmental barrier.

The findings of this SitAn are holistically examined to determine the most pressing issues related to children with disabilities in Myanmar and take into consideration their most current challenges and opportunities. Overall, quantitative data (household surveys) are elaborated with qualitative findings (KIIs, FGDs) to particularly examine the social aspects of these children's lives, recognizing that further research will be needed in many other areas of inquiry. To the extent possible, diverse perspectives on the same issue are included, and in some cases extended views of findings, including regional analysis, can also be found in the annexes. Findings noted in each section's Key Points guide the overall recommendations provided in the last chapter.

Importantly, Voices of Children has also been added at the end of each section, thus highlighting the candid opinions of children with disabilities. Critically, the findings detailed in this section are strongly dependent on the barriers and bottlenecks elaborated in Section IV, which form the strong underpinning for all these findings.

Among the households surveyed for the SitAn, 55 per cent of the children with disabilities were



boys and 45 per cent were girls. These proportions largely hold for most age groups, except for the 2- to 4-year-olds, where the figures are nearly the same (51 per cent are boys, 49 per cent are girls).

At the same time, the percentage of children with disabilities in urban areas (56 per cent) is markedly higher than in rural areas (42 per cent). While further investigation into this finding is warranted, it may be indicative of limited professional facilities in rural areas for identifying disability, a point highlighted in interviews. Meanwhile, the greatest proportion of children with disabilities (24 per cent) come from the poorest fifth of the population, while the lowest proportion (18 per cent) is from the richest fifth of the population. However, as these figures indicate, the disparity between the richest and poorest children is not significant.

#### 3.1 How do stakeholders define disability?

Although Myanmar has an approved national disability law, as discussed in Section I, no explicit and widely understood definition of disability (or associated common terminology) yet exists in Myanmar. The current definition in the law was proposed by disabled persons organisations in concert with the government.

Most stakeholders were able to provide their own definitions/explanations of disability, but findings revealed that these were largely outdated and reflected a charity model that was not aligned with the CRPD's establishment of persons with disabilities as rights holders.

- All parents expressed disability as a physical impairment, with many reporting that their children were born with hearing impairment, speech impairment, or nervous system issues. Some, however, cited inappropriate medical treatment, illness or trauma as precipitating factors for the disability.
- Some township education officers (TEOs) reported that the definition of children with disabilities varies from school to school, but is generally along the lines of "those who were born disabled or born without limbs," those with impairments due to polio, and those born with "mental or learning" disabilities. Others described children with disabilities as those "who cannot do things that normal children can do, and cannot do as much as normal children." In a third example, disability again was understood as physical impairment, e.g. physical deformity or irregularity. In turn, this lack of coherent understanding of disability is reflected in the lists of children with disabilities compiled by the TEOs, which in many cases serve as the main data-gathering mechanism related to children with disabilities, which encompasses children with difficulty with upper or lower limb movements, children with visual impairments or difficulty with communication, children with impairments related to polio, and children who "have a low IQ."
- For health care professionals, a physical or mental condition that limits a person's movements, senses or activities, and physical or mental impairments, help to identify children with disabilities. Lastly, even if they do not have direct knowledge related to disability, community members' perceptions of children with disabilities also are important because they represent the general public. More than half of all the interviewed community members (107 out of 197) said they were aware of children with disabilities living among their friends, relatives and neighbours. The most common types of disability described by them were visible, or those easily identified, such as physical impairments (59 cases), polio-related impairments (19 cases), those originating at birth (84 cases), and those arising from the maladministration of immunisations in infancy (33 cases).

Amid this complex context, 88 per cent of the surveyed parents/caregivers reported their child had a single disability, while 11 per cent reported two types of disability. Parents/caregivers were able to identify 30 types of disabilities or limitations – and all were a physical condition –, but in no cases did they mention an environmental barrier such as accessible transportation or a lack of knowledge about sign language as disabling/limiting.

The most often-mentioned types of disability/limitation identified include: low IQ (23 per cent); mobility concerns (about 18-20 per cent); speech difficulties (about 12 per cent); deaf and mute (9 per cent); visual

impairment (about 7 per cent); and hearing impairment (about 2 per cent). Various other conditions comprise the remaining 27 per cent. It is noteworthy that the term "low IQ" was used frequently to convey a variety of conditions likely associated with intellectual impairments, but the term "intellectual/cognitive impairment" itself was never used.

With regard to the severity of disability/limitation among their children, 34 per cent of the surveyed parents/caregivers indicated "some difficulty," 40 per cent indicated "a lot of difficulty," and 26 per cent indicated that the child "cannot do anything without assistance" (see the annex to this chapter for more details). Interestingly, children age 5-9 years had the highest rate among the children who were not able to do anything without assistance. The reasons for this are unclear.



In terms of gender, boys make up a larger percentage

than girls in all three groups of functional difficulties: 56.4 per cent have "some difficulty," 52.8 per cent have "a lot of difficulty" and 54.7 per cent "cannot do anything without assistance."




# 4. Daily life of the child

#### **KEY FINDINGS**

- 1. Three-fourths of the children with disabilities face challenges in leading their daily lives with ease;
- 2. A total of 67 per cent of the children with disabilities are out of the formal education system and do not attend school far higher than the 11 per cent of the children without disabilities who are not in school;
- 3. Shame may be as much a barrier to social inclusion for children with disabilities as parents' perceptions of threats of discrimination or bullying.

Children in Myanmar are traditionally expected to be hardworking and have little time for play and recreation. In general, their homes often lack age-specific development-oriented toys and they have limited access to safe, child-centred play environments.<sup>23</sup> At the same time, there exists a "widespread acceptance of working children and little evidence of children's participation in decisions affecting them in service provision."<sup>24</sup> These observations from the literature are verified in this research, both for children with and without disabilities.

Critically, data gathered from household surveys indicate that 75 per cent of the children with disabilities face challenges in leading their daily lives with ease.

While most difficulties in self-care arise from functional limitations due to impairments, limited environmental modifications/adaptations also affect children's ability to learn how to live independently (see section below). Thus, difficulties were reported in areas such as self-health and hygiene, eating, and changing clothes (for details, see the annex for this chapter). Although many children with disabilities can do things for themselves, it was found that from 44 to 60 per cent of the children with disabilities require assistance, with eating being the category where the highest proportion of children are independent. No differences by gender were available, but a sharp rise in independence was noted between the 5-9 age group and the 10-13 age group for all activities. A smaller increase in independence was seen with the 14-17 age group. In comparison, more than 70 per cent of the children without disabilities were reported to always independently perform activities related to personal hygiene, eating and changing clothes.

Despite the identified difficulties, one-third of the parents/caregivers reported that their children with disabilities have regular daily activities, such as going to school, playing with friends, studying, and sometimes helping with household chores. More than half of the children do these daily activities by themselves,

<sup>23</sup> Ministry of National Planning and Economic Development & UNICEF (2012), p. 89

<sup>24</sup> Ministry of National Planning and Economic Development & UNICEF (2012), p. xiv



with little or no assistance. Moreover, all the children with disabilities have hobbies or activities they enjoy doing, e.g. sports, art/entertainment, video games and repairing items. In this regard, they are not unlike the children without disabilities, almost all of whom attend school, help with household chores and have hobbies, although lower proportions of the children with disabilities do all these things. Significantly, however, some of the children with disabilities have to curtail their activities sometimes because of factors such as shame or bullying/teasing (see below).

Both sets of children also spend most of their time with their mothers. For example, of the 75 parents/ caregivers of children with disabilities interviewed, 55 were mothers. The remaining 20 were other family members.

In almost all cases, the children live at home, with only a very few spending time at daycare or at a grandparent's home. School attendance, seen as an extremely important part of the life of children and adolescents as a whole, particularly needs to be considered when exploring the daily life of children. While this theme is further discussed in other sections, it is important to note that at the time of this study, 67 per cent of the children with disabilities were out of the formal education system and did not attend school. Only three of the 75 parents/caregivers of children with disabilities reported that their children attend a regular school. One parent also reported that their child had to drop out due to their disability. In all, this represents an exponentially higher percentage of children out of school than among the children without disabilities, 11 per cent of whom do not attend school, according to the most recent national census.

In addition, an overwhelming 93 per cent of the 2- to 4-year-olds with disabilities have no exposure to school readiness programmes, while attendance of children with disabilities at monastic schools, vocational training centres and special schools was found to be negligible. All these data indicate a genuine need for action with regard to educational opportunities for children with disabilities.

Evidence indicates that a lack of support is felt by both children with and without disabilities with regard to enhanced participation in community life and has been documented elsewhere. Again, however, children with disabilities may face heightened barriers in this regard. Although little is found in the literature regarding the daily lives of children with disabilities, some documents indicate that many families are ashamed of these children, often not wanting to take them out of the house in the belief they may shame them when they are going out into the community.<sup>25</sup> The first Myanmar National Disability Survey, conducted in 2010, highlighted that "almost half of the population does not believe that [intellectually impaired children] are capable of engaging in simple tasks,"<sup>26</sup> and thus the assumption is made that they are excluded from

<sup>25</sup> Local Resource Center (2014), p. 31

<sup>26</sup> Department of Social Welfare and the Leprosy Mission International (2010), as cited by Local Resource Center (2014), p.6

society.<sup>27</sup> Likewise, findings from this study also indicate that shame may be a barrier to social inclusion among about half of the parents/caregivers, while the other half say they are concerned with the safety of their children and choose to shelter them from perceived dangers, discrimination and bullying.

<sup>27</sup> Local Resource Center (2014), p. 6





# 5. Caregiving and living environment

### **KEY FINDINGS**

- 1. Family members, especially mothers, are the main caregivers of children with disabilities.
- 2. Almost all parents of children with disabilities (99 per cent) have never been advised on the use of assistive technology/devices. However, 10 per cent had taken the initiative to provide their children with assistive devices.
- 3. Almost all the parents had never modified the physical environment to make daily life easier for their child.

According to government documents from 2014, basic child development services are often remote or inaccessible. In particular, the remoteness of a location along with the cost of services frequently act to effectively marginalise many communities, which is of special concern since most of the people in Myanmar live in rural areas. This adds to the complexity of ensuring that children with disabilities obtain appropriate and adequate services.

The findings in this report support the existing literature and confirm that family members – especially mothers – are the main caregivers for all children, including children with disabilities. Of the 75 parents/ caregivers of children with disabilities interviewed, eight prepare everything their children might need



throughout the day before they go to work, or they leave the children with other family members who can help them with their needs. No parent reported having hired help for this task. Only one parent/caregiver reported that they provide care and assistance doing most daily chores such as preparing meals, bathing or going to the toilet. Almost half of the parents reported that taking care of their children does not impinge on other tasks, but more than 1 in 4 (21 parents) indicated that they could not find adequate time for other household tasks because of the extra care required for their child with disabilities. Most of the parents/ caregivers think they spend enough time with their children with disabilities, with nearly 2 in 3 saying that their children with disabilities receive more care and attention from them than the other children in the household. When parents cannot spend time with their children with disabilities, an aunt or grandmother often does so, although other family members – the father, an uncle or siblings – also may assist.

As noted in the chapter above, children with disabilities are less able to assist with household chores compared to children without disabilities. For example, children with disabilities participate most in cleaning/ washing activities (32 per cent) and taking care of livestock (27 per cent), and children without disabilities contribute mostly to cleaning (60 percent), taking care of livestock (56 per cent), and cooking (35 per cent). Those without disabilities are also more likely (10 per cent more) than children with disabilities to do such chores as going to market or look after other children in the family. Overall, neither sets of children do most household chores on a regular basis, although exceptions were found with regard to cleaning and taking care of livestock. Moreover, few gender differences were seen, with boys and girls from both sets of children participating equally in chores.

Despite the critical role of assistive devices in ensuring the self-sufficiency of children with disabilities, almost all the parents/caregivers and children with disabilities alike (99 per cent) reported never having received advice on the use of assistive devices to aid a child's mobility, vision or hearing. Nonetheless, 10 per cent of the parents/caregivers had provided their children with assistive devices on their own initiative. In turn, 65 per cent of the children who had used such devices (108 out of 165) were still using them at the time of the study, and the other 35 per cent had discontinued using them. Wheelchairs were the most commonly used assistive devices (for 33 per cent of children, or 36 out of 108), followed by crutches/walking sticks (25 per cent, or 27 out of 108). Spectacles, braces and hearing aids were among the other devices being used.

Critically, between 70 and 100 per cent of the parents who responded to questions related to potential environmental modifications said they had never felt a need to modify their physical environment or household structure to accommodate the requirements of their child with disabilities. This illustrates the depth of the challenges continuing to face children with disabilities in living without difficulty.



# 6. Community and social life

#### **KEY FINDINGS**

- 1. 20 per cent of the children with disabilities have reportedly been bullied by other children, and 13 per cent have been bullied by adults.
- 2. Only 11 per cent of the community members have observed children with disabilities participating in social life, indicating they are largely invisible.
- 3. Of all the children with disabilities, 16 per cent do not go out regularly and 15 per cent do not go out at all
- 4. One in every 10 children with disabilities does not have friends a far higher proportion than among the children without disabilities (1 in 25).
- 5. Only 20 per cent of the parents of children with disabilities are satisfied with the extent to which their children participate in social activities.

Engaging in community life plays a key role in ensuring equal opportunities for the growth and development of all children, and it is crucial to creating social inclusion opportunities for children with disabilities. In particular, social relationships in schools (with teachers, peers and parents) are a major enabling factor for many children with disabilities, allowing them to participate in everyday activities.<sup>28</sup> For comparison purposes, the same set of questions was asked of the parents/caregivers of children with and without disabilities.

Critically, a 2012 survey<sup>29</sup> found that in 71 per cent of the families who have at least one family member with a disability, he or she was often prevented from participating in community activities due to feelings of shame or necessities of care, leading to deepened discrimination and exclusion. Likewise, a report by the Ministry of National Planning and Economic Development and UNICEF, also published in 2012<sup>30</sup>, highlights that the most prevalent feeling of family members toward a person with disabilities is pity, again underscoring the persistence of the charity model as an approach to dealing with such persons.

Data from this study showed that perceptions regarding social interactions varied among stakeholders, with no differences for girls or boys with disabilities. Overall, 81 per cent of the children with disabilities reportedly faced the same treatment by the community, good or bad, as all the other children. For example, 79 per cent of the parents with children with disabilities said they felt that community members were generally understanding and supportive, a sentiment reflected in almost equal proportion (73 per cent) by

<sup>28</sup> ECDC & VSO, 2015

<sup>29</sup> Bawi, 2014

<sup>30</sup> Situation Analysis of Children in Myanmar

the parents/caregivers of children without disabilities. Notably, however, 20 per cent of the children with disabilities had reportedly been bullied by children, and 13 per cent had been bullied by adults.

Community members themselves largely agreed that all children, including children with disabilities, are entitled to a happy life. Even so, only 11 per cent of the community members have observed children with disabilities participating in social life, e.g. having friends, playing with friends and taking part in festivals. One participant from Moe Kaung said, "Sometimes I see children with disabilities playing with their friends," and another participant, from Shwepyitha, stated, "They participate in entertainment programmes and other festive activities in the community."

Despite such observations, however, this overall "invisibility" is particularly concerning because it perpetuates the idea that only a very small proportion of the population has a disability, and it indicates the potential that children with disabilities encounter shame and discrimination.

In all, the children with disabilities go out daily much less often than those without disabilities (69 per cent vs. 90 per cent). Significantly, of those children with disabilities who do not go out daily, 16 per cent do not go out regularly and 15 per cent do not go out at all – meaning that nearly 1 in 3 children with disabilities may not enjoy regular social contact outside the family. The parents/caregivers reported that sometimes no one is available to take the children out, while at other times, the children do not want to go out for fear of being teased by their peers.

Nearly all the parents interviewed (23of the 24 children without disabilities, and 64 of the 75 children with disabilities) reported that their children have friends. About 40 per cent of all the children in both groups reportedly spend



time with friends every day, often at each others' homes. Nevertheless, parents report that the interactions of the children with disabilities with friends differs from that of the children without disabilities. While the children with disabilities reportedly do have friends in and around their homes, and they are encouraged to make new friends, only one-third of them interact with friends regularly. Of those who do, many go to their friends' houses or their friends come to visit them. Importantly, however, more than 1 in every 10 children with disabilities do not have friends – a much higher percentage than that of the children without disabilities (1 in every 25). One parent reported that her child has no friends because of the risk of injury while playing, "which would be very painful for her." Another reported that other children discriminate against her child. "I never play, because I am worried that I might hurt others. I play with my elder brother. I only play with him. I have never participated in community events," reported one 13-year-old boy.

More than half (44 out of 75) of the children with disabilities reportedly participate in social activities, although the scope of these activities is generally much narrower than that of the children without disabilities, who may participate in a wide variety of events, including sports, games, fairs, school events, religious festivals, charities, wedding receptions and funeral rites, among others. Two children with disabilities said they participate socially by helping in a monastery during religious festivals, and one parent reported that her child "participates in almost all social and cultural events, and many people in [the] village love him." In all, the numbers of girls with disabilities who participate in social events is slightly less than the number of boys. In addition, only a few children with disabilities participate without family members, neighbours and community members assisting them by taking them to places.

About one-third of the children with disabilities (23 out of 75) say they are able to go to festivals and social

activities along with their family, but this is far less than the 58 per cent of the children without disabilities. In what may reflect a common perception, one caregiver mentioned that it is a burden for the family to go out socially with their child with a disability, who cannot walk on her own.

Significantly, the proportion of the parents/ caregivers of children with disabilities and the children without disabilities who are "satisfied to a great extent" with their children's participation in social/cultural events varies widely. Only 20 per cent of the parents/caregivers of children with disabilities report a great extent of satisfaction, compared to more than twice that



number (46 per cent) among the parents of children without disabilities. Nonetheless, this means that more than half of the parents of all children are less than fully satisfied in this regard. At the same time, far more parents/caregivers of children with disabilities (33 per cent) than those of children without disabilities (11 per cent) say they are not satisfied.

A notable percentage (15 per cent) of the parents/caregivers of children with disabilities reported that they ensured their children were brought to social events more than their siblings were. 29 per cent reportedly brought their children, both those with and those without disabilities, to events the same amount of times. However, 39 per cent of the parents said that they either brought the children with disabilities to social events fewer times than their other children, or they did not bring them at all. Only 24 per cent of the parents of children with disabilities said their children faced resistance attending such events, and there was no difference in the findings for girls and boys. Nevertheless, it is interesting that only one-third of the parents/caregivers (23 out of 75) of children with disabilities think their friends, neighbours or community leaders do not pose obstacles to their child's participation in community activities. About 16 per cent of the parents (4 out of 24) indicated that children with disabilities do not participate at all because of their immobility, their lack of interest in social life, or because their parents could not take them. Within the government, officials at the Department of Social Welfare (DSW) said they agree that children with disabilities do not have many opportunities to participate in social and community activities and are rarely seen at these events as a whole. They



report that measures are being taken to fulfil the right to social inclusion for children with disabilities by including them in sports activities for persons with disabilities as well as in other (unspecified) events.

An important finding in this study is related to agreement among the parents/caregivers of children both with and without disabilities that having a child with a disability in the household is not a source of shame.

An overwhelming 89 per cent of the parents/caregivers strongly

disagreed or disagreed with the idea that children with disabilities are a source of embarrassment. Even in households without children with disabilities, 62 per cent of the parents said they felt that there was no embarrassment associated with having a child with disability.

Most parents/caregivers also reported receiving little assistance from the community, which is similar to results for the parents of children without disabilities with regard to health, financial or routine services. Education was



the only one of the four service categories where a marked discrepancy was recorded, with 11 per cent of the parents/caregivers of children without disabilities reporting community help versus 7 per cent among the parents of children with disabilities.

Indicating the extent of the remaining challenges of awareness raising on disability in Myanmar, the overwhelming majority of the parents/caregivers of all the children (93 per cent) could not recall any public advocacy campaigns related to disability. Of the few who could recall such campaigns, most were from Yangon, the capital. Likewise, 96 per cent of the parents/caregivers had not heard of community-based rehabilitation services for children with disabilities and had never heard of the CRPD.

#### **DPO perspectives**

As one of the few DPOs in the country, the Myanmar Independent Living Initiative (MILI) operates out of Yangon. Although considerable progress has been seen in recent years for persons with disabilities and the number of DPOs is increasing – including outside of Yangon –, MILI officials say it has been difficult to include persons with disabilities in the development process. By and large, persons with disabilities are still looked at as charity cases and beneficiaries, not rights holders, MILI officials say. For the most part, NGOs and some DPOs do not include children with disabilities in their programming. Likewise, many in the disability community believe that government planning, policy development and/or mechanisms of implementation related to persons with disabilities do not include DPOs, although findings of this study contradict this claim. Coordination among the DPOs also has proven difficult, and little cross-sectoral work related to children with disabilities has occurred.



# 7. Right to education

### **KEY FINDINGS**

- 1. 2 in 3 children with disabilities on not attend school, and in 46 instances schools also refused admission to a child with disability.
- More than half of the children with disabilities aged 5-9 years reported receiving no education, and only 36 per cent of the children with disabilities know how to read and/or write.
- 3. Most schools do not have accessible facilities for students with disabilities (55 per cent of the clasroooms and 74 per cent of the toilets).
- 4. It is particularly difficulty for children with disabilities to complete a full cycle of basic education, especially for girls. Only 2.2 % of the children with disabilities were in high school.
- 5. Among education professionals, the idea strongly persists that children with disabilities should attend "special schools" (75 per cent).
- 6. Nearly 1 in 3 of the parents/caregivers of children with disabilities said their children had been mocked or bullied in the classroom.

# 7.1 The education system

Education is an important component in ensuring that persons with disabilities know about and can claim their rights. In Myanmar, the education-related legislative and policy landscapes remain in transition. A recent positive indicator for education overall is that the country's basic education system has expanded, with a 10.4 per cent increase in the number of schools, a 30.4 per cent increase in the number of teachers, and a 24.5 per cent increase in the number of students.<sup>31</sup> Under the National Education Law, further expansion of the education system to 12 years of compulsory schooling plus kindergarten is envisioned. Sharp rises also have been recorded in both monastic schools (46.3 per cent) and monastic school students (81.0 per cent). These students are typically from low-income families.<sup>32</sup>

Yet access to and the quality of education continues to be a key concern. The use of teaching methods that promote child-centred, family-focused and developmentally appropriate learning still needs further strengthening and is particularly linked to the urgent need for a formal pre-service training system for professionals

<sup>31</sup> MoE, 2014 cited by UNESCO, 2015

<sup>32</sup> MoRA, 2014 cited by UNESCO, 2015

in early childhood care and education. In 2012, for example, 24 per cent of the early childhood care and education teachers were not trained.<sup>33</sup> While an early childhood care and development policy exists, many parents and communities are still not aware of the importance of ECCE, including for children with disabilities, necessitating the implementation of a system that employs all media to provide relevant advocacy and communication across the country. With only 22.9 per cent of all the preschool-age children – most from middle- to high-income urban families – having access to preschool services, investment in complementary services such as parent education/support, mother circles, home visits and quality day care that are culturally and linguistically appropriate becomes increasingly essential.<sup>34</sup> Creation of a nationwide kindergarten programme to facilitate the transition between pre-school and the early grades of primary school, to be introduced in the 2016-17 school year, also will aid efforts toward a standardised system of education, including for children with disabilities.<sup>35</sup>

Primary education has been found to be very inefficient in recent years. For the average child to complete primary school, for example, 9.4 years were required in 2007, rather than the expected 5 years.<sup>36</sup> Surveys of secondary schools and monastic schools have concluded that the education infrastructure requires significant strengthening. Critically, the availability of classes taught in the more than 100 local languages in Myanmar would likewise be an important step toward ensuring that all children succeed in school.

### 7.2 Children with disabilities in the education system

The situation of children with disabilities within the Myanmar education system must be contextualized within the above analysis of the challenges within the overall education system in the country. According to the First Myanmar Basic Disability Survey, which gathered data in 2008-2009, one in every two persons with disabilities (PWDs) has never attended school. Inclusive education – here understood as the integration of children with disabilities in mainstream schools – was initiated for children who are mentally or physically handicapped, deficient in sight and hearing, or socially excluded and those who have difficulty attending school or dropped out of school before completing their education. This encompassed basic education schools, non-formal primary education programmes, monastic schools and special schools for children with visual and/or hearing impairements.

By the 2011-2012 school year, 9,738 students with disabilities were registered at basic education primary schools, 11,536 at basic education middle schools, and 47 at basic education high schools.<sup>37</sup> In addition, 1,450 children with disabilities were enroled in special schools,<sup>38</sup> but while there have been some significant legislative provisions, there are still many barriers to receiving a proper education due to a lack of technical skills and a lack of qualified special education teachers,<sup>39</sup> particularly for children with intellectual impairments. Numerous such children are reported to have been denied enrolment in mainstream schools, despite a recent study that found social relationships in school are a major enabling factor for many children with disabilities to participate in everyday activities.<sup>40</sup>

In a 2015 study by the ECDC and the VSO, it was found that "intellectually impaired children were less likely to go to school than children with physical disabilities because of the general perception that they would not benefit from an education."<sup>41</sup> Overall, the three most cited reasons by parents for keeping their children with disabilities out of school were: impairment, which was rarely mentioned as the only factor; financial reasons; and difficulties with teachers. In addition, most schools did not have accessible facilities for students with

<sup>33</sup> UNESCO Institute of Statistics, 2012, as cited by The Republic of the Union of Myanmar, 2014, p. 29

<sup>34</sup> MNPED & MoH & UNICEF, 2010; The Republic of the Union of Myanmar, 2014

<sup>35</sup> UNESCO, 2015; The Republic of Myanmar, 2014

<sup>36</sup> UIS website (2012), as cited by The Republic of the Union of Myanmar, 2014, p. 29

<sup>37</sup> MoE (2014), as cited by UNESCO, 2015, p.17

<sup>38</sup> MoE (2012, 2014) as cited by ECDC & VSO, 2015, p. 19

<sup>39</sup> Local Resource Center (2014)

<sup>40</sup> Local Resource Center (2014)

<sup>41</sup> Ibid. p. 21

disabilities (55 per cent of the classrooms and 74 per cent of the toilets). Only 2 per cent of the schools collected information regarding disability.

#### 7.3 Current challenges

Again, it is important to note that many of the concerns related to the Myanmar education system are not specific to children with disabilities, rather they are indicative of a system undergoing deep transformations. Numerous findings from this study confirm the challenges already highlighted above, which cut across most areas of the system. Yet as evidenced below, these challenges are often felt more by children from vulnerable and marginalised populations, such as children with disabilities. A persistent and deeply rooted lack of understanding of education as a right all children have, including children with disabilities – as evidenced by misconceptions associated with the need for special schools, not to mention the traditionally accepted charity model of disability – , contributes to difficulties in providing a clear legal framework and associated implementation road map for inclusive education.

Overall, 67 per cent of the children with disabilities were not in school, compared to a much lower – but still high – 19 per cent of children without disabilities. Moreover, in 46 instances, schools had refused admission to a child perceived as having a disability.

While both rates of out-of-school children are cause for serious concern, the disproportionate number of children with disabilities clearly indicates that factors leading to non-attendance are exacerbated for children with disabilities.

At the same time, the proportion of boys and girls across the two categories was nearly the same, indicating that both boys and girls face similar barriers in accessing education.

Attendance declines as children progress in age. While 41 per cent of the children with disabilities age 10-13 years were attending school, only 20 per cent of the 14- to 17-year-olds were, indicating that half of all the children with disabilities drop out between ages 14 and 17. In addition, this is one of the few instances where gender-based disparities were observed: While the proportion of girls attending school was generally the same as boys across the age groups, in the 14- to 17-year-old cohort, the proportion of girls attending school was significantly lower





(16 per cent) than that of boys (23 per cent). Interestingly, this trend is the opposite of that observed for children without disabilities, where boys drop out of post-primary level at a higher rate than girls.

Education attainment also declines as the child progresses in age, with only about 29 per cent of the children with disabilities in the 14- to 17-year-old cohort having completed secondary education. Most children, both with and without disabilities, start dropping out of school after completing primary education.

Of special concern is the number of children with disabilities who have never had the opportunity to attend school. Not surprisingly, 97 per cent of the parents/caregivers of children with disabilities age 2-4 years

reported their children had received no education, but it is notable that even in the age group 5-9 years, 56 per cent of the parents/caregivers reported no education. Rates of no education were very high in the two other age cohorts: 41 per cent of the children with disabilities age 10-13 years and 45 per cent of the parents/ caregivers of children with disabilities age 14-17 years. Just 36 per cent of the children with disabilities knew how to read and/or write.

#### Table 7.1:

Distribution of children age 6-17 years by level of education and status of disability (%)

Education	Children with disabilities	Children without disabilities	All	
Preschool /ECCD	5.9	1.6	4.0	
Primary	36.2	52.8	43.7	
Middle	9.7	34.3	20.7	
High School	2.2	9.9	5.7	
University	0.0	0.8	0.4	
None	46.0	0.6	25.6	
Total	100.0	100.0	100.0	

#### Table 7.2:

Distribution of children with disabilities by level of education and age group (%)

Education	2-4 years	5-9 years	10-13 years	14-17 years	Total
Preschool / ECCD	2.7	9.5	4.1	4.5	5.7
Primary	0.0	34.0	41.6	28.1	30.7
Middle	0.0	0.0	12.9	15.2	8.1
High School	0.0	0.0	0.0	6.9	1.8
None	97.3	56.5	41.3	45.4	53.6
Total	100.0	100.0	100.0	100.0	100.0

Community members, including the parents/caregivers of children without disabilities, are divided in their opinion of whether or not children with disabilities should attend mainstream schools. Although all community members interviewed agree that children with disabilities should seek education, two-thirds of them (135 out of 197) indicated that studying in special schools would be in the best interest of a child with disability.

### 7.4 Education officials' perspectives

All the parents of both children with and without disabilities, as well as the vast majority of community members, identify education as the pathway to a successful and independent life for any child. As one parent indicated, "I hope my child will be successful in life. I want to send him to a good school. If he gets to go to a good school, he will get a better education." Likewise, in almost all cases both the children with and those without disabilities equate going to school and being a hard-working student with becoming a professional, which in turn leads to becoming a self-sufficient adult.

At the same time, however, data gathered for the SitAn show that not all education officials, teachers and principals consider education in a mainstream environment as a right all children have, including children with disabilities (see this sub-section and also the sub-section below). Similarly, there is no indication that they believe or understand that placing children with disabilities into special schools, as well as failing to ensure that teachers are supported in the classroom to adequately teach children with disabilities, are fundamental contraventions of these children's rights.

Township education officials (TEOs), principals and teachers all agree that legislation, policy, guidelines and

resources (both human and financial) are insufficient to adequately provide education to children with disabilities (detailed descriptions of the data collected in interviews can be found in Annex 4). All mentioned a lack of materials, a lack of adequate infrastructure, and a lack of technical capacity as particular barriers to education for children with disabilities. Again, however, it must be noted that most of these challenges are not specific to children with disabilities and instead reflect the needs of the entire education system.

Some TEOs said they felt existing legislation was sufficient to address the integration of children with disabilities into mainstream education, but others indicated the need for formal government instructions and/ or guidelines. One official stated, "If there is a legal framework, the more the general public and teachers will become aware of children with disabilities and better understand their rights." Adequate learning materials, when they exist, are not available to all schools, and training opportunities do not cover all regions and townships. While very few questions related to budgeting were answered, education officials said they believed that separate budget allocations for children with disabilities would allow schools to better provide educational services, facilitate better infrastructure and learning equipment, and employ better teachers for those with special needs.

Beyond issues related to resources, however, the TEOs do not agree as to whether the education of children with disabilities should take place in mainstream or special schools. Moreover, further probing revealed that some children with disabilities perceived to be severe are often encouraged to attend special schools. Reportedly, the DBE facilitates/prioritises the enrolment of children with disabilities with severe conditions in special schools if they do not wish to attend a mainstream school or feel too "shy to go to a mainstream school together with normal children." However, only a few special schools in three cities. Because there are no township-run special schools for children with disabilities, those with perceived severe disabilities must either enrol in a special school away from home or, far more likely, drop out of school altogether.

Among all those interviewed, a strong belief was found that special schools are better equipped to provide children with disabilities with an education that is specific to a particular impairment, with a specific curriculum, materials, instructors and so on. According to the TEOs, some children with disabilities, e.g. those who are hearing- or visually-impaired, need additional support and special learning equipment. Almost all of the TEOs (9 out of 10) indicated that it would be more effective if children with disabilities were provided education separately so that they "could get a chance to improve themselves, and some good students could come out as a result."

Concern also exists with regard to the presence of children with disabilities in a mainstream classroom potentially lowering the level of achievement for all the students. One TEO said, "If [children with disabilities] are mixed with normal students, it would slow down the class and it wouldn't be effective for those with disabilities and those without. Classes that provide special needs for children with disabilities would be much beneficial for them." One education official indicated that special schools could serve the purpose of employing teachers with disabilities, since they would be able to provide the understanding needed to care for children with (similar) disabilities. At the time of the interviews, the Department of Basic Education employed persons with disabilities in office staff positions but not in teaching jobs, although this differentiation has been addressed in the new Education Law.

Education officials further distinguished between students who should be in special schools – those with "severe conditions" – and those who should attend mainstream schools, with the latter comprised of "those who are physically disabled but mentally able and are intellectually equal to normal children." Going to school together with children without disabilities would "encourage them more psychologically because they would feel they are equal to normal children." Even so, according to many respondents, mainstream schools are only designed to provide education services to "normal children," and thus are not appropriate for children with disabilities. Because a classroom has many children, this argument asserts, teachers might not be able to give full attention to all the children as needed. In addition, children with disabilities who attend mainstream schools are likely to be discriminated against by other children, which "could be depressing for children with disabilities."

Overall, education officials' expectations of children with disabilities are quite low. This opinion matters greatly because education officials are responsible for implementing legislation and policies as well as leading by example. In turn, this indicates that if inclusive education is to become a systemic reality in Myanmar, a great deal of attitudinal change will have to occur at all levels, given that inclusive professionals are those able/willing to envision children with disabilities as rights holders. There are currently very few such people in the country, although they agree with the CRPD that when children with disabilities are separated from other children, their learning environment is restricted and a smaller variety of subjects/courses is taught. Furthermore, these officials state that children with disabilities do not like being treated differently than other children or "with sympathy." "They feel proud knowing that they can also do things normal children can do. They usually try to do things normal children would do. In one case, there was a child with 11 fingers, who was usually mocked by other children during math class. She felt embarrassed each time and later left school."

Children without disabilities may not be the only ones who are uncomfortable with having children with disabilities in their classrooms. According to TEOs, some of the parents of children without disabilities do not like their children being friends with children with disabilities, and even some teachers do not like to have children with disabilities in their classrooms.

For the most part, education officials' perceptions are based on oral reports and not on actual observations or personal assessments in situ in either regular or special schools. Only a few education officials mentioned that there were teachers who provide extra care to children with disabilities with special needs in their classrooms. Worryingly, more than half of the education officials were not able to provide specific suggestions as to what support would be needed to ensure quality education for children with disabilities. Future education policy and guidance notes for professionals will need to include methods of decision making set against strict criteria for observation, consultation and the monitoring of progress, thereby ensuring that decisions are made with a minimum of individual/systemic bias. Moreover, who is considered a child with disability varies from school to school, and only one-third of the schools collect data on/list such children. Likewise, the purpose and use of these lists varies widely.

In addition, only one education official interviewed had attended training related to disability mainstreaming. In this regard it was suggested by the participants that future trainings "teach techniques on how to approach and teach different kinds of children with disabilities," "what curriculum is suitable for children with disabilities," and "how to psychologically encourage children with disabilities." Officials also expressed the need for coordination with DPOs/NGOs, the government, the DBE and the public when planning programmes for children with disabilities. Lastly, they expressed the need to learn from other countries about what types of successful education systems are in place for children with disabilities.

#### 7.5 Principals' and teachers' perspectives

Like the TEOs, the 40 principals and teachers interviewed for the SitAn have largely never been trained on topics related to teaching children with disabilities. However, in each of the schools involved, from 1 to 10 children with disabilities are enroled, with boys outnumbering girls. Most reportedly come from "well-off" households. About half of the teachers and principals reported that these students attend with someone's help. They stated that parents take their children with disabilities to school, "and friends help them carry their bags." The largest proportion of students with disabilities have physical impairments, followed by those with visual impairments and those with difficulty with communication (speaking). Only one school has a toilet that children with disabilities could use, and none has made any disability-friendly modifications to infrastructure to comply with the newly enacted National Building Code regulations.

The principals and teachers interviewed for this study have never been trained in subjects related to children with disabilities, despite having attended professional development sessions on various themes. Thus, confirming the opinions of both TEOs and parents, most teachers indicated that they teach children with disabilities in the same way as other students in their classes. Concurrently, they did not report experiencing any specific challenges teaching children with disabilities. Two teachers reported that children with

disabilities at their schools are treated more favourably than others or are further encouraged, while five teachers said that children with disabilities are taught one-on-one if they are falling behind. Three mentioned that they are taught at a slower pace if they cannot follow the lessons. Other measures taken to ensure that children with disabilities are not left behind academically include: "not scolding them or administer-ing corporal punishment for their weaknesses;" "teaching them again and again until they understand the lessons," and "requesting that parents help their children with their school lessons." Learning assessments are reportedly conducted the same way for all children.

A large majority of the principals and teachers said that children with disabilities are not bullied, teased or abused at their schools, in direct contradiction to reports from parents/caregivers and children with disabilities themselves. Six schools specifically mentioned that children with disabilities are involved in their school clubs, although this was not mentioned by any parents/caregivers or children themselves. While all the reports should be taken with caution, it is important that future professional development opportunities address the potential issue of abuse and bullying, making clear the fact that different stakeholders perceive and respond to bullying in different ways.

In all, the principals and teachers said they believe that children with disabilities are not accepted at schools due to their disabilities. Three-quarters of them indicated that children with disabilities should attend special schools because "it is in their best interest" and because "they will learn more when in special schools and will not encounter any mistreatments that they might possibly face in regular schools."

Again, it is believed that special schools are better equipped to provide education to children with disabilities. Very few alternatives were cited. One teacher said that some religious schools accommodate children with disabilities, while another reported on a programme organised by township authorities in Sekotaya, under which schooling at home is provided to ensure the child is able to communicate with others. However, no academic subjects are taught.

### 7.6 Parents' perspectives

According to interviews with 24 parents of children without disabilities, all of their children attend mainstream schools and are generally considered happy at school. Most walk to school on their own or with friends. Only three parents were aware of having children with disabilities in the school, and most said children with disabilities should attend special schools.

However, the situation of the children with disabilities from the 75 families interviewed is markedly different. Only one-third (27) attend mainstream schools, while five others were enroled in mainstream schools but

no longer attend. Two children have had to repeat a grade, and one parent indicated that her child cannot keep up with school demands. Only one child is attending a special school, while nine school-age children have never been in any type of educational setting.

Different views were found on the extent to which schools fulfil the learning needs of children with disabilities. One parent felt the school budget was insufficient to meet children's needs, while 1 in 5 parents indicated that just getting their child to school can be challenging. Nearly all parents (97 per cent) reported that their children attended school within 0-2 miles from



home. Indeed, how close the school is to the home (accessibility), quality and lack of alternatives emerged as the prime determinants behind the selection of a school.

All but two children with disabilities can access all parts of their schools with or without assistance. Only one child can not go to most places inside the school without assistance. Some 27 per cent of the parents/ caregivers of children with disabilities reported they were not satisfied with the physical infrastructure available at school.

Many parents/caregivers of children with disabilities said that children found it discouraging to go to school for reasons such as not fitting in with classmates; teachers not being supportive of their disabilities; not doing as well in school as their classmates; failing some grades; and not being able to make friends like their classmates. A total of 32 per cent of the parents/caregivers of children with disabilities reported their children having been mocked or bullied at school - by classmates and teachers alike -, while only 11 per cent of the parents/caregivers of children without disabilities reported the same problem. One mother reported carrying her child to school on her back and asking teachers "to teach her child as a normal child with a regular school curriculum." However, her child failed a grade three times, became depressed, and did not want to go to school anymore. The child now attends private classes. Another parent recounted that her child was initially willing to go to school, but later felt embarrassed because he could not speak like the other children. A third parent mentioned that her child did not want to go to school because "he often got wrongly accused and beaten since he could not speak." Despite these observations, however, more than 80 per cent of all the parents, both those with of children with disabilities and those who have children without disabilities, said they were fully satisfied with the behavior and attitude of the teachers toward their children, and more than 90 per cent were satisfied with the services rendered by the schools. Meanwhile, almost half (45 per cent) of the parents/caregivers of children with disabilities reported that their child had other children with disabilities as friends. However, in the case of children without disabilities, this proportion was much lower, only 28 per cent.

Most of the parents of children with disabilities said they would like their children to at least learn to read and write, and they appeared to value basic education regardless of the setting. At the same time, 66 per cent of the parents/caregivers of children with disabilities indicated that student assessments were not adapted to the learning needs of their children. Of the 40 parents/caregivers with out-of-school children, only two did not want to send their child to school, one because the child was "too young" and the other because the child had to see a doctor every year.

# 7.7 Community members' perspectives

A substantial majority of the community members' comments related to the education of children with disabilities were focused on the provision of vocational training. In their opinion, vocational training should be provided in handicrafts, arts and painting, sewing and embroidery, and electronic device/electrical appliance repair.

While many community members who participated in FGDs suggested that children's individual talents should be enhanced, e.g. "They should be taught how to sing or play piano," others stressed that vocational training should aim to prepare children with disabilities to "be independent and enable them to stand on their own feet." Among the observations were: "Once the children reach the age of 14, it should be ok for them to work. They can earn money and learn professional skills at the same time," and "Children with disabilities can make their own living if they have a job."

# 7.8 NGOs' perspectives

Interviews with NGOs revealed the perception that the NGO and DPO landscape in Myanmar is fragmented, with few or no coordinating mechanisms available, including for inclusive education. While a long tradition of acceptance of children with disabilities in mainstream schools was acknowledged, NGOs cited numerous difficulties related to the lack of technical capacity in mainstream schools, as well as stigma associated with disability that prevents some parents from enroling children with disabilities in mainstream schools. NGO

officials said they felt that a change in policy, with an explicit law on inclusive education as well as capacity development for professionals at all levels related to the CRPD, is essential.





# 8. Right to health

### **KEY FINDINGS**

- 1. 64 per cent of the parents/caregivers of children with disabilities say they were the first persons to identify a disability.
- 2. Health professionals, particularly in rural areas, do not have specific procedures for identifying children with disabilities, e.g. early detection and prevention services, and few health professionals have more than basic knowledge about community-based rehabilitation.
- 3. Although about 1 in 3 children with disabilities requires regular visits to a health facility, 87 per cent of the parents of children with disabilities do not visit the doctor, and of those who do go, half visit private clinics

# 8.1 Background

Many children, including those with developmental delays and disabilities, are currently unable to access the individualised and intensive early childhood intervention services they require for optimal development. Development of an early childhood intervention system by the DSW with technical support from UNICEF is at an early stage<sup>42</sup>. Moreover, children with disabilities and their families are often subjected to discrimination when they seek such care and may encounter poor-quality or unaffordable health care.<sup>43</sup>

Good health care can prevent many disabilities. Difficult labour and birth can cause a baby to be born with a disability such as cerebral palsy. Obstructed and prolonged labour asphyxiates an estimated 3 percent of all newborns, resulting in death for nearly 25 percent of these infants and brain damage for another 25 percent. Women suffering from poor nutrition and infections during pregnancy are more likely to have low birth-weight infants (weighing less than 2,500 grams). Low birthweight infants are 20 to 30 times more likely to die in the first week of life than infants of normal weight, and those who survive are more likely to suffer disabilities such as cerebral palsy, disorders such as seizures, and severe learning disabilities. Good nutrition is, therefore, a foundation of a child's survival and growth, allowing children to reach their full growth potential. Global evidence has shown that essential nutrition interventions, including appropriate infant and young child feeding and micronutrient supplementation at critical times during pregnancy and childhood, not only prevents stunted physical growth but prevents cognitive impairements. It is well known that children who are not stunted or suffering from micronutrient deficiencies perform better in schools, have higher productivity and wage earning potential in adulthood, and a lower risk of developing non-communicable diseases later in life.<sup>i 44</sup>

<sup>42</sup> The Republic of Myanmar, 2014

<sup>43</sup> Local Resource Center, 2014

<sup>44</sup> Lancet series on nutrition, 2008, 2013

High rates of anaemia in pregnant women and young girls, widespread micronutrient deficiencies, high infant mortality rates, and low birthweight - all of which are found in Myanmar - are all factors with a strong correlation to child disability and an increased risk of developmental disabilities. Sufficient micronutrients during pregnancy and early childhood also are critical in preventing disabilities. Although limited data are available on the coverage of micronutrient supplementation programmes for pregnant and lactating women in Myanmar, these programmes generally vary in quality. Furthermore, many pregnant women do not consume an adequate dose of iron folic acid supplements, which are vital for preventing anaemia, due to a lack of supplies, limited knowledge of its benefits, or lack of willingness to comply. Although national vitamin A supplementation campaigns for young children cover significant proportions of the population as a whole (>90 per cent), many remote townships and hard-to-reach areas report much lower coverage - a cause for concern that requires further investigation. Infantile beri beri (Vitamin B1 deficiency) remains an important cause of under-5 mortality, at 5.9 per cent in 2013.<sup>45</sup> In all, good health care is essential in preventing many disabilities. For example, difficult labour or birth can cause a baby to be born with a disability such as cerebral palsy. Trained birth attendants who can identify risks and handle emergencies can prevent babies from being born with impairments that can lead to delays and/or disabilities. However, in 2014 only 72.3 per cent of all births<sup>46</sup> were attended by skilled health personnel. Proper immunisation, administered by a health care professional, can prevent diseases leading to impairments, delays and disabilities. However, many times vaccines are not available, or are an added financial burden to poor families. In 2014 national coverage for the third dose of polio was 88 per cent.47

#### 8.2 Current challenges

While some stakeholders interviewed reported a great deal of progress, according to the literature, "no measures of child development currently exist in Myanmar."<sup>48</sup> As noted above, screening and early childhood intervention services and medical disability diagnosis systems for physician training are still at a very early stage of development, and both services and institutions for children with disabilities are scarce, usually serving children older than age 6.<sup>49</sup>



Most of the parents/caregivers of children with disabilities (64 per cent) reported that they were the first persons to identify a disability, with doctors/psychologists a distant second (28 per cent). As expected, the wealthier the family, the more likely that disability/limitation is identified by a doctor/psychologist.

<sup>45</sup> Ministry of Health (2014): Study on the Causes of Under-5 Mortality in Myanmar

<sup>46</sup> HMIS 2014, Statistical Yearbook 2015

<sup>47</sup> Ministry of Health (2014) Health Management Information System data

<sup>48</sup> The Republic of the Union of Myanmar, 2014, p. 28

<sup>49</sup> Bawi, 2012 & The Republic of the Union of Myanmar, 2014

By state/region, only in Mon State are doctors/psychologists cited as the most common identifier of disability or impairment. Critically, once identification of disability is completed, the criteria for identification are seldom reviewed. Thus, the status of children with disabilities is deemed static and lifelong, despite the expected development of the child. All the children with a particular impairment, e.g. Down syndrome, are generally considered to have the same characteristics, the same needs, and the same expected outcomes.

An important finding in the SitAn is that doctors/ psychologists generally identify disability/ limitation in children younger than age 2. Identification rates decrease as a child ages. In turn, this underscores the urgent need for expanded early identification services. In cases where information about a disability was provided by someone other than the parent/caregiver, only 29 per cent of the children had been referred to a specialist or health care institution. In nearly 2 out of 3 cases, they were referred to the township hospital.



Among the causes of disability or impairment, congenital conditions (the existence of disability at birth) were reported by 65 per cent of the parents/caregivers. Only 5 per cent reported disability resulting from disease or illness, while an additional 5 per cent reported mis-injection as the cause. The latter term is widely used to explain instances of a vaccine or injection being administered to a young child by an untrained person, resulting in impairment or death. Reported causes of disability were very similar by gender.

#### 8.3 Health care professionals' perspectives

Health concerns of all children, including children with disabilities, are part of the Ministry of Health's (MoH) five-year strategic plan. The MoH provides a range of services, including rehabilitation, while specialty services are provided in some hospitals.

Among the 31 health professionals interviewed (e.g. central government health officials, township medical officers, assistant medical officers, health assistants, nurses and midwives), all agreed that a physical or mental condition that limits a person's movements, senses or activities helps to identify children with disabilities. They most commonly identified Down syndrome and cerebral palsy, followed by polio, hearing impairments and physical impairments. Health care services for all children, including children with disabilities, are accessed through township hospitals, station hospitals, rural health centres, and sub-rural health centres, but specialised/separate health care services for children with disabilities are not available at the township level.

In turn, many health professionals, particularly at the township and rural levels, do not have specific procedures for the identification of children with disabilities, including early detection and prevention services. Although some relevant training programmes are available, these have reportedly not been accessed by a number of professionals. Moreover, very few health professionals said they had any relevant documents, manuals, guidelines or audio-visual materials for support services for children with disabilities. Likewise, health service infrastructures suitable for children with disabilities are almost nonexistent, particularly in remote areas.

Almost all the health officials and half of the interviewed DSW officials had at best basic knowledge about community-based rehabilitation (CBR) services in Myanmar. Nonetheless, they felt that CBR programmes, which are only now beginning, would be useful.

In addition, health officials indicated that changes in the legal/policy framework would be useful for protecting the rights of the children with disabilities, and they said that people in general had "sympathy for children with disabilities and they willingly helped them to improve their lives by donating money or providing assistive devices to them." Moreover, although no cooperation protocols or specific policy guidelines exist for the

physical rehabilitation of children with disabilities at the township level, increasing coordination between the DSW and the MOH was reported.

Contradictory responses were received with regard to fees and expected payment for health services. While most health officials agreed that services were free, including for children with disabilities, some simultaneously indicated that the services required by some such children are too expensive for parents. Specific reports focused on fuel charges, lab tests and specialty medicines. Some health officials also pointed out that referral services and financial support for health care services in remote areas are available. All the interviewees agreed that the government and NGOs/civil society organisations should provide financial support, rehabilitation programmes and assistive devices, e.g. hearing aids, wheelchairs and learning aids, to children with disabilities, as well as specific trainings for health staff. Confirming findings from interviewed prepare a list of children with disabilities living in each township. They do so with the help of the wards and village administrators, rural health centres, sub-rural health centres, or the township Department of Health. In almost all cases, however, the lists are not updated regularly, and issues of both usefulness and confidentiality exist. For the most part, the lists are not linked with any other data collection systems.

#### 8.4 Parents' perspectives<sup>50</sup>

The vast majority of the parents/caregivers of children with disabilities (87 per cent) and those without disabilities (89 per cent) reported they rarely visited a health facility or medical practitioner, and only when necessary. This was the case despite the fact that nearly 1 in 3 children with disabilities reportedly require regular health checkups, some as often as once a week. Distance to the health facility and the non-availability of doctors were cited as key reasons for not visiting a doctor. Of those parents/caregivers who sought health care for a child with a disability, about half went to a private clinic, a finding that bears further investigation. A very small proportion of the respondents visited rural health service providers or facilities such as monastic clinics or NGO-run clinics.

The surveyed parents of children without disabilities indicated that they do not need to visit health facilities or see a medical practitioner regularly. If required, parents (or a family member) prefer to take the child to a private health facility by a proportion of almost 2 to 1. Almost all the parents of children without disabilities say they are satisfied with the services received.

The parents/caregivers of children with





<sup>50</sup> Please note that the findings in this section, which are specifically related to the parents/caregivers surveyed, should be taken with caution. Very few respondents were actually availing of health services regularly, 167 in the case of children with disabilities and 184 in the case of children without disabilities.

disabilities reportedly visited mostly general physicians (56 per cent), paediatricians (27 per cent), practice nurses (26 per cent), and physiotherapists (5 per cent), a trend largely similar to that among children without disabilities. Almost no children visited specialists such as psychologists, gynaecologists, ophthalmologists, podiatrists, speech therapists or dentists.

A strong majority of the parents/caregivers of children with disabilities who regularly seek medical treatment for their children (16 out of 22) do so at private clinics and with private doctors. One parent mentioned that the doctor she takes her child to has a younger brother with a disability, which makes the doctor more understanding of the child's situation and better able to take care of her child well.

If a clinic cannot treat the child, however, parents generally take him/her to the hospital despite the additional financial expenses incurred. Unlike parents of children without disabilities, these parents offer somewhat more divergent views on satisfaction with health care services. Among those parents/caregivers who do not seek regular medical treatment for a child with disabilities, some indicated that the child is generally healthy. However, almost half of the parents conceded that their children should have checkups more often, but they expressed financial or accessibility difficulties. For example, each doctor visit is estimated to cost about 3,000-5,000 Ks (about US\$2.25-\$3.75), plus the cost of any medicines prescribed.

### 8.5 Community members' perspectives

Community members reported that both public and private health facilities are available, and they believed that all were accessible to children with disabilities. Out of the 197 community members who participated in FGDs, only 10 reported going to private health facilities. In addition, three participants said they have specialists in their communities, such as paediatricians or orthopaedic surgeons, who can provide treatment to children with disabilities. They also indicated that specialists are available only in district or provincial public hospitals, and that certain treatments, types of medicines, and diagnostic tests require out-of-pocket payment. One noted that "there are many health facilities, private and public, here. If we can pay money, we can get everything."

# 8.6 NGOs' perspectives

The primary responsibility for the provision of health care services, including to persons with disabilities, falls on the state, although in Myanmar some NGOs provide additional disability services, e.g. physiotherapy, occupational therapy, assistive technology support and training for parents. NGO personnel reported that in general they believe persons with disabilities are segregated because of a lack of understanding as to what disability is, and that a demand for rights at the grassroots level was negligible. It was felt that the younger generation of parents are somewhat more aware of disability, perhaps due to the influence of the mass media, but many professionals still exclude children with disabilities, and children with severe disabilities are largely confined to their homes and receive no support other than that given by their parents. At the same time, persons with disabilities have the responsibility to ensure that the difference between felt, real and perceived needs is clarified.





# 9. Right to a protective environment

### **KEY FINDINGS**

- 1. 1 in 4 parents said their child is afraid of other people and perceives dangers in the community.
- 2. 1 in 3 parents said their children have been bullied or mocked outside the home, and some have been hurt. However, only 3 out of 197 community members said they were aware of bullying and harassment.
- 3. The government's aim is to ensure that all services are disability inclusive, as opposed to creating parallel services for persons with disabilities.

# 9.1 Parents' perspectives

Perceptions regarding the safety and security of children in general, and children with disabilities in particular, are widely varied among stakeholders. While most parents of children without disabilities believe their children are safe outside the home, parents of children with disabilities worry about their children's safety and protection from harassment, bullying and exploitation.

Of the 24 interviewed parents of children without disabilities, only one indicated that their child is afraid of someone living in the house and therefore "has to behave himself." Furthermore, when asked about their perceptions regarding the safety of children with disabilities, only one parent of a child without disabilities said she is aware of children with disabilities being subjected to mocking, bullying or abuse.

However, the parents/caregivers of children with disabilities have a very different perception. While a strong majority (64 out of 75) said their child is not afraid of anything in or around their house, 1 in 4 mentioned that their child is afraid of people and dangers outside in their community. Concerns related to harassment and bullying when their child goes outside the home were particularly prevalent, e.g. "I'm worried when my child goes out alone. I'm afraid that he will either get into an accident or will get bullied by other children. If that happens, there will be no one to help him."

One-third (23 out of 75) of the parents said their children had been bullied or mocked by other children, and sometimes physically hurt. Nonetheless, it should be noted that only 2 of the 75 children with disabilities indicated not feeling safe outside the home because "people don't respect one another on the streets." One parent of a child with a disability reported that the child's teachers accompany him home after school or his brother and sister pick him up. Three other parents also mentioned receiving extra help from other family members to ensure their child's safety. At least one-third (27 out of 75) of the parents/caregivers of children with disabilities are not aware of a person or an organization to which they can report abuse. Instead, they indicated that in the case of abuse, they would "deal with it on their own first" and "if they could not, they would go to the head of the village." As described by DSW officials (see below), no child protection services

are specific to children with disabilities at the township level, although officials reported that a system was in place to report abuse and exploitation.

#### 9.2 DSW officials' perspectives

The Department of Social Welfare (DSW) of the Ministry of Social Welfare, Relief and Resettlement has a longstanding interest in issues related to disability. DSW officials say they feel the National Law on Disability is very significant, and they are now working on bylaws to provide rules and regulations for fuller CRPD implementation as well as a platform for their work. The DSW also runs eight special schools for about 1,000 children with disabilities. While the DSW reports a very close and positive working relationship with other ministries as needed, officials said that coordination with the DPOs is challenging. Nearly all the DSW officials at the regional level (11 out of 14) reported there is no training programme on disability awareness and/or disability mainstreaming. Services are very limited at the regional and state levels. No separate programmes/ services for children with disabilities are provided at the township level. The intention, rather, is to ensure that existing and future services and programmes are fully inclusive of children and persons with disabilities. Likewise, the DSW does not support adolescents with disabilities in income generation through vocational training, e.g. computer skills, motorcycle repair technician training programmes and sewing training, but it provides information to those who seek it.

All the DSW officials reported that changes in the existing legal framework would be highly useful to ensure the protection of the rights of children with disabilities. They also agreed that having specific processes and procedures for providing services to persons with disabilities would be useful, including formalising cooperation with other government entities and both national and international NGOs. In addition, they stated that having a separate budget allocation for children with disabilities at the township level would help with the implementation of physical rehabilitation programmes. On a related note, they felt that procedures for the identification of children with disabilities should be revised and implementation should be enforced.

Officials said the top three priorities for the DSW in the near term to strengthen the protective environment for persons with disabilities are: (1) to encourage education about the rights of persons with disabilities; (2) to engage in disability-friendly advocacy aimed at high-ranking policymakers and mid-level technical staff; and (3) to initiate implementation of the new Disability Law, taking both top-down and bottom-up approaches.

### 9.3 Community members' perspectives

Community members do not all agree as to where and with whom children with disabilities should live to ensure a protective environment. However, they unanimously said decisions for such children should be made by taking into consideration the best interest of the child. As many as 1 in 4 (48 out of 197) felt that children with disabilities should live in institutions, which they believed have better facilities than the children's homes or mainstream schools. "Children with disabilities would not feel upset because they would be living among people like them," said one respondent. However, three-fourths of all the community members (149 out of 197) believed children with disabilities should live with their parents and in their communities. They asserted that children with disabilities "need warmth and love from their family members," and that "only the parents can fulfil their needs, and only the family members can know them well and be patient with them."

Nearly all (90 per cent) of the community members do not believe there are safety concerns related to children with disabilities, and only 3 out of 197 feel these children are bullied or abused. These opinions stand in stark contrast to those of the parents of children with disabilities. At the same time, 31 of the 197 community members acknowledged that girls with disabilities in particular are more vulnerable to accidents and other security issues.



# 10. Other issues of rights and aspirations

### **KEY FINDINGS**

- 1. 1 in 3 parents of children with disabilities indicated that their children do not have rights equal to other children.
- 2. 27 per cent of all the children with disabilities do not have a birth certificate, with strong regional dispariti.
- 3. The life aspirations of children with disabilities do not differ significantly from children without disabilities.

### 10.1 Right to registration and the preservation of identity

Overall, more than 1 in 4 children with disabilities (27 per cent) did not have a birth certificate. Data indicated a wide geographic variation, with only Magway Region claiming 100 per cent registration of births.

In particular, the cases of Tanintharyi, Rakhine and Kayin Regions are extremely concerning, with rates of birth registration at around 50 per cent, which is in clear violation of Articles 7 and 8 of the CRC and Article 12 of the CRPD. In addition, very few children with disabilities (2 per cent) have any certification pertaining to their disability. These certificates are not official. Critically, only 12 per cent of the parents/caregivers of the 722 eligible children with disabilities older than age 10 years said their child had a national registration certificate. Birth and national registration thus represent urgent priority issues of concern for the government. The DSW, in partnership with UNICEF, is beginning to develop steps to address these early violations of children's rights.



## 10.2 Right to privacy

Overall, children – both those with and those without disabilities – are still not perceived as rights holders, and evidence throughout this SitAn shows that children with disabilities in particular do not have the opportunity to make their own choices regarding their daily lives, education, health and other issues. In addition, experiences encountered during this study indicate that many officials who collect data related to children, from demographic information to perceived disability, appear not to respect the minimum confidentiality guidelines such as those described in CRC Article 16 and CRPD Article 22.

## 10.3 Children's aspirations

Evidence shows that all children have life aspirations, but not all have equal opportunities to achieve them. One-third of the parents/caregivers of children with disabilities (26 out of 75) indicated that their children do not have rights equal to other children, but they believe they should have equal rights.

The majority of the mothers of children without disabilities said their children want to become professionals such as doctors, engineers or teachers. A few mentioned that their children would like to join the army; play sports, especially football; start their own business; become a celebrity; or become a monk.

Likewise, according to their parents/caregivers, children with disabilities have similar aspirations and wish to become doctors, teachers or engineers. A number of parents mentioned various other professions such as soldier, merchant/trader, artist or actor/actress, and sports player. One parent stated, "I want him to be a teacher, because I don't want him to have a physically tiring job." In all, only one parent indicated that her child did not have any dreams about the future because of her/his disability, and two others said they could not expect much from their children "because of the disability." Even so, all these parents hoped their children would become educated, and some said they would support their child's aspirations, no matter what they might be.



# 11. Prevalence of disability in Mon State: A case study

### **KEY FINDINGS**

- 1. Complete blindness was not found in Mon State, and the use of eyeglasses is very low.
- 2. Although the total percentage of 5- to 17-year-olds who have difficulty in hearing is low, almost two-thirds of all the children in that category are severely impaired.
- 3. More boys than girls (9.0 vs 7.6 per cent respectively) have difficulties performing self-care activities.
- 4. A total of 1.9 per cent of the children in Mon State have difficulty being understood by family members, and 3.0 per cent have difficulty being understood by people outside the household. In both cases, the percentages are higher for girls.
- 5. Very young boys have more difficulty than girls with emotions. However, in the older age group (5-17), girls are much more vulnerable to feelings of anxiety and depression.
- 6. While few children age 5-17 have difficulty controlling their behaviour, difficulties are experienced by girls in particular in focusing on their favourite activities, accepting changes in routine, and making friends.

As noted above, the 2014 Population and Housing Census in Myanmar included for the first time disability-related questions aimed at gathering data related to functional limitations, and there were four categories: "Seeing, even if wearing glasses," "Hearing, even if using a hearing aid," "Walking, climbing steps or carrying items," and "Remembering or concentrating." Respondents were asked to choose one of four responses in each category: "No, no difficulty," "Yes, some difficulty," "Yes, a lot of difficulty" and "Cannot do at all." Also as noted above, the disability prevalence in Myanmar (overall and among children specifically) was found to be much lower than expected.

This case study, which is associated with the SitAn, provides an example of data collection aligned with global standards, and in which child disability is understood through the lens of the social model of disability. Accordingly, it does not focus on an account of children with specific impairments, their level of severity, or medical diagnosis, although this information can be found in the relevant annex. Rather, it supports the work of the 2014 census and continues to clarify what are acceptable concepts, language and definitions in accordance with the CRPD, providing a baseline for future work.

Primary data were collected using two age-specific child functioning and disability (CFD) modules for ages 2-4 years and 5-17 years. These modules, adapted from the newly developed UNICEF/UN Washington Group on Disability Statistics CFD modules,<sup>51</sup> provide information collected from the primary caregivers of the children, mostly mothers. The case study thus provides insight into the lives of the children in various domains, the challenges they face, and the functional limitations they may experience. Taking this approach, it provides a

<sup>51</sup> As of January 2016 still in final testing phase; not yet, published.

holistic view of the children and helps to identify the sub-populations/populations of the children ages 2 to 17 years who experience functional difficulties. These difficulties may place children at risk of experiencing limited participation (developmental delay or disability) if they live in a non-accommodating environment. Further, the CFD modules are considered to be age-specific, age-appropriate, and able to capture children as they transition through their various stages of development. They avoid the medical approach to disability by using the ICF bio-psycho-social model, and allow for responses to be given according to a continuum. In its entirety, the CFD modules cover 12 domains of functioning: seeing, hearing, mobility, self-care, communication, learning, emotions, behaviour, attention, coping with change, relationships, and playing. While results from specific domains are examined below, a summary of how these results may be particularly useful in gaining a better understanding of the prevalence of disability is included at the end.

The figures presented below are weighted estimates for Mon State as a whole, prepared as a scientific and stratified sampling process.<sup>52</sup> The estimated prevalence of functional limitations for two additional townships outside Mon State are included for comparison purposes, and expanded data can be found in the relevant annex. In addition, data from young children should be taken with extreme caution. All data in this case study were gathered via proxy (parent/caregiver reporting), and very young children – especially children with intellectual and/or sensory impairments – may not be able to properly communicate to the parent/caregiver their difficulties in any of the domain groups below.

#### 11.1 Seeing

Data gathered in Mon State reveals that 4 per cent of all children ages 5-17 years have difficulty seeing. Majority of them (3.8 per cent) have "some degree of difficulty," girls (4.8 per cent) more often than boys

(3.1 per cent). Only a few parents/caregivers reported "a lot of difficulty" for their children in this age group.

As seen in Figure 11.1, the prevalence of difficulty for children ages 5-17 in Mon State is much lower than in the two control townships, but because comparisons are being made between a state and townships, the graph should be read with caution. However, it would be particularly advisable to explore the origin of the differences between Mon State and the township in Yangon.

The prevalence of difficulties seeing for children ages 2-4 years is 0.3 per cent in Mon State and data from the control townships is 0 per cent and 1.3 per cent. Interestingly, 3.3 per cent of the boys



in this age group are estimated to have some difficulties.

A notable finding is that complete blindness was not reported among either age group in Mon State. Data also showed that the use of eyeglasses is very low in that state, only 1 to 2 per cent overall. This confirms data gathered across the SitAn that indicate assistive technology/devices and learning aids are seldom recommended or used.

52 For more information, see Section II of the SitAn and the annexes.

### 11.2 Hearing

The incidence of difficulties hearing among children in Mon Stat is reportedly quite low. Again, further investigation should be considered to understand the causes of the wide disparities in the two comparison

townships. None of the children ages 2-4 years in Mon State were reported to have difficulties, and the estimated prevalence is only 1.4 per cent among those ages 5-17. Disparities in the overall prevalence of hearing difficulties between boys and girls are few.

At the same time, it is critical to note that about 1 per cent of the boys ages 5-17 and 1 per cent of the girls that age are reported to not be able to hear people's voices or music, indicating severe hearing impairment. Thus, although the total percentage of 5- to 17-year-olds who have difficulty hearing is low (1.4 per cent), almost two-thirds of these children are severely impaired. As with the use of eyeglasses, the use of hearing aids among children is not common in Mon State or the other two locations. However, a comparatively higher proportion of children ages 5-17 in Hlaingtharya (Yangon) were estimated to be using this assistive technology.

## 11.3 Walking

In general, the estimated prevalence of difficulty in walking was found to be quite low for children in the age group 2-4 years old. For Mon State, it was less than 1 per cent, compared to almost 2 per cent for the two control townships. Use of any equipment or assistive devices for walking among toddlers was particularly uncommon.

For children 5-17 years old in Mon State, the estimated incidence of difficulty walking 100 metres is 2.3 per cent and walking 500 metres is 8.3 per cent. Virtually no gender difference was found for walking 100 metres, but a significant gender disparity was revealed for walking 500 metres (9.4 per cent for girls and 6.8 per cent for boys). Again, equipment or assistive devices were not prevalent, and they were used by only about 1 per cent of the children ages 5-17 in Mon State.

### 11.4 Self-Care

In the broad area of inquiry for self-care, the parents/ caregivers of children 2-4 years old were asked whether their child faced any challenges picking up small objects with her/his hands compared to other children of the same age. Only 1.1 per cent







of the children in Mon State were estimated to have some degree of difficulty, with a higher incidence among girls.

For children ages 5-17, ease of performing certain self-care activities, e.g. eating and dressing on their own, were probed and revealed much higher results. In Mon State, 8.2 per cent of all the children were estimated to have self-care difficulties. The estimated prevalence was noticeably higher among boys (9.0 per cent) than girls (7.6 per cent).

## 11.5 Communication

For communication, the caregivers of children ages 2-4-4 were asked "Does your child understand language when spoken to?" This revealed that an estimated 2.7 per cent of these children in Mon State were having difficulties, and this was far more prevalent among boys (4.1 per cent) than girls (1.8 per cent). Caregivers of these very young children in Mon State were also asked if their child is understood by others when he/she communicates, and an estimated 8.3 per cent have difficulties (9.1 per cent of the boys and 7.8 per cent of the girls).

Thus, as with most other areas of inquiry, the domain of communication warrants further investigation, particularly taking into consideration its importance at an early age. While data gathered in the two townships are not as robust as that from Mon State, it is particularly important to explore why the prevalence of communication difficulties among very young children in the Yangon township were three times higher than elsewhere.

Ease of communication for children ages 5-17 years was also probed through two questions, including whether the child is understood while in conversation by people living in the same household. In Mon State, 1.9 per cent of these older children are estimated to have difficulty being understood, with marked gender differences (2.6 per cent of the girls and 1.0 per cent of the boys). The second question related to whether the child is understood while in conversation by people from outside the household. The findings here



indicate that 3.0 per cent of the children in Mon State have difficulty being understood (3.7 per cent of the girls and 2.2 per cent of the boys).

# 11.6 Learning

Globally, about 12 to 15 per cent of all children have learning difficulties. In Mon State, it was estimated that only 3.2 per cent of the children ages 2-4 years were facing difficulties in learning. Notably, the prevalence of such difficulties was much higher for boys (4.1 per cent) than for girls (2.7 per cent). At the same time,

however, the overall rate of difficulty was exponentially lower than in the two control townships (13.0 and 13.1 per cent). Similarly, the rate of difficulties in learning for the 5- to 17-year-olds in Mon State was estimated at 8.3 per cent (9.2 per cent of the girls and 7.2 per cent of the boys), again far lower than the 14.9 and 19.5 per cent estimated in the control townships as well as the global average. Given the extreme importance of learning for children, this warrants urgent further exploration.

#### 11.7 Emotions

In terms of emotional status, caregivers for the 2- to 4-year- olds were asked about the general behaviour of their child in terms of kicking, biting, or hitting other children compared to others the same age. Estimates based on the information gathered show that in Mon State, 8.1 per cent of these children were considered to do this more often, or a lot more often, than others the same age. Incidence of such behaviour was found to be strikingly more prevalent among boys (11.7 per cent) than girls (5.9 per cent). For children ages 5-17, emotional aspects were probed through different questions:

- "How frequently does the child seem to be anxious, worried or nervous?" It was found that 4.5 per cent of the children in Mon State appear anxious, worried or nervous at least once a month, with marked gender differences (5.7 per cent of the girls and 2.9 per cent of the boys).
- "How frequently does the child seem to be sad or depressed?" This showed that 5.7 per cent of the children in Mon State were perceived to be depressed or sad at least once a month, again with striking gender differences (8.1 per cent of the girls and 2.4 per cent of the boys).

The caregivers of children in the age group 5-17 years in Mon State were also asked whether their child is controlling her/his behaviour compared to others the same age. Only 1.1 per cent overall (1.8 per cent of the girls and less than 1 per cent of the boys) were felt to have difficulty controlling their behaviour.

Lastly, emotional aspects of the 5- to 17-year-old children were investigated in terms of their ease in:







1. Focusing on their favourite activities. It is estimated that 7.2 per cent in Mon State have difficulty

doing this (10.3 per cent of the girls and 2.9 per cent of the boys).

- 2. Accepting changes in their normal routine. This was a problem for 4.8 per cent of the children in Mon State (5.3 per cent of the girls and 4.1 per cent of the boys).
- 3. Making friends. It is estimated that 4.4 per cent of the children in Mon State have difficulty making friends (6.5 per cent and 1.5 per cent for girls and boys respectively).

#### 11.8 A new way to look at the prevalence of disability

Overall, looking at disability prevalence through the lens of the social model provides a very different view of disability and how it impacts the lives of children. While tools such as the CFD modules do not provide specific information that quantifies the number of children with Down syndrome, for example, or the number of children who have received an inappropriate an vaccination/injection, they do highlight the need for impairment-related services. By learning how many children have difficulty in specific functioning areas and where they are, policy and programme resources then can be appropriately allocated to investigate the levels of difficulty, the needed environmental accommodations, and the human resources required for professional assistance, among many other important areas.

Thus, the data gathered above can be used by a variety of stakeholders and for a multitude of purposes. In particular, they can be used to compare the prevalence rates in Mon State with other national and international data sources to inform policymaking. Likewise, these data can help determine where prevention and early detection services already exist and where investments need to be made. In turn, they can be used to adequately distribute public resources (financial, material and human), depending on the higher/lower incidence data points. Lastly, and perhaps most importantly in light of the anomalies revealed in Mon State, the data can help determine where further investigation/research should be conducted. Critically, below are a few key examples of specific ways in which the data gathered in Mon State might be used:

According to the International Agency for the Prevention of Blindness, for example, Southeast Asia has one-quarter of the world's population, but as much as one-third of the world's blind people, and half of the world's 1.5 million blind children live in the region. Human resources are a major challenge impeding progress. In most countries, there is only one ophthalmologist for every 200,000 people, and about one mid-level eye care professional for every half-million people.<sup>53</sup> Considering the findings above – in Mon State, 4 per cent of the 5- to17-year-olds reported difficulty seeing, but only 1 to 2 per cent reported wearing spectacles –, a possible action would be to investigate the extent of the coverage of school health services in the state, as well as the ability to screen for visual impairments and consequent follow-up.

At the same time, hearing loss is on the rise globally. According to the World Health Organization, 9 per cent of all children younger than age 15 suffer from disabling hearing loss, with a prevalence rate of 2.4 per cent in South Asia.<sup>54</sup> If this trend holds true for Myanmar, then it would be important to investigate the causes of a significantly lower (1.4 per cent) prevalence rate in Mon State. One way of doing so would be to inventory all the services available for the screening and diagnosis of hearing loss. Furthermore, because the findings indicate that children younger than age 17 in Mon State generally do not use hearing aids, it would be important to examine why.

In addition, data resulting from the inquiry into the walking domain could be used to inform a campaign for social change, making the case that (only) 8 children out of 100 have difficulty crossing the length of five football grounds. Information on self-care could be used as a baseline for probing into socially accepted gender roles and gender biases. A possible application of the data in the communication domain would be to investigate co-morbidity (when two impairments happen either simultaneously or sequentially) between children with a communication difficulty and children who reported difficulty hearing. While communication difficulty is not always linked to hearing loss, this could then be ruled out by audiologists/speech and language pathologists.

<sup>53</sup> International Agency for the Prevention of Blindness

<sup>54</sup> For more information, see http://www.who.int/pbd/deafness/WHO\_GE\_HL.pdf
The domains of learning and emotions are extremely important and should be considered both separately and together. For children in the lower age group, data could be used to estimate the number and types of early learning and school readiness programmes necessary in a given geographical area. Depending on these needs, focus could then be shifted from learning activities (child focus) to socio-emotional support (family focus) and vice versa. With regard to the findings for the older age group, data could be communicated to education authorities, principals and teachers to inform the types and locations of focused learning interventions, screening for childhood depression, and anti-stress activities. Because the emotional status of children greatly affects their learning and academic achievement, it is important to examine both domains when designing curricula and instruction materials.



#### **SECTION IV** OVERALL BARRIERS AND BOTTLENECKS CHILDREN WITH DISABILITIES FACE



Barriers and bottlenecks are terms commonly used to describe structural and other impediments to the realisation of rights.

Analysing the findings of this situation analysis through a bottleneck and barriers lens builds on the existing human rights-based approach to programming and is intended to highlight the factors that represent the most critical impediments for children with disabilities.

For children with disabilities, equity means having an opportunity to survive, develop and reach their full potential without discrimination, bias or favouritism. Equity is critical for all children, but especially for children with disabilities, who often do not have access to the same level of services as children without disabilities due to structural barriers in access, discrimination and stigma, and less availability of appropriate services.

The use of a barrier and bottleneck analysis<sup>55</sup> is useful in grouping the findings of this situation analysis so as to be able to provide pointed recommendations as to how to remove the most critical barriers preventing children with disabilities in Myanmar from realising their full potential and fulfilling their rights.

The determinants framework analysis focuses on the following overlapping dimensions:

- **1. Enabling environment**: Factors that relate to law; finances; coordination; management; cultural practices; social norms and attitudes that prevent children with disabilities from realising their full potential; dignity; and contribution to society.
- **2. Supply:** Factors that impede public and private providers of goods and services, including remoteness; lack of infrastructure; poor human resources and skills; insufficient financial capital; and other explicit or implicit costs that are disincentives for producers, given that these factors raise the cost of service delivery and create a high fixed-cost market, thereby rationing supply.
- **3. Demand**: Factors that impede children with disabilities and their families from demanding goods and services, including prices (costs), incomes and budget at the household and national levels; availability of substitutes or parallel products; information and awareness; ease of access; safety; and environment.
- **4. Quality**: Factors affecting the quality of goods and services delivered, which also is affected by societal expectations and preferences, as well as the need for a commitment to adhere to standards that do not discriminate between groups of children.

The major bottlenecks and the recommendations to remove them are listed in Tables below.

#### **ENABLING ENVIRONMENT**

<sup>55</sup> http://www.unicef.org/about/employ/files/MoRES\_Briefing\_Note.pdf

<b>Bottleneck 1</b> : Social norms and entrenched stereotypical attitudes towards disability exacerbate the discrimination and marginalisation of children with disabilities and perpetuate the charity model among all stakeholders responsible directly or indirectly for fulfilling the rights of children with disabilities.	re inclusive society and remove barriers for children with disabilities to their full participa	Recommendations:	<ul> <li>Parliament: <ul> <li>Build commitment and capacity on disability according to the social model;</li> <li>Form child rights and women's rights committees to ensure all sectors are disability-inclusive and all decision-making is responsive to the voices of children with disabilities.</li> <li>GoM:</li> <li>GoM:</li> <li>Form the National Committee for Disability (as per CRPD commitment) with a form the National Committee for Disability is resourced to fulfil its coordination and monitoring mandates to ensure all ministries and government agencies comply with the CRPD and to raise awareness and knowledge about children with disabilities;</li> <li>Ensure the National Committee for Disability is supported in the development of a National Action Plan (the "vision"), with the participation of all stakeholders, including the DPOs and children with disabilities; as well as all the ministries.</li> </ul> Development partners: <ul> <li>Support the government and the National Committee for Disability is supported in the development of a National Action Plan (the "vision"), with the participation of all stakeholders, including the DPOs and children with disabilities, as well as all the ministries.</li> </ul></li></ul>
	Overall recommendations: Enhance commitment among all stakeholders to build a more inclusive society and remove barriers for children with disabilities to their full participation in Myanma society.	Findings:	Uneven understanding of issues related to children with disabilities prevent key stakeholders (the national government, township-level officials, community leaders and parents) from formulating a vision around social inclusion for children. Strongly divergent opinions were expressed regarding the most appropriate educational and care settings for children with disabilities, reflecting a lack of clear understanding of children's rights as well as a lack of inclusive directives at all administrative levels and a persistent preference for special/parallel systems.

Low expectations and negative attitudes towards disability are exacerbated by poverty and traditional patriarchal charity/pity attitudes, discrimination, neglect/abuse, exposure to bullying, and the marginalisation of children with disabilities. Because of generally low expectations for children with disabilities, very little importance is given to ensuring meaningful actions that can lead to the provision of quality inclusive services for children with disabilities at the national, community and household levels alike.

Children's voices are rarely heard in Myanmar or given any weight in decision making. The situation is much worse for children with disabilities, for whom decisions are often made without their consent and often by a household head with low expectations and limited knowledge of the rights of children with disabilities.

### Parliament:

 Parliament should engage with the National Committee for Disability on issues related to social norms and attitudes that affect children with disabilities, e.g. through a regular reporting mechanism, to remain appraised of evolving social norms and attitudes, and efforts and plans by the National Committee for Disability in order to address them.

#### GoM

- The GoM should support the National Committee for Disability in implementing communication for development activities aimed at addressing misconceptions related to children with disabilities;
- All the line ministries (including but not limited to the MoE and the MoH) should work with the National Committee for Disability to address internal misconceptions with regard to children with disabilities;
- Formally adopt the social model of disability when planning and programming at all administrative levels.

# Development partners:

 Support the MoSWRR (DSW) in implementing communication for development campaigns and training to address misconceptions with regard to children with disabilities.

### CSOs/DPOs:

- Organize events and activities to promote the vision that children with disabilities have the same rights as other children and are capable members of society with a positive contribution to make;
- Strengthen ongoing activities at the community level to increase awareness and the inclusive participation of children with disabilities.

#### GoM:

# All ministries and government agencies:

 Involve children and adolescents, particularly children and adolescents with disabilities, when making decisions that affect them at all levels.

## MoSWRR (DSW)

 Strengthen existing Township Support Groups (TSGs) and Township Child Rights Committees and include children and adolescents with disabilities, and establish appropriate mechanisms to ensure opportunities for the inclusive participation of children with disabilities in community and social activities;

<ul> <li>children to express themselves.</li> <li>Bevelopment partners: <ul> <li>Support children with disabilities in participating freely in community events and support them in making their voices heard through innovative mechanisms (media, online platforms and mobile phones), including working with the private sector (e.g. mobile operators and helplines);</li> <li>Support Township Support Groups and/or Child Rights Committees (mentioned above) to establish a mechanism to hear children's voices regularly.</li> </ul> </li> <li>DROs/CSOs: <ul> <li>Develop children's capacity to participate meaningfully in different forums, and provide space for them to freely express their views and influence decision making in matters that concern them.</li> </ul> </li> </ul>	<ul> <li>Parliament:</li> <li>Ensure signature and ratification of the CRPD's Optional Protocol to ensure children with disabilities have the mechanisms by which complaints can be lodged and penalty actions can be applied against those who violate their rights.</li> <li>GoM:</li> <li>All ministries and government agencies:</li> <li>C Ensure laws and policies refect the smirt of the CBD and that mechanisms</li> </ul>
	d secure environment conducive for 13 parents of children with disabilities iculed, teased, shamed or ostracised. ant to keep children with disabilities children's interactions with others as g health services. Schools, hospitals, not yet disability sensitive (including even parents/caregivers).

Children with disabilities lack an inclusive, safe and are concerned about their children being bullied, ridic These behaviors lead parents and caregivers to wa at home and away from harm, thus limiting their ch transport and overall infrastructure systems are no well as their school attendance and use of existing learning and childhood development. More than 1 in teachers, principals, TEOs, community leaders and

exist to prevent, monitor and respond to abuse/neglect at all levels and by all Ensure laws and policies retect the spirit of the URPU and that mechanisms stakeholders.

# MoSWRR (DSW)

- Continue and expand its Violence Prevention Project, educating professionals and the general public on the rights of children with disabilities;
- Establish a mechanism for case managers to report on all forms of child abuse/ neglect; 0
- Establish a system by which children with disabilities can report, anonymously, instances of abuse/neglect, ensuring that children's reports are taken seriously and followed through. 0

# Development partners

 Support all stakeholders in their efforts against abuses and violence, particularly those related to anonymous reporting and the investigation of complaints;

in the country, and coordinate the provision of adequate fora and spaces for all

1011

ensure they reach all children, including children with disabilities, everywhere

Expand the role and capacities of DSW social workers (case management) to

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	<ul> <li>Support the development of materials that raise awareness of disability and inclusion to be used as educational tools in various professional settings.</li> </ul>
	<ul> <li>DPOs/CSOs</li> <li>Carry out anti-bullying campaigns and sensitisation activities related to the rights of children with disabilities;</li> <li>Devolve partnerships with professional partner and introduce adjustional</li> </ul>
	<ul> <li>Develop particles inposition processional networks, and influence educational materials about disability and inclusion in a participatory way.</li> </ul>
Bottleneck 2: Lack of coordination across all sectors and unclear allocation of roles in championing a national Disability Action Plan.	oioning a national Disability Action Plan.
<b>Overall recommendations</b> : Coordinate services across all sectors to address the full range of challenges facing children and adolescents with disabilities and their families.	of challenges facing children and adolescents with disabilities and their families.
Findings:	Recommendations:
<ul> <li>Leadership, coordination and mandates across ministries are not synchronised, resulting in gaps and overlaps:</li> <li>While the DSW is the official government focal point for disability and is responsible for the coordination of all efforts regarding social inclusion, overall resources for children with disabilities (to be shared by all ministries and stakeholders) remain insufficient;</li> <li>Coordination mechanisms between all responsible stakeholders require strengthening as responsibilities towards children with disabilities are being misinterpreted at the national level and a lack of clarity is communicated to the local level, impacting the actual provision of inclusive services and likely impacting resource allocation;</li> <li>Line ministries do not follow a single vision of social inclusion, in which children are rights holders. Instead they often exist at cross purposes, e.g. the New Education Law promotes special and parallel education systems for children with disabilities, while the MoSWRR envisions no special systems.</li> </ul>	<ul> <li>Parliament:</li> <li>Support ministries to develop clear reporting lines and assignments of roles and responsibilities that ensure coverage of all necessary services by the most appropriate line ministry and no resource wastage;</li> <li>Require regular reports from ministries as well as the National Committee for Disability on their activities related to inclusive and effective service provision for persons with disabilities/children with disabilities, including budgets.</li> <li>GOM:</li> <li>President's office:</li> <li>Develop clear reporting lines and a clear assignment of roles and responsibilities at all administrative levels and across all ministries.</li> <li>Improve intersectoral coordination by (1) clearly defining the role of the DSW as the leading entity in initiaties.</li> <li>Work with the National Committee for Disability to implement all provisions of the GoM.</li> <li>Work with the National Committee for Disability to implement all provisions of the GoM.</li> <li>Strate for Disability to implement allow is fully realised by further amending of the mostion of adequate human and financial resources;</li> <li>Work should be aligned with SDG4, the CRPD, and the Indeving the note of the novision of adequate human and its bylaw(s) should be aligned with SDG4, the CRPD, and the Indeving the role of the novision of adequate not its bylaw(s) should be aligned with SDG4, the CRPD, and the Indeving the role of the novision of the novision of the movision of the novision of the novision of the movision of the novision of the movision of the movision of the novision of the movision of the novision of the</li></ul>

definition of disability included in the Rights of Persons with Disabilities Law; 

- Child rights in general, and the rights of children with disabilities in particular, need service provision for children with disabilities through the life-cycle at the national the prevention, identification, intervention in, abilitation and rehabilitation of, and to be clearly included in the legislative framework, creating legal provisions for district and local levels;
- ties) with the mandate and resources to jointly educate, coordinate, monitor and There are no national mechanisms (such as a National Committee for Disabilievaluate the situation of persons with disabilities in Myanmar;
- As reviewed for this situation analysis, the purpose, concepts and language in the should be undertaken under the supervision of Parliament and the advisement of CRPD, the CEDAW, the Incheon Stategy and the SDG. When needed, revisions majority of Myanmar's legislative framework are not aligned with the CRC, the the National Committee for Disability.

- subsequent amendment(s), and associated bylaws are aligned with and respectful of international commitments;
- tion, policy and the National Action Plan on Disability as per the recommendations Ensure thatministries allocate adequate financial resources to implement legislaof the National Committee on Disability

#### GoM:

# All ministries and government agencies:

- Comply with the CRPD's definition of disability;
- Mainstream disability and highlight actions that target multiple vulnerability needs, e.g. disability and gender, disability and ethnicity, and disability and income level;
- households that face multiple vulnerabilities, including through the implementa-Allocate the funds needed to address the increasing social assistance needs of tion of the National Social Protection Strategic Plan 2014; 0

	<ul> <li>Underscore the legitimacy of the Myanmar National Committee of the CRPD, ensuring that all actions subsequent to the passing of the Law on the Rights of Persons with Disabilities meet with the full approval and endorsement of persons with disabilities in Myanmar;</li> <li>Allocate adequate resources to ensure inclusive services, and report on planned and/or existing expenditures in transparent ways.</li> </ul>
	<ul> <li>Development partners:</li> <li>Provide technical support to all ministries and government agencies so that they comply with the CRPD and the MPDL. Support knowledge building and exposure to international best practices;</li> </ul>
	<ul> <li>Continue to advocate social inclusion measures that lead to the efficient allocation of resources, including subsidies/incentives for the supply of essential services;</li> <li>Advocate with the private sector to allocate resources for children with disabilities through corporate social responsibility and other schemes.</li> </ul>
	<ul> <li>DPOs/CSOs</li> <li>Engage in and report on monitoring and evaluation activities that provide clear feedback to all line ministries (via the National Committee for Disability) on inclusive legislation.</li> </ul>
Bottleneck 4: A lack of reliable, accurate and/or comparable data for evidence-based plan	evidence-based plans, policies and programmes benefiting children with disabilities.
<b>Overall recommendations</b> : Generate reliable, disaggregated, accurate and comparable data related to disability, including prevalence.	ata related to disability, including prevalence.
Findings:	Recommendations:
Despite having signed and ratified the CRPD, Myanmar has not yet completed its first monitoring report to the UN CRPD Committee.	GoM: ■ National Committee for Disability (and the DSW as its coordinating body):
In Myanmar, there are no reliable, accurate or internationally comparable data on child disability prevalence.	<ul> <li>In close consultation with international experts and CRPD National Committees from neighbouring countries, DPOs and CSOs and persons with disabilities</li> </ul>
<ul> <li>The calculations on the prevalence of disability in Mon State presented in this study, based on the social model and calibrating functional limitations (UNICEF, 2016), suggest that disability may be considerably higher than what was reported</li> </ul>	<ul> <li>Should complete with all urgency the overlade linst monitoring report to the ON CRPD Committee.</li> <li>All ministries and government agencies:</li> </ul>
<ul> <li>in the latest census or in earlier studies;</li> <li>Overall, there are poor statistical information systems, and weak linkages between database statistical information systems.</li> </ul>	<ul> <li>Develop guidelines regulating data gathering, data sharing, and confidentiality issues related to the same;</li> <li>Revise existing practices of data collection, from procedural, privacy and</li> </ul>
<ul> <li>There is limited disaggregation of information by gender and age, and no disability level/severity/type disaggregation;</li> </ul>	<ul> <li>discriminatory standpoints;</li> <li>Provide transparent and disaggregated budgetary data related to existing and/or planned policies and programmes for children with disabilities;</li> </ul>

Birth registration coverage is incomplete, particularly of children with disabilities.

There is a lack of data on the proportion of the government budget devoted to programmes covering issues related to disability.

- Coordinate the expansion of statistical information systems to inform programming and budgeting in collaboration with CSOs and DPOs. At a minimum, the new system should include a disaggregation and breakdown of data by age, gender, geographical distribution, place of residence (rural vs urban), type of impairments, severity, area and level of functioning limitation, and co-morbidity.
   The UNICEF/Washington Group Child Functioning Module should be added to
  - all future DHS and MICS surveys to ensure longitudinal and comparable data on children with disabilities is gathered.

### MoSWRR:

- Design and implement, in conjunction with the MoE and the MoH, an appropriate and effective disability identification and registration system that helps ensure meaningful social inclusion of children with disabilities and the provision of high quality, inclusive services.
- Initiate routine data collection related to disabilities, and/or strengthen existing data collection mechanisms to ensure evidence-based decision making.

### MoE specific:

 Ensure data on children with disabilities is incorporated into the EMIS system, including level of impairment, setting where education takes place (and the percentage of time of instruction), and the support services needed and provided.

#### MoH:

• Ensure that all children are registered at birth with the MoIPL.

# Development partners:

- Support the GoM in its work with the private sector to set up real-time, centralised data gathering mechanisms, and ensure that a centralised gathering hub exists under the Central Statistical Organisation;
- Support further study to explore specific intersections between gender and disability in more depth.

#### DPOs:

 Engage in and report on monitoring and evaluation activities that provide clear feedback to all the line ministries (via the National Committee for Disability) on inclusive data gathering mechanisms.

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Bottleneck 1: A lack of adequate infrastructure and low supply of essential goods and services negatively impacts service provision to children with disabilities

Overall recommendations: Strengthen the commitment to provide incentives for service providers to expand the supply of goods and services for children with disabilities, thereby ensuring fair and equitable distribution

Recommendations:	<ul> <li>Parliament:</li> <li>Ensure that the line ministries and the private sector develop sustainable and innovative options to improve infrastructure and service provision.</li> </ul>	<ul> <li>GoM:</li> <li>MoSWRR (DSW):</li> <li>Develop national guidelines for the identification and registration of persons with disabilities that are in accordance with the UNCRPD and use protocols compliant with the International Classification of Functioning (ICF).</li> </ul>
Findings:	Infrastructural bottlenecks do not provide a conducive environment for the efficient provision of quality goods and services essential for children, including children with disabilities.	<ul> <li>Early detection of disability and early intervention do not yet exist in a systemic way;</li> <li>National health systems are still being developed, inclusive education has not yet been implemented, and physical infrasctucture is still largely unaccessible, resulting in large gaps in service provision;</li> </ul>

- Support services for children with disabilities, e.g. accessible toilets in schools, sign language interpreters; Braille and other alternative formats, are largely not existing;
- Universal design principles, assistive devices and technologies, and ICTs aimed at supporting the social inclusion of children with disabilities do not exist nationwide.

# MoSWRR, MoH and MoE:

- Accelerate the development of an early detection and early intervention system is conducted by teams of multi-disciplinary professionals, and leads to service that is respectful of the definition of disability according to the social model provision in inclusive settings;
- movement, communication, learning and behaviour/emotion throughout the life Extend school health programmes to screen school-age children for the development of functional limitations in the domains of hearing, seeing, cycle using standardised protocols.

## MoE specific:

they require the support of other teachers or specialized professionals, and they Invest in the capacity development of teachers and education professionals to work in, and help foster, an inclusive education system. All teachers must be adequately trained to teach all students in a regular classroom. Teachers and education professionals must also be trained to identify the occasions when must be compelled to utilise mechanisms for collaboration and cooperation among professionals.

### MoH specific:

 Provide adequate community-based rehabilitation for all citizens, including children with disabilities, in accordance with Article 25 of the CRPD

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## MoPF specific:

 Examine options for the sustainable financing of goods and services, e.g. subsidies to service providers, that enable children with disabilities to fully realise their potential.

# Development partners:

 Advocate and support the development of private sector partnerships to encourage an innovative and affordable provision of goods and services on a national scale.

### DEMAND

Bottleneck 1: Safety, environmental and attitudinal concerns, e.g. bullying, negatively affect the lives of children with disabilities and prevent them from accessing services.

### Findings:

- At least half of all the interviewed parents and caregivers of children with disabilities reported fearing for their child's safety when away from home;
- Parents and caregivers of children with disabilities reported that their children are often victims of bullying, teasing, verbal and even physical abuse by both other children and adults;
- Parents and caregivers of children with disabilities reported that schools are not welcoming of their children, nor do they provide adequate services. Structural issues in the school system, e.g. a lack of individualized instruction, extremely low pass rates, and alack of school-to-work transition policies, compound the low demand for education, likely even more so for children with disabilities;
- Although very few parents and caregivers of children with disabilities seek health services, those who do report searching for professionals who are believed to be knowledgeable, experienced and caring towards children with disabilities;
- Distance to home and perceived quality of the professionals are the main standards guiding parents' choices of education and healtch care services.

# Recommendations:

# Parliamentarians:

 Each line ministry should establish a monitoring system to track the development and enforcement of strict anti-discriminatory policies that ensure the safety of all children in all arenas of social life.

#### GoM:

# All ministries and government agencies:

 Ensure that prevention of disability is included in all line ministry actions related to (1) the development of disability-friendly cities; (2) disability-friendly municipal plans, (3) road safety measures, (4) conflict resolution, and (5) demining efforts.

# MoSWRR (DSW):

- Improve the capacity of DSW case management workers to respond to cases of marginalisation, violence, bullying and other forms of violence towards children with disabilities. Where no case management workers exist, ensure other means of response;
- Improve the capacity of DSW case management workers to refer households with children with disabilities to appropriate services. Where no case management workers exist, ensure other means of response.

	<ul> <li>MoE specific:</li> <li>Revise inclusive education policies and their implementation to ensure children with disabilities are welcome in schools and their learning is supported in ways that are individualized;</li> <li>Ensure the nationwide out-of-school children initiative encourages higher attendance rates in mainstream schools in Myanmar and targets children with disabilities.</li> </ul>	MoH specific: <ul> <li>Improve the capacity of all health care professionals to ensure non-discrimina- tory practices and adequate referral to specialists when needed.</li> </ul>	<ul> <li>Advocate inclusive education as the foundation for the social inclusion of children with disabilities;</li> <li>Advocate measures that make all forms of discrimination and bullying unlawful.</li> </ul>	<ul> <li>CSOs / DPOs:</li> <li>Actively participate in community-level monitoring and mobilization towards essential health and nutrition services to ensure the full inclusion of all children, including children with disabilities, and support communication efforts.</li> </ul>
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Bottleneck 1: Inadequate levels of training of relevant professionals result in their low capacity to provide quality services to children with disabilities.

General recommendation: Develop a framework for assessing strengths, weaknesses, opportunities and threats within ministries, and determine technical capacity needs to support children with disabilities.

	Recommendations:	oM: Autional Committee for Disability (and the DSW as its coordinating body):	<ul> <li>Establish a monitoring and evaluation system to track progress while implementing the CRPD and to identify gaps in quality, human resources and finances.</li> </ul>	All ministries and government agencies:	Develop quality benchmarks and protocols for all goods and service providers in line with international standards;	Develop coordinated training agenda and curricula for staff in line with interna- tional disability protocol standards;	Enhance the technical capacity of frontline service providers through access to training opportunities.	<ul> <li>Development partners:</li> <li>Explore options for collaboration with private sector providers for good quality goods and services at affordable prices.</li> </ul>	)POs:	Ensure that persons with disabilities, including children, contribute to the develop- ment of standards and guidelines for the provision of goods and services for children with disabilities.
		GoM: <b>Nat</b>	о С		⊖ :≡ 0	0 	о 4 Ш	Develo Exp goo	CSOs/DPOs:	<ul> <li>Ens</li> <li>mer</li> <li>child</li> </ul>
support children with disabilities.	Findings:	Professionals do not assume themselves responsible toward children with disabilities, their families, or other professionals.	DSW officers, health and education officials, health care providers, principals, teachers, community-based caretakers and decision-makers have had little or no training related to disability awareness and/or disability mainstreaming.							



#### **12.** Stakeholder recommendations

Because the SitAn is only meant as a snapshot of the current situation and not a prescription for action, the list of recommendations is not exhaustive. Only the government, in close collaboration with persons with disabilities, can commit to a Disability National Plan of Action and its associated budget. In addition, although the recommendations are grouped by responsible stakeholder(s), they should not be read as the sole responsibility of any one group. Instead they are presented in the spirit of the CRPD as a whole, as highlighted in this overarching recommendation for all stakeholders:

Enhanced inter-ministerial cooperation and coordination with various sectors (public and private alike) is essential (CRPD Articles 32, 33, 34, 37) to the development of legislation and services that are disability inclusive; to the provision of much-needed information regarding the rights and responsibilities of both duty bearers and rights holders; and to ensure a transparent, all-encompassing system of monitoring and evaluation.

#### 12.1 Recommendations for Parliament

- Build commitment and capacity on disability according to the social model;
- Create child rights and women's rights committees to ensure all sectors are disability inclusive and all decision-making is responsive to the voices of children with disabilities;
- Engage with the National Committee for Disability on issues related to social norms and attitudes that affect children with disabilities, e.g. through regular reporting mechanisms, to remain appraised of evolving social norms and attitudes and of efforts/plans by the National Committee for Disability to address them;
- Ensure the signature and ratification of the CRPD's Optional Protocol to ensure that children with disabilities have the mechanisms by which complaints can be lodged and penalty actions can be applied against those who violate their rights:
- Support ministries as they develop clear reporting lines, assignments, roles and responsibilities, and ensure coverage of all necessary services by the most appropriate line ministry and that there is no resource wastage;
- Require regular reports from ministries as well as the National Committee for Disability on their activities related to inclusive and effective service provision for persons with disabilities/children with disabilities, including budgets;
- Re-examine and analyse relevant legislation through the social model of disability lens;
- Revise, as needed, all pieces of legislative framework to ensure that laws, subsequent amend-

ment(s), and associated bylaws are aligned with and respectful of international commitments;

• Ensure that ministries allocate adequate financial resources to implement legislation, policy and the National Action Plan on Disability as per the recommendations of the National Committee for Disability.

#### **Supply**

• Ensure line ministries and the private sector develop sustainable and innovative options to improve infrastructure and service provision.

#### Demand

• Establish a monitoring system at each line ministry to track the development and enforcement of strict anti-discriminatory policies that ensure the safety of all children in all arenas of social life.

#### 12.2 Recommendations for the government of Myanmar (all ministries and government agencies)

**President's Office**: Develop clear reporting lines and have a clear assignment of roles and responsibilities at all administrative levels and across all ministries.

- Form the National Committee for Disability (as per the CRPD commitment) with a clear mandate to promote the right to social inclusion of persons with disabilities, including children with disabilities;
- Ensure the National Committee for Disability is resourced to fulfil its coordination and monitoring mandates, to ensure that all ministries and government agencies comply with the CRPD, and to raise awareness and knowledge about children with disabilities;
- Ensure the National Committee for Disability is supported in the development of a National Action Plan (the "vision") by the participation of all stakeholders, including DPOs, children with disabilities and all ministries;
- The GoM should support the National Committee for Disability in implementing communication for development activities aimed at addressing misconceptions related to children with disabilities;
- All line ministries, including but not limited to the MoE and the MoH, should work with the National Committee for Disability to address internal misconceptions with regard to children with disabilities;
- Formally adopt the social model of disability when planning and programming at all administrative levels;
- Involve children and adolescents, particularly children and adolescents with disabilities, when making decisions that affect them at all levels;
- Ensure that laws and policies reflect the spirit of the CRPD and mechanisms exist to prevent, monitor and respond to abuse/neglect at all levels by all stakeholders;
- Improve intersectoral coordination by (1) clearly defining the role of the DSW as the leading entity in initiating and coordinating work related to persons with disabilities, and (2) strengthening its capacity through the provision of adequate human and financial resources;
- Work with the National Committee for Disability to implement all the provisions of the GoM;
- Comply with the CRPD's definition of disability;
- Mainstream disability and highlight actions that target multiple vulnerability needs, e.g. disability and gender, disability and ethnicity, and disability and income level;
- Allocate the funds needed to address the increasing social assistance needs of households that face multiple vulnerabilities, including through the implementation of the National Social Protection Strategic Plan 2014;

- Underscore the legitimacy of the Myanmar National Committee of the CRPD and ensure that all actions subsequent to the passing of the Law on the Rights of Persons with Disabilities meet with the full approval and endorsement of persons with disabilities in Myanmar;
- Allocate adequate resources to ensure inclusive services, and report on planned and/or existing expenditures in transparent ways;
- Develop guidelines for regulating data gathering, data sharing, and confidentiality issues related to the same;
- Provide transparent and disaggregated budgetary data related to existing and/or planned policies and programmes for children with disabilities;
- Coordinate the expansion of statistical information systems to inform programming and budgeting, in collaboration with the CSOs and DPOs. At a minimum, the new system should include a disaggregation and breakdown of data by age, gender, geographical distribution, place of residence (rural or urban), type of impairments, severity, area and level of functioning limitation, and co-morbidity;
- The UNICEF/Washington Group Child Functioning Module should be added to all future DHS and MICS surveys to ensure that longitudinal and comparable data on children with disabilities is gathered.

#### Demand

Ensure that prevention of disability is included in all line ministries' actions related to (1) development of disability-friendly cities, (2) disability-friendly municipal plans, (3) road safety measures, (4) conflict resolution, and (5) demining efforts.

#### Quality

- Develop quality benchmarks and protocols for all goods and service providers in line with international standards;
- Develop a coordinated training agenda and curricula for staff in line with international disability protocol standards;
- Enhance the technical capacity of frontline service providers through access to training opportunities.

#### 12.3 Recommendations for the National Committee for Disability (and the DSW as its coordinating body)

#### **Enabling environment**

• In close consultation with international experts and the CRPD National Committees from neighbouring countries, DPOs, CSOs and persons with disabilities should complete with all urgency the overdue first monitoring report to the UN CRPD Committee.

#### Quality

• Establish a monitoring and evaluation system to track progress while implementing the CRPD and to identify gaps in quality, human resources and finances.

#### 12.4 Recommendations for line ministers

- Ensure laws and policies reflect the spirit of the CRPD and that mechanisms exist to prevent, monitor and respond to abuse/neglect at all levels and by all stakeholders;
- Improve inter-sectoral coordination by clearly defining the coordination mandate of the DSW, and strengthen its capacity through the provision of adequate human and financial resources;
- Work with the National Committee for Disability to implement all the provisions of the GoM.

#### • MoSWRR (DSW) specific:

- Strengthen existing Township Support Groups (TSGs) and Township Child Rights Committees and include children and adolescents with disabilities, and establish appropriate mechanisms to ensure opportunities for the inclusive participation of children with disabilities in community and social activities;
- Expand the role and capacities of DSW social workers (case management) to ensure they reach all children, including children with disabilities, everywhere in the country and thus ensure the ability to coordinate the provision of adequate fora and spaces for all children to express themselves;
- Continue and expand its Violence Prevention Project and educate professionals and the general public on the rights of children with disabilities;
- Establish a mechanism for case managers to report on all forms of child abuse/neglect;
- Establish a system by which children with disabilities can report, anonymously, on instances of abuse/neglect to ensure that children's reports are taken seriously and followed through;
- Design and implement an appropriate and effective disability identification and registration system that helps ensure meaningful social inclusion of children with disabilities and the provision of high quality, inclusive services in close partnership with the MoE and the MoH;
- MoSWRR should initiate routine data collection related to children with disabilities, and/or strengthen existing data collection mechanisms to ensure evidence-based decision making.

#### • MoE specific:

- o Ensure that the right to inclusive education is fully realised by further amendment of the most recent Law Amending the National Education Law. The amendment and its bylaw(s) should be aligned with SDG4, the CRPD, and the Incheon strategy;
- o Ensure data on children with disabilities is incorporated into the EMIS system, including level of impairment, setting where education takes place (and the percentage of time of instruction), and the support services needed and provided.

#### • MoH specific:

- Lead in developing a nationwide child development strategy that is disability inclusive and includes professionals from various disciplines, parents, and children;
- In close partnership with the MoIPL, ensure that all children are registered at birth;
- Provide adequate community-based rehabilitation for all citizens, including children with disabilities, in accordance with Article 25 of the CRPD;
- Improve the capacity of all health care professionals to ensure non-discriminatory practices and adequate referral to specialists when needed.

#### Supply

#### • MoSWRR (DSW) specific:

- Develop national guidelines for the identification and registration of persons with disabilities that are in accordance with the UNCRPD and use protocols compliant with the International Classification of Functioning (ICF);
- In close partnership with MoE and MoH, accelerate the development of an early detection and early intervention system that is respectful of the definition of disability according to the social model, is conducted by teams of multi-disciplinary professionals, and leads to service provision in inclusive settings;
- In close partnership with MoE and MoH, extend school health programmes to screen school-age children for the development of functional limitations in the domains of hearing,

seeing, movement, communication, learning and behaviour/emotion throughout the life cycle using standardised protocols.

#### • MoE specific:

 Invest in the capacity development of teachers and education professionals to work in and help foster an inclusive education system. All teachers must be adequately trained to teach all students in a regular classroom. Teachers and education professionals must also be trained to identify the occasions when they require the support of other teachers or specialized professionals, and they must be compelled to utilise mechanisms for collaboration and cooperation among professionals.

#### • MoH specific:

- Provide adequate community-based rehabilitation for all citizens, including children with disabilities, in accordance with Article 25 of the CRPD;
- Ensure quality and universal coverage of all children, including children with disabilities, in the implementation of an essential package of health and nutrition services, including skilled birth attendance, immunisation, infant and young child feeding support and micronutrient supplementation.

#### • MoPF specific:

• Examine the options for a sustainable financing of goods and services, e.g. subsidies to service providers, that enable children with disabilities to fully realise their potential.

#### Demand

#### • MoSWRR (DSW) specific:

- Improve the capacity of DSW case management workers to respond to cases of marginalisation, violence, bullying and other forms of violence towards children with disabilities.
   Where no case management workers exist, ensure other means of response;
- Improve the capacity of DSW case management workers to refer households with children with disabilities to appropriate services. Where no case management workers exist, ensure other means of response.

#### • MoE specific:

- Revise inclusive education policies and their implementation to ensure that children with disabilities are welcome in schools and that their learning is supported in ways that are individualized;
- Ensure that the nationwide out-of-school children initiative encourages higher attendance rates in mainstream schools in Myanmar and targets children with disabilities.

#### • MoH specific:

• Improve the capacity of all health care professionals to ensure non-discriminatory practices and adequate referral to specialists when needed.

#### 12.5 Recommendations for development partners

- Support the government and the National Committee for Disability to fulfil their mandate and ensure compliance with the CRPD;
- Support the National Committee for Disability in its specific efforts related to the National Action Plan on disability, thereby strengthening the capacities of stakeholders to develop appropriate knowledge about the rights of children with disabilities through training, exposure to knowledge, and best practices;
- Support the MoSWRR (DSW) in implementing communication for development campaigns and

training to address misconceptions with regard to children with disabilities;

- Support children with disabilities in participating freely in community events, and support them in making their voices heard through innovative mechanisms, e.g. media, online platforms and mobile phones, including working with the private sector, e.g. mobile operators and helplines;
- Support Township Support Groups and /or Child Rights Committees (mentioned above) to establish a mechanism to hear children's voices regularly;
- Support all stakeholders in their efforts against abuses and violence, particularly those related to the anonymous reporting and investigation of complaints;
- Support the development of materials that raise awareness of disability and inclusion and are to be used as educational tools in various professional settings;
- Provide support to Parliament and the GoM/the National Committee for Disability to develop capacity for better coordination and leadership across all sectors;
- Provide technical support to all ministries and government agencies so that they can comply with the CRPD and the MPDL. Support knowledge building and exposure to international best practices;
- Continue to advocate social inclusion measures that lead to the efficient allocation of resources, including subsidies/incentives for the supply of essential services;
- Advocate with the private sector to allocate resources for children with disabilities through corporate social responsibility and other schemes;
- Support the GoM in its work with private sector to set up real-time, centralised data gathering mechanisms;
- Ensure that a centralised gathering hub exists under the Central Statistical Organisation;
- Support further study to explore specific intersections between gender and disability in more depth.

#### **Supply**

• Advocate and support the development of private sector partnerships to encourage innovative and affordable provision of goods and services on a national scale.

#### Demand

- Advocate inclusive education as the foundation for the social inclusion of children with disabilities;
- Advocate measures that make all forms of discrimination and bullying unlawful.

#### Quality

• Explore options for collaboration with private sector providers for good quality goods and services at affordable prices.

#### 12.6 Recommendations for civil society organisations, including NGOs and DPOs

- DPOs and child-rights CSOs should support community development awareness raising interventions and inclusive activities aimed at educating and sensitizing all community members;
- Organize events and activities to promote the vision that children with disabilities have the same rights as other children and are capable members of society with a positive contribution to make;
- Strengthen ongoing activities at the community level to increase awareness and the inclusive participation of children with disabilities;
- Develop children's capacity to participate meaningfully in different forums, and provide space for them to freely express their views and influence decision making in matters that concern them;

- Carry out anti-bullying campaigns and sensitisation activities related to the rights of children with disabilities;
- Develop partnerships with professional networks and introduce educational materials about disability and inclusion in a participatory way;
- Engage in and report on monitoring and evaluation activities that provide clear feedback to all line ministries (via the National Committee for Disability) on inclusive service provision;
- Engage in and report on monitoring and evaluation activities that provide clear feedback to all line ministries (via the National Committee for Disability) on inclusive data gathering mechanisms;
- Engage in and report on monitoring and evaluation activities that provide clear feedback to all line ministries (via the National Committee for Disability) on inclusive legislation.

#### Quality

• Ensure that persons with disabilities, including children, contribute to the development of standards and guidelines for the provision of goods and services for children with disabilities.



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**Accessibility**: The degree to which an environment, service or product allows access by as many people as possible, in particular, persons with disabilities.

**Activity limitations**: Difficulties an individual may have in executing activities. An activity limitation may range from a slight to a severe deviation in terms of quality or quantity in executing the activity in a manner, or to the extent that is expected, of people without the health condition.

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

**Augmentative and alternative communication**: Methods of communicating that supplement or replace speech and handwriting, e.g. facial expressions, symbols, pictures, gestures and signing.

**Assistive devices (also assistive technology)**: Any device designed, made or adapted to help a person perform a particular task. Products may be specially produced or generally available for persons with a disability.

**Charity model**: The oldest and most outdated model of disability, where disability is viewed as a punishment or tragedy, usually because of the intervention of a deity. Under this model, the individual is seen as needy and pitiful, and can only find salvation through the mercy, love and care of others.

**Communication**: Includes language, display of text, Braille, tactile communication, large print and accessible multimedia, as well as written, audio, plain-language, human-reader and augmentative and alternative modes of communication, including accessible information and communication technology.

**Developmental disability or disorder**: Also referred to as "child disability." An impairment typically first evident before or during birth, or during infancy, childhood or adolescence. Defined relative to age-specific norms. May be genetic or acquired and usually lasts throughout a person's lifetime. May cause difficulty with language, mobility, learning and independent living. Examples include autism spectrum disorders, cerebral palsy, hearing loss, intellectual disabilities and visual impairment.

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

**Disabled people's organisations**: Organisations or assemblies established to promote the human rights of persons with disabilities, who comprise most of the members as well as the governing body.

**Discrimination on the basis of disability**: Any distinction, exclusion or restriction on the basis of disability that has the purpose or effect of impairing or nullifying the recognition, enjoyment or exercise, on an equal basis with others, of all human rights and fundamental freedoms in the political, economic, social, cultural, civil or any other field. It encompasses all forms of discrimination, including denial of reasonable accommodation.

**Early intervention**: Involves strategies that aim to intervene early in the life of a child and to provide individually tailored solutions. Early intervention typically focuses on populations at a higher risk of developing disability-related issues, or on families that are experiencing such issues that have not yet become well-established or entrenched.

Functioning: An umbrella term for body functions, body structures, activities and participation. It denotes

the positive aspects of the interaction between an individual (with a health condition) and that individual's contextual factors (environmental and personal factors).

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

**Inclusive schools**: Schools where children with disabilities attend regular classes with age-appropriate peers, learn the curriculum to the extent feasible, and are provided with additional resources and support depending on need.

**Integrated schools**: Schools that provide separate classes and additional resources for children with disabilities and that are attached to mainstream schools.

**Impairment**: Loss or abnormality in body structure or physiological function (including mental functions), where abnormality means significant variation from established statistical norms.

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

**International Classification of Functioning, Disability and Health (ICF)**: The classification that provides a unified and standard language and framework for the description of health and health-related states. ICF is part of the family of international classifications developed by the World Health Organization.

**International Classification of Functioning, Disability and Health - Children and Youth Version (ICF-CY)**: A version of the ICF that takes into account the characteristics of the developing child and the child's interaction with the surrounding environment. It recognises that functioning and disability interact in particular ways with children's development, for example, as children learn or establish new relationships.

Language: Includes spoken and signed languages and other forms of non-spoken languages.

**Medical model**: Views disability as an attribute of a person, arising as a result of a health condition or injury. Managing disability is thus primarily a matter of professional medical care, with treatments and services to help the individual adapt to given circumstances.

Participation: A person's involvement in a life situation, representing the societal perspective of functioning.

**Persons with disabilities**: Persons with long-term physical, mental or sensory impairments that, owing to barriers in society and the environment, may limit their ability to effectively participate in society and enjoy equal status with those who do not have such impairments.

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

**Reasonable accommodation**: Necessary and appropriate modification and adjustment where needed in a particular case, but not imposing a disproportionate or undue burden, to ensure that persons with disabilities enjoy or exercise, on an equal basis with others, all human rights and fundamental freedoms.

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

**Social model**: Views disability as a result of a social environment that does not meet the needs of individuals with impairments. Such individuals are disabled in the sense of being excluded from full participation as a result of physical, organisational or attitudinal barriers. Managing disability is thus primarily a matter of social change aimed at removing such barriers. **Special schools**: Schools that are meant to provide highly specialised services for children with disabilities and remain separate from broader educational institutions. They are also called segregated schools.

**Universal design**: The design of products, environments, programmes, and services to be usable by all people, to the greatest extent possible, without the need for adaptation or specialised design.

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



#### ANNEX 1 SAMPLE SIZE CALCULATION FOR THE HOUSEHOLD SURVEY UNDER OBJECTIVE 2

The desired sample size for the household survey within a cluster in a township was calculated using the following formula:

$$n_0 = p(1-p)(Z_{(1-\alpha/2)} / e)^2 \times 1/(C \times h) \times k \times deff; \text{ where,}$$

 $\boldsymbol{n}_{0}$ : Sample size in a cluster within a township

p: Population proportion (i.e. the proportion of successes in the population for observing a dichotomous indicator of interest), which in this case is whether a sample household has a child with some form of disability. In the absence of a priori knowledge about the prevalence rate for disability of any form among children, we have assumed p to be same as the global rate for disability (10 per cent)

 $\alpha$ : Level of significance, i.e. the probability of rejecting a null hypothesis that is correct. Following standard practice, this is set at 5 per cent  $Z_{(1-\alpha/2)}$ : Standard normal deviate at desired level of significance  $1-\alpha/2$ . For  $\alpha = 5$  per cent, Z is 1.96

*e*: Desired margin of error for the estimated indicator of interest. Following usual practice, it is set at 5 per cent

C: Proportion of the target group in the reference population, which in this case is the share of the child population (age below 18 years) in the population in a cluster, assumed to be 30.7 per cent (Source: UNICEF 2012)

 $m{h}$ : Average household size in a cluster, assumed to be 4.4 persons (Source: Provisional Census Results 2014, Myanmar)

 $m{k}$  : Non-response rate, assumed to be 5 per cent following standard practices

*deff*: Design-effect to account for the effect due to cluster sampling (i.e. inter-cluster correlation within a township). This is assumed as 1.5.

The sample size calculated above is adjusted further using the finite population factor as follows:

$$n = \frac{n_0}{1 + \frac{n_0}{N}}$$
, where

 $\pmb{n}$ : Final sample size for households in a cluster;  $\pmb{N}$ : Total household.



#### ANNEX 2 NOTE ON THE SAMPLING UNDER OBJECTIVE 2

The purpose of sampling under Objective 2 was to produce "confidence interval estimates with a specified margin of error (precision)" for the prevalence of disability in children for Mon State and two townships elsewhere in the country. Consequently, the estimate of prevalence could be generalised for the state and the two townships only. The sampling under Objective 2 was done in three broad steps: (1) selection of a township using the PPS method; (2) random selection of two clusters (rural, comprising villages; urban, comprising wards) within each township; and (3) selection of households through circular systematic sampling within a cluster, as well as canvassing of Child Functioning and Disability (CFD) modules for children living in a family, until a pre-decided number of households in a cluster was completed.

The sample size for households within a cluster was decided using the standard formula that generates a 95 per cent confidence interval (CI) estimate for a dichotomous outcome of interest (in this case, whether the child has some form of disability or not) with an absolute precision/margin of error of 5 per cent. Other required parameters included in the formula were (1) an informed assumption that the share of children in the population living in a cluster is 30.7 per cent; (2) the average size of households living in a cluster is 4.4; and (3) the historical prevalence rate for disability among children is 10 per cent (similar to the global rate), which was assumed in absence of a priori knowledge. Sample size thus calculated ensures that the data produce a 95 per cent CI estimate of the proportion of children found to have any form of disability, and that this is within 5 per cent of the true proportion.

State/ Region	District	Township	Cluster	Minimum # of HHs required to produce Cl estimate with a given precision	Final sample size of HH using inflation and finite population factor	Total # of HHs approached for the survey	Total # of HHs participat- ing in the survey
Mon	Mawlamyine Thaton	Mawlamyine	Rural	100	160	191	128
			Urban	100	160	181	105
		Mudon	Rural	100	160	192	99
		IVIUUOII	Urban	100	160	198	85
		Thaton	Rural	100	160	175	118
		maton	Urban	100	160	165	132
Rakhine	Myauk U	Myebon	Rural	100	160	191	137
nakhine			Urban	100	160	173	117
Yangon	Yangon (North)	Hlaingtharya	Rural	100	160	215	115
rangon	rangon (North)	r namgtharya	Urban	100	160	196	139
			Total	1,000	1,600	1,877	1,175

#### Annex Table 2.1

Calculated and final sample sizes for household survey in 5 townships of Myanmar under Objective 2

As standard precautionary practice, the household sample size for a cluster was inflated by (1) multiplying 1.05 to counter non-response from households and (2) multiplying 1.5 to account for inter-cluster correlation

within a township (i.e. the design effect), while also further refining the sample size using a finite population factor. In summary, the maximum target sample size of 160 households for a cluster (320 for rural/urban clusters within a township) was well above the number warranted under the statistical formula (100 for a cluster and 200 for a township).

The table above also shows (1) the required number of HH to produce aCl estimate with a given precision; (2) the final sample size for HHs using inflation factors and finite population factors; (3) the total number of HHs approached for the survey; and (4) the total number of HHs with children that participated in the survey. This table shows that the number of households with children that participated in the survey exceeds the required number to produce the Cl estimate in the majority of the cases, except for Mudon Township, where the total shortfall was only 16 HHs. Given this, the loss of sample size does not greatly affect the Cl estimate of the prevalence of disability with a specified precision. In addition, because the efficiency of an estimate increases by the square root of sample size and not linearly, the marginal loss of sample size does not significantly impact the estimated rate.

#### ANNEX 3 SAMPLING ERROR AND CALCULATION OF SAMPLE WEIGHT UNDER OBJECTIVE 2

Sampling errors arise due to in-built features of the sampling strategy, such as unequal probabilities of selection of households, unequal response rates across sample locations, or non-coverage of the population. These may lead to bias and other departures between the sample and the reference population. To counter this, the SitAn prepared estimates for the prevalence of disability in children separately for each township using a sample weighing mechanism on the quantitative data collected under Objective 2. Moreover, the use of sample weights ensured that the estimated prevalence rate for disabilities in children is representative for an entire township, not just for the surveyed households.

The sample weight calculation process also addressed two specific sampling errors: (1) the inclusion of some households without children in the survey, and (2) the exclusion of some children while canvassing the CFD modules in households with multiple children. The process of preparation of a sample weight for each child surveyed in all townships is described below.

The sampling framework implemented under Objective 2 is a multi-stage design, such as:

- Stage 1: Select five townships in three pre-decided states/regions using PPS as the primary sampling unit (PSU).<sup>56</sup>
- Stage 2: Select two clusters (one poor and one not as poor) randomly within each township. It was decided that the poor and non-poor clusters would be selected from rural and urban areas respectively. Consequently, the survey had selected villages (rural) and wards (urban) through random sampling with replacement.
- Stage 3: Select households with children living within each cluster using circular systematic random sampling. Some households without children were also selected in the survey. Consequently, Stage 3 should be further broken down into two parts, one that includes households with children in the analysis and one that excludes households without children from the analysis.
- Stage 4: Select a child out of all the children for whom a household agrees to fill in the CFD module.
- Consequently, the sample weight for each child (the FSU) must take into consideration the following:
- Probability of selection of a township (p1)
- Probability of selection of a cluster within a township (p2)
- Probability of selection of a household living in a cluster within a township (p3)
- Probability that information under the CFD module is provided by a household for one child out of all the children living in the household (p4)

To calculate p1, p2 and p3, the study used the 2014 census and geographic data (as available from the MIMU). For p4, primary data collected during the survey work were used. Following standard practice, the sample weight (w) for estimation of the prevalence of disability in children in any of the townships was calculated as:

<sup>56</sup> Two townships, Myebon (Rakhine State) and Hlaingtharya (Yangon State) were pre-decided at the terms of reference stage. However, the study treats the process of selection of these two locations as the same as the other three townships in Mon State. This enabled the study to calculate the probability of selection of all five townships uniformly.

$$w = \frac{1}{p_1 \times p_2 \times p_3 \times p_4 \times p_5} \times \frac{1}{r}$$

where,

r: Response rate in a cluster = (number of households interviewed ÷ the number of households approached)

Non-sampling errors: Non-sampling errors arise due to lapses in the implementation of data collection activities and data processing, such as failure to locate and interview the target households, misunderstanding of the questions on the part of either the interviewer or the respondent, and data entry errors. It is to be noted that non-sampling errors in the current context may arise during implementation of the fieldwork for Objectives 1 and 2 alike. As mentioned previously, the study team used various techniques of convenience sampling to reach the target households under Objective 1. This seemed to be the best solution given the lack of any register for children with disabilities.

In general, the study tried to minimise non-sampling errors through the following means:

- The field supervisors and field investigators were trained on the questionnaires and different concepts within those tools through desk- and field-based orientation/training exercises;
- The data collection process included appropriate monitoring, supervision and follow-up activities;
- The data entry process was closely monitored and cross-verified with filled-up questionnaires independently; and
- After the first round of data entry, the raw data were quickly analysed to identify and resolve any inconsistencies. Once inconsistencies were resolved, the final cleaned data were used for analysis and report writing.

### ADDENDUM TO CHAPTER 2

The following section provides a detailed description of the nature and types of activities performed in the first phase of the research. Activities under Phases 2 to 4 were performed as per the broad plan indicated in Box 2.3.

In the first phase of the SitAn, the research team performed the following activities: stakeholder mapping; the preparation of the sampling plan and strategy for the identification and contacting of all types of stakeholders; the design of research tools; a quick desk review; and the preparation of a draft analysis plan.

#### Stakeholder mapping

Stakeholders for this research include children with and without disabilities, their families, community members, service providers and programme implementers at the township level and below, DPOs working at the national and sub-national levels, policymakers, and other development partners, e.g. donor agencies. Fieldwork aiming to reach these target stakeholders included household survey interviews, FGDs and KIIs. Household survey interviews under Objective 1 were quantitative, aiming to access and use various services, e.g. demand-side factors, by children with disabilities and their families, as compared to other families. Household survey interviews undertaken for Objective 2 were also planned to be quantitative. However, the survey protocol was prepared differently (please refer to the section on research design).

FGDs and KIIs under Objective 1 provided qualitative information on the enabling environment and supply-side factors (e.g. participation in local social and cultural events; protective environment in families and schools; perception and experience regarding quality of services; and attitudes of service providers and communities), as well as on demand-side issues, e.g. the expectations/aspirations of children with disabilities and their families. These qualitative areas of inquiry were probed further through KIIs and FGDs with children, both those with and without disabilities. The formats for the FGDs and KIIs were semi-structured and included open-ended questions.<sup>57</sup>

The sampling framework and sample size for the fieldwork related to children, their families and community members – the primary stakeholders for the SitAn – are explained in the section below. A list of stakeholders, other than those contacted during the study, is also provided.

#### Sampling plan under Objective 1: Situation analysis of children with disability

In the absence of an official register of children with disabilities that could be used as a sampling frame, a purposive sampling plan and a convenient/"snowball" identification strategy for contacting stakeholders was used for selection of the FSUs under Objective 1. The FSUs in the current context were the households in the townships (i.e. the PSUs).

The sampling strategy describes the selection process for the PSUs first and subsequently explains the same for the FSUs.

Selection of the primary sampling units, i.e. the townships. The quantitative and qualitative surveys under Objective 1 were originally planned to be conducted in 25 townships spread over 13 states and regions of Myanmar.<sup>58</sup> For the selection of the townships, the probability proportionate to size (PPS) method was

<sup>57</sup> Similar versions of the qualitative tool were used for Objective 2 to collect data on the types and quality of the different services available for children with disabilities in the target locations.

<sup>58</sup> There are 407 townships in Myanmar, including 8 townships in the national capital region of Nay Pyi Taw. However, Nay Pyi Taw itself is not included in the sampling. Also, households living in the diplomatic missions were excluded from the sampling.

used, and it was based on a list of all the townships, with the cube root of the number of households in a township as the measure of size. The PPS method ensures that the probability of selection of townships with a higher number of households (and likely to have a higher number of children) is greater. Moreover, repeated exercise of the PPS method ensured that the selected townships were spread over all 13 states and regions. The study also considered accessibility as a factor – dependent on local weather conditions, security and the political situation – before finalising the township sampling plan.

Selection of the final sampling units, i.e. the households. To determine the household sample size, the PPS method warranted that an equal number of FSUs from each township be selected in order to exclude the probability of selecting a larger number of FSUs from a location with a higher number of households. Moreover, it was required that the household sample represent two primary stakeholder groups equally: families with children with disabilities (the primary area of inquiry) and families with children without disabilities (the comparison group). Following this, and to optimise survey costs, it was proposed to survey 50 households from each category in each township.

After calculations, the sample size was:

- 1,250 households with children with disabilities in 25 townships
- 1,250 households without children with disabilities in the same 25 townships
- Total size of the household sample: 2,500

However, the actual fieldwork faced serious challenges due to unprecedented floods in Myanmar in 2014. As a result, the target number of households could not be covered in some selected townships. In those cases, the survey was conducted in adjacent townships that remained accessible. In a few cases, over-sampling of households also occurred. Consequently, the survey was conducted in 28 townships, for a total of 2,547 households (1,271 with children with disabilities and 1,276 with children without disabilities. Altogether, 1,289 children with disabilities were covered under the survey.

#### Annex Table 4.1:

State/ Region	Township	HHs with children with disabilities	HHs without children with disabilities	Total HHs
Kachin	Moe Kaung	50	50	100
K av vala	Loikaw	20	20	40
Kayah	Bawlakhe	38	38	76
Kayin	Kyaidon (ST)	50	50	100
Sagaing	Ye U	50	50	100
Taninthary	Palauk (ST)	51	52	103
Daria	Yaedashe	50	50	100
Bago	Tharyarwad	50	51	101
	Minbu	13	13	26
Magway	Saytottara	37	37	74
	Pyin Oo Lw	50	50	100
Mandalay	Taungtha	50	50	100
	Wundwin	50	50	100
Mon	Kyaikto	51	54	105
Delukine	Pauktaw	51	51	102
Rakhine	Thandwe	49	51	100

Household sample size under Object	ve 1: Situation analysis of children with disabilities			
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State/ Region	Township	HHs with children with disabilities	HHs without children with disabilities	Total HHs
---------------	-------------	-------------------------------------	---	-----------
	Shwepyitha	50	51	101
Yangon	Dagon North	53	52	105
	Dala	51	49	100
	Taunggyi	19	16	35
	Pindaya	50	50	100
	Panglong(S	34	34	68
Shan	Lashio	50	50	100
	Kutkai	50	50	100
	Talay(ST)	50	54	104
	Kyaiklatt	53	53	106
Ayeyawady	Pyapon	51	50	101
	Wakema	50	50	100
	Total	1,271	1,276	2,547

#### Annex Table 4.1:

#### Household sample size under Objective 1: Situation analysis of children with disabilities

**Selection process of households**: As stated earlier, a mix of convenient and snowball sampling, plus a "random walk" approach, was used for identifying and contacting the FSUs. First, contacts were established with the DPOs engaged in (1) IBR and CBR activities in the selected townships and (2) advocacy and other activities at the national and sub-national levels. Contact was made by the study team, with assistance from UNICEF and the DSW. Through these connections, families with children with disabilities in the selected townships were identified and contacted, through convenient sampling. This convenient sampling technique was also used to establish contacts with families who had received, or were currently receiving, services from the government-run IBR services or who were registered at ECCD centres, formal/informal schools, monasteries/churches, or health facilities. This was achieved through support from the local offices of the DSW; township administration and education and health officials; and DPOs, civil society organisations and NGOs.

Because there existed a high possibility that families with children with disabilities had never been in touch with any DPOs or public services, a snowball sampling technique was used to ensure they were captured in the sample. Each family with children with disabilities selected and interviewed through convenient sampling in the 28 townships was requested to provide contact details of other such households they might be aware of. The DPOs and local DSW offices also were used to locate such families. Lastly, households without children with disabilities were selected randomly in each township.

**Qualitative sample survey in the townships**: Qualitative information from the children with disabilities was collected through KIIs and FGDs. IFGDs were primarily conducted to corroborate information collected from individual interviews. KIIs were conducted for the parents/primary caregivers of the children (both with and without disabilities), and the children without disabilities were specifically engaged through FGDs to obtain their perspective.

During visits to the townships, key community members, e.g. village elders and community leaders, were identified through interaction with families and the DPOs. Qualitative information from these community members was elicited through FGDs. In addition, various public service providers (education, health and social welfare) in the townships were interviewed using semi-structured formats. Apart from this, qualitative information also was collected from members of the DPOs, policymakers and other development partners, e.g. the NGO network.

#### Annex Table 4.2:

#### Sample size for qualitative survey under Objective 1: Situation analysis of children with disability

Sampling unit	Mode	Sample size per Township	Total sample
Children with disabilities	KII	3	75
	FGD	1	25
Children without disabilities	FGD	1	10*
Parent/caregiver of children with disabilities	KII	3	75
Parent/caregiver of children without disabilities	KII	1	24
Community members	FGD	1	25
Education sector	KII	4	36*
Health sector	KII	3	30*
Social welfare sector	KII	3	14*
DPOs (National level)	KII	-	5
Policymakers (National level)	KII	-	5
Other development partners (National level)	KII	-	3

Note: (1) \* Conducted in 10 townships. The 10 locations were selected randomly from the list of 25 townships presented in Table 1. (2) KII – Key Informant Interview, FGD – Focus Group Discussion.

#### Sampling plan under Objective 2: Estimation of the prevalence of disability

The purpose of the sampling plan under Objective 2 was to collect data through a quantitative household survey to (1) estimate the prevalence of disability in Mon State, and (2) compare it with the disability rates estimated for two predetermined townships, Hlaing Thar Ya in Yangon and Myebon in Rakhine. The revised child functioning and disability (CFD) modules, one each for children ages 2-4 years and children ages 5-17 years, were designed using the revised Washington Group methodology and used for the household survey.

Selection of townships in Mon State: It was determined that the household survey would be done in 3 townships in Mon State. Mon State has 12 townships. However, Kyaikto Township in Thaton District was left out of the selection process for Objective 2, because it had already been chosen for survey under Objective 1. For the rest of the places, the PPS method was used. In the end, the survey in Mon State under Objective 2 was conducted in three townships: Mawlamyine, Mudon and Thaton.

Sampling framework for the household survey in five townships: The study team followed the directions given in the Guidelines and Principles for the Development of Disability Statistics, United Nations, 2001. According to the UN guidelines, a household survey for estimating the prevalence of disability in a particular location (in this case a township) should be conducted in at least two clusters: (1) formal/economically better-off settlements, and (2) informal/squatter/poor neighbourhoods. The team accessed the number and identity of sub-township locations (i.e. towns and wards, and village tracts and villages) from the Myanmar Information Management Unit (MIMU) using 2014 data,<sup>59</sup> and it consulted with local sources. Based on these inputs, wards (urban areas) and villages (rural areas) were identified for the fieldwork under Objective 2 (see Table 4). The selected villages represent poor areas in general, while the wards are commercially active and economically better-off urban pockets. Secondly, a circular systematic random sampling<sup>60</sup> process was used for the selection of households in each location.

<sup>59</sup> Note sub-township-level information is yet to be published by the census.

<sup>60</sup> In this method, a random start is chosen between 1 and N (population size) and then k (= N÷n; n sample size) interval number is added to that start random number until exactly n sampling units are chosen. Suppose the sample size (n) is 160, population (N) is 1,000 and the start random number between 1 and 1,000 is 63. Then starting with the 63<sup>rd</sup> household from an identifiable spot in a location, every 6<sup>th</sup> (1,000÷160=6) household (69<sup>th</sup>, 75<sup>th</sup>, 81<sup>st</sup>, and so on) is sampled until the desired sample size of 160 is reached.

Sample size for the household survey in five townships: The sample size for the households was determined using a standard formula for sample size calculation that generates a confidence interval (CI) estimate for a dichotomous outcome of interest (in this case, whether the child has some form of disability or not) with absolute precision (or margin of error) and with a fixed set of assumptions for CI, margin of error, household size, and the proportion of children in each location. Using the formula, the required sample size for a cluster within a township was calculated as 100 (i.e. 1,000 households spread over 10 clusters in five townships). Following standard cautionary practice, the target sample size was further adjusted using various inflation factors to counter different eventualities like non-response, inter- and intra- cluster correlation, and so on. Consequently, the household sample size for each cluster in each township was fixed between 100 and 160.

The survey faced various challenges, such as non-response; finding a large number of households without children; finding households that only had children below 2 years old; not finding enough households with children between 2-17 years in a particular village or ward to complete the target; and other logistical issues. Consequently, some households were excluded from the final analysis, despite being covered in the survey. The final (or effective) sample with children between 2-17 years old used for the estimation includes 1,096 families. This sample provided information on 1,318 children, with 329 and 989 children in the 2-4 year and 5-17 year age groups respectively. The effective sample size used for the estimation was higher than the number required for producing CI estimates with a given level of precision for most of the townships. Moreover, the SitAn study team prepared the estimates using a sample weighing procedure to account for the various sampling errors. Lastly, stringent quality control measures were put in place during the data collection and analysis phases to negate possible non-sampling errors.

#### Annex Table 4.3:

State/Region	Township	Cluster (Ward/ Village)	Household
	Maxularavina	Urban (Hpet Tan Ward)	95
	Mawlamyine	Rural (Ka Toe)	122
Mon		Urban (Myoma (1) Ward)	84
Won	Mudon	Rural (Thar Yar Kone)	94
	Thaton	Urban (Leik Inn Ward)	126
		Rural (Taung Kyar Ywar Gyi)	110
Rakhine Myebon		Urban (Zay Paing Ward & Thea Tan Ward)	109
		Rural (Bi Lu Khway & Ko Yan Pyin)	125
Vangon	Haingthanya	Urban (No (6) Ward	123
Yangon	Hlaingtharya	Rural (Ah Pyin Pa Dan, Kyun Gyi & Ka Pyo)	108
		Total	1,096

Lastly, qualitative data were collected from the Township Education Office and schools in Mawlamyine (Mon State), Myebon (Rakhine State) and Hlaingtharya (Yangon State). Three KIIs were conducted, one each for education office, and one each for the school principal and the school teachers in each township, for a total of 9 KIIs.



# ANNEX 5 ADDENDUM TO CHAPTER 3

This section is an addendum to the quantitative findings described in Chapter 3.

# **Respondents' profile**

A total of 1,289 children with disabilities were found to be living in the 2,547 sampled households. Responses to questions were given by their primary caregivers. Among the respondents, an overwhelming majority were the parents of children with disabilities (86 per cent), followed by grandparents (11 per cent). Siblings and others constituted a very small proportion of respondents. When the field teams were further questioned about this information, it was revealed that most parental respondents were the mothers of children with disabilities. Fathers responded in very few cases. The field teams further mentioned that, more often than not, the mother was usually the one to take



care of the child with disabilities in addition doing to the household chores. Fathers were either too busy with work or simply not interested.

# Disability by gender and age

Disaggregation of data by gender reveals that overall boys account for 55 per cent of the children with disabilities and girls comprise the remaining 45 per cent. This distribution is almost common to all age groups, with ages 2-4 years the only exception. Here, the proportion of boys to girls is almost the same, 51 per cent and 49 per cent respectively.

An analysis by location reveals that 58 per cent of the children with disabilities live in urban areas and 42 per cent in rural areas. However, this finding should be treated with caution, since it may be indicative of limited professional facilities in rural areas for identifying disability.

#### Annex Table 5.1: Distribution of CWDs by age, gender and location

Age group	Rural	Urban	Total
<2 yr	48%	53%	100%
2-4 yr	41%	59%	100%
5-9 yr	41%	59%	100%
10-13 yr	44%	56%	100%
14-17 yr	42%	58%	100%
Total	42%	58%	100%

The highest proportion of children with disabilities are from the poorest quintile of the population, accounting for nearly 24 per cent of the total. Children from the richest quintile account for 18 per cent, the lowest proportion of children with disabilities. The disparity the between children from the richest and poorest quintiles is therefore not significant.

Among the regions, Shan State accounts for the largest proportion of children with disabilities, followed by Yangon, Ayeyawady and Mandalay. Furthermore, children younger than age 2 comprise the largest proportion of children with disabilities in 6 out of 13 regions (Kachin, Kayah, Sagaing, Bago, Magway and Shan).

State/Region	<2 yr	2-4 yr	5-9 yr	10-13 yr	14-17 yr	All
Kachin	5%	4%	4%	4%	4%	4%
Kayah	10%	4%	4%	4%	5%	5%
Kayin	0%	5%	4%	5%	3%	4%
Sagaing	10%	3%	3%	4%	4%	4%
Tanintharyi	3%	3%	4%	5%	4%	4%
Bago	15%	12%	11%	6%	4%	8%
Magway	0%	9%	3%	4%	3%	4%
Mandalay	13%	16%	13%	11%	10%	12%
Mon	0%	3%	4%	6%	2%	4%
Rakhine	5%	5%	7%	7%	11%	8%
Yangon	3%	7%	11%	14%	15%	12%
Shan	30%	19%	21%	18%	21%	20%
Ayeyawady	8%	10%	11%	12%	14%	12%

#### Annex Table 5.2: Distribution of children with disabilities by age and location

### Disabilities by multiplicity and severity

Of the total number of children surveyed, the vast majority of children with disabilities were reported to have a single disability (88 per cent), while 11 per cent reported two types of disability. When asked, parents/ caregivers identified 30 types of disability/limitation, in all cases reporting a physical condition as disabling/ limiting. In no cases was an environmental barrier considered disabling/limiting. The most often mentioned types of disability/limitation identified are: "low IQ" (23 per cent); mobility concerns (18-20 per cent); speech

# Annex Table 5.2:

#### Number of disabilities (%)

Number of disabilities	%
Only one type of disability	88%
Two types of disabilities/limitations	11%
More than two types of disabilities/ limitations	1%



#### Annex Table 5.3:

# Distribution of children with disabilities by age group and severity

• •	•			
Age group	Some difficulty	A lot of difficulty	Cannot do anything without assistance	Total
		Row %		
<2 yr	18%	40%	43%	100%
2-4 yr	22%	32%	46%	100%
5-9 yr	29%	42%	28%	100%
10-13 yr	39%	43%	18%	100%
14-17 yr	42%	37%	21%	100%
Total	34%	40%	26%	100%
		Col %		
<2 yr	2%	3%	5%	3%
2-4 yr	7%	9%	21%	11%
5-9 yr	25%	31%	32%	29%
10-13 yr	34%	33%	21%	30%
14-17 yr	32%	24%	21%	26%
Total	100%	100%	100%	100%

difficulties (about 12 per cent); "deaf and mute" (9 per cent); visual impairment (about 7 per cent); and hearing impairment (about 2 per cent). With regard to the severity of the disability/limitation, 34 per cent of the respondents indicated "some difficulty," 40 per cent indicated "a lot of difficulty," and 26 per cent reportedly "cannot do anything without assistance."

The table above presents the distribution of children with disabilities by severity of disability and age group (within and across groups). Most of the children in the younger age groups were reported to be unable to do anything without assistance (43 per cent for < 2 years and 46 per cent for 2-4 years). On the other hand, distribution across age groups shows that the children with disabilities who were reported to be unable to do anything without assistance were most prevalent among children aged 5-9 years.

#### Annex Table 5.4:

Distribution of children with disabilities by gender and severity of disability

Severity	Boys	Girls	ALL				
Row %							
Some difficulty	56%	44%	100%				
A lot of difficulty	53%	47%	100%				
Cannot do anything without assistance	56%	44%	100%				
Total	55%	45%	100%				
	Col %						
Some difficulty	35%	33%	34%				
A lot of difficulty	39%	42%	40%				
Cannot do anything without assistance	26%	25%	26%				
Total	100%	100%	100%				

On the other hand, the distribution of children with disbailities by severity of disability and gender shows that higher proportions of boys than girls were reported to have disability in each of the three categories of severity. Distribution across severity groups also reveals that most children with disbailities (40 per cent overall; 39 per cent of the boys and 42 per cent of the girls) were reported to have "a lot of difficulty."



# ADDENDUM TO CHAPTER 4

This section is an addendum to the quantitative findings described in Chapter 4.

### **Self-care activities**

Responses on self-care activities were elicited from the parents/caregivers of children ages 4 and above. The parents/caregivers of 1,158 children with disabilities and 1,023 children without disabilities were asked questions regarding the self-performance of activities related to health and hygiene, eating and changing clothes. The table below contains detailed data on the reported performance of various self-care activities by both children with and those without disabilities across three broad age groups.

While more than 70 per cent of the children without disabilities always performed the three activities themselves, only 40 to 56 per cent of the children with disabilities could do so. The highest level of ability was found in the case of eating on their own. Around 40 per cent of the children with disabilities reportedly never performed self-care activities by themselves and needed assistance. Lastly, the parents/caregivers reported that 75 per cent of the children with disabilities faced challenges in leading their daily lives with ease.

Children with disbailities			Children without disabilities							
Age group	Always	Often	Sometimes	Never	Total	Always	Often	Sometimes	Never	Total
				a. Person	al hygien	е				
5-9 yr	28%	5%	13%	54%	100%	62%	7%	19%	13%	100%
10-13 yr	50%	9%	11%	30%	100%	90%	3%	2%	4%	100%
14-17 yr	59%	5%	7%	28%	100%	96%	1%	0%	3%	100%
Total	46%	6%	11%	38%	100%	79%	4%	9%	8%	100%
				b. E	ating					
5-9 yr	39%	8%	15%	39%	100%	70%	7%	14%	9%	100%
10-13 yr	65%	7%	8%	20%	100%	91%	3%	2%	4%	100%
14-17 yr	71%	4%	5%	20%	100%	96%	1%	0%	3%	100%
Total	58%	6%	9%	26%	100%	83%	5%	7%	6%	100%
				c. Changi	ng clothe	s				
5-9 yr	25%	6%	14%	56%	100%	56%	8%	20%	16%	100%
10-13 yr	50%	7%	11%	32%	100%	89%	3%	2%	5%	100%
14-17 yr	61%	5%	6%	28%	100%	96%	1%	0%	3%	100%
Total	45%	6%	10%	39%	100%	76%	5%	10%	10%	100%

#### Annex Table 6.1: Self-care activities by children with and without disabilities across age groups



# ADDENDUM TO CHAPTER 5

This section is an addendum to the quantitative findings described in Chapter 5. The caretaking and living environment of children with disabilities was analysed against the parameters of schooling, participation in household chores and children's participation in community events.

# **Attending school**

It is worrisome to note that 67 per cent of the children with disabilities were out of the formal education system and did not attend school. For the age group 2-4 years, this proportion was even higher: 93 per cent. In comparison, 89 per cent of the children without disabilities regularly attended school.

In addition to mainstream schools, the institutional structure for education and skills development is comprised of monastic schools, vocational training centres and special schools. However, attendance at these places by children with disabilities was found to be negligible.

### Participation in household chores

Children's participation in household chores was measured against the most common household functions, such as cooking, cleaning, collecting firewood, collecting water, taking care of children and the elderly, taking care of livestock, and going to the market.

Overall, as reported by the parents/caregivers, children did not participate in all household chores regularly. This holds true both for children with and those without disabilities. The only exceptions were activities related to cleaning and taking care of livestock, where 45 per cent and 40 per cent respectively were regularly engaged.

As expected, the children without disabilities participated more in household chores. However, their participation was only marginally greater than that of the children with disabilities. A particularly noteworthy finding in this regard is that children with disabilities participate most in cleaning and washing activities (32 per cent) and taking care of livestock (27 per cent), whereas children without disabilities contribute the most to cleaning (60 per cent), taking care of livestock (56 per cent) and cooking (35 per cent). Boys and girls from both sets of children participated equally in chores.

#### Use of assistive devices

Nearly all the respondents (99 per cent) said they had not been advised with regard to assistive devices to aid mobility, vision and hearing. Just 34 out of the 1,289 respondents said they had been so advised, and 131 of the 1,289 children with disabilities had started using assistive devices of their own accord.

Of the 165 children with disabilities who had used assistive devices, 108 were using them at the time of the survey. The remaining 57 had discontinued doing so, citing reasons such as the device breaking down or being difficult to use.

Wheelchairs were the most commonly cited assistive devices (36 out of 108), followed by walking sticks/ crutches (27 out of 108). Spectacles, braces and hearing aids were other devices being used.

Similarly, when asked if the children with disabilities had been advised on the use of any learning aids/ devices, virtually all the respondents replied in the negative (1,286 out of 1,289).

#### Disabled-friendly modifications in the household

The parents of only 468 of the 1,286 children with disabilities responded to questions about whether they had ever felt the need for any disability-sensitive modifications in the household. In almost every state or region, between 70 and 100 per cent of the responding parents/caregivers said they had never considered it. Between 75 and 100 per cent of these respondents in each state reportedly said they had made no structural modifications to the house.

# ADDENDUM TO CHAPTER 6

This section is an addendum to the quantitative findings described in Chapter 6. Community plays a key role in the mainstreaming of children with disabilities and ensuring that they receive equal opportunities for growth and development. The study delved into interactions by children with disabilities with their communities. For comparitive purposes, the same set of questions was asked of children without disabilities.

#### Social and community life of children with disabilities

Mostly commonly, children with disabilities and children without disabilities spend their free time interacting with family members other than their primary caregivers and with friends. Thus, nearly 60 per cent of the children across both categories spent time with family members on a daily basis, and 40 per cent spent time with friends every day. About 14 per cent of the children without disabilities reported participating in sports, while only 6 per cent of children with disabilities did so.

About 40 per cent of the children with disabilities and 58 per cent of children without disabilities were reported to participate in events such as religious functions or fairs. Disparities on the basis of gender were slight across both sets of children.

#### Participation in economic activities

Almost all the respondents said neither children with or without disabilities are engaged in income-generating activities. This finding matches the low presence of children in vocational centres, as discussed in the education section.

#### Community's behaviour toward children with disabilities

Overall, communities indicated they were understanding of the situation of children with disabilities, with 81 per cent of the children with disabilities being treated the same by the community as all other children. No gender-based variations were found. Nevertheless, 20 per cent of the children with disabilities had reportedly been bullied by other children, and 13 per cent by adults. A total of 79 per cent of the children with disabilities were generally supportive, a sentiment reflected by the parents/ caregivers of children without disabilities in almost equal proportion (73 per cent).

# Participation in social events

One-third (33 per cent) of the parents/caregivers of children with disabilities were not satisfied with the extent of their child's/children's participation in social/cultural events. A total of 41 per cent expressed satisfaction to some extent, but just 20 per cent were satisfied to a great extent. On the contrary, nearly half (46 per cent) of the parents of children without disabilities were satisfied with the extent of their children's participation in social/cultural events. While there is a significant difference between the two groups of children, it should be noted that at least half of all the parents were not satisfied with their child's/children's participation in social events. When parents were asked how often they brought children with disabilities to social/cultural events, 15 per cent said they ensured that their children with disabilities were brought to these events more often than their siblings without disabilities, whereas 29 per cent said they brought all their children to the events equally. However, 39 per cent said they either brought their children with disabilities to social events less often than their other children or did not bring them at all.

Most of the parents/caregivers said their children faced no resistance when participating in community events. Among the parents of children with disabilities, 69 per cent disagreed or strongly disagreed with the

perception of resistance being encountered, tbut this proportion was notably higher among the parents of children without disabilities (87 per cent). A total of 24 per cent of the parents of children with disabilities – nearly 1 in 4 – agreed that their children faced some resistance at community events. Disparities by gender were negligible in terms of treatment at these events.

#### Help received from the community

Respondents were asked about help received with services related to health, education, finances and routine activities. Barring routine activities, where the community reportedly helped children with and without disabilities alike (21 and 20 per cent respectively), community assistance was largely not forthcoming to either category of children.

#### Awareness campaigns on disability

#### Annex Table 8.1:

Whether respondents could recall any mass awareness campaign on disability organised in the community in the last year

State/Region	Children with disabilities	Children without disabilities	All
Kachin	0%	4%	2%
Kayah	9%	16%	12%
Kayin	0%	0%	0%
Sagaing	0%	4%	2%
Tanintharyi	2%	0%	1%
Bago	3%	3%	3%
Magway	2%	0%	1%
Mandalay	1%	1%	1%
Mon	0%	0%	0%
Rakhine	0%	1%	0%
Yangon	39%	20%	30%
Shan	3%	3%	3%
Ayeyawady	3%	1%	2%
Total	7%	5%	6%

Respondents were asked if they had witnessed any awareness campaigns on disability in the preceding year, and the data were analysed by region/state. An overwhelming majority of the respondents (93 per cent), regardless of whether they had children with or without disabilities, could not recall any such campaign. Of the very limited number of respondents who did recall a campaign, most were from Yangon (39 per cent). In all the other regions, recall of a campaign was negligible. A total of 65 per cent of the respondents who had children with disabilities and 45 per cent of respondents who had children without disabilities said they believed the organisers of these campaigns were NGOs.

#### **Community-based rehabilitation programmes**

#### Annex Table 8.2:

# Whether respondents have ever heard about CBR services/programmes (only for children with disabilities)

State/Region	Yes	No	Total
Kachin	4%	96%	100%
Kayah	10%	90%	100%
Kayin	0%	100%	100%
Sagaing	0%	100%	100%
Tanintharyi	0%	100%	100%
Bago	7%	93%	100%
Magway	0%	100%	100%
Mandalay	1%	99%	100%
Mon	0%	100%	100%
Rakhine	0%	100%	100%
Yangon	18%	82%	100%
Shan	2%	98%	100%
Ayeyawady	3%	97%	100%
Total	4%	96%	100%

As in the case of awareness campaigns, 96 per cent of the respondents from both categories of children had never heard of community-based rehabilitation services for children with disabilities, with little variation by region/state, except for Yangon. A similarly very high proportion of respondents across both categories (95 per cent) were unaware of the CRPD. A total of 91 per cent of the children with disabilities and 85 per cent of the children without disabilities knew of no community-based rehabilitation services functional in their area.



# ANNEX 9 ADDENDUM TO CHAPTER 7

This section is an addendum to the quantitative findings described in Chapter 7. The situation related to the education of children was studied across the parameters of attendance, accessibility of school, quality of education, and behaviour of peers toward children with disabilities, among others. The parents/caregivers of 1,207 children with disabilities and 1,294 children without disabilities who were over 3 years old responded to these questions.

### **School attendance**

About 67 per cent of the children with disabilities were not attending any school at the time of the survey, which is a cause for serious concern. Among children without disabilities, a much lower – but still high – 19 per cent were not attending school. The proportion of boys and girls out of school across the two categories was nearly the same, underscoring the absence of gender-based discrimination with regard to education.

Of the total number of children attending school, 88 per cent of the children with disabilities and 93 per cent of the children without disabilities were attending mainstream schools. Around 6 per cent of the children with disabilities were attending special schools, 4 per cent were attending ECCD centres,



and 2 per cent were attending monastic schools. None of the children with disabilities attended daycare centres. The proportions were almost the same for children without disabilities as well as for boys and girls.

Among children with disabilities, 38 per cent of the 5- to 9-year-olds, 41 per cent of the 10- to 13-year-olds, and 20 per cent of the 14- to 17-year-olds were reportedly attending school, indicating a sharply declining trend of attendance among the oldest children. Generally, the proportion of girls and boys attending school is the same across age groups, except for among the 14- to 17-year-olds (16 per cent of the girls and 23 per cent of the boys).



# Level of education

Of the 1,101 responses received with regard to the ability to read and/or write, only 36 per cent of the children with disabilities were literate. An analysis by region revealed the highest proportion of children with disabilities who could read and write lived in Ayeyawady (63 per cent). Yangon came in a distant second at 45 per cent, followed by Kachin (42 per cent). In the remaining states/regions, this proportion hovered between 30 and 40 per cent, with Sagaing and Mandalay reporting very low rates, 19 and 16 per cent respectively.

#### Distance of school and mode of transport

#### Annex Table 9.1:

Usual mode of transport used to go to school (%) (for children ages 3 years and above)

Mode	Children with disabilities	Children w/o disabilities	All
On foot	64%	65%	65%
Own bicycle/tricycle	14%	18%	17%
Hired bicycle/tricycle	2%	1%	2%
Private motor vehicle	15%	12%	13%
School bus (arranged by private provider)	2%	2%	2%
School bus (arranged by the school/ institute)	1%	0%	0%
Public transport	3%	1%	2%
Other	1%	0%	0%
Total	100%	100%	100%

A total of 78 per cent of the children with disabilities and 83 per cent of the children without disabilities went to school on their own, commonly walking or using a bicycle or tricycle.

#### **Determinants of school selection**

Accessibility, quality and lack of alternatives emerged as the prime determinants behind the selection of schools. A total of 80 per cent of the children with disabilities and 81 per cent of the children without disabilities cited accessibility as their chief reason for attending a particular school. This was followed by quality of education, referred to by 63 per cent of the children with disabilities and 69 per cent of the children without disabilities. Lack of alternatives was the main reason for 45 per cent of the children with disabilities and 39 per cent of the children without disabilities. Hostel facilities were also mentioned as a factor by 24 per cent of the children with disabilities and 32 per cent of the children without disabilities, while 11 per cent of the children with disabilities and 12 per cent of the children without disabilities mentioned affordability.

About 71 per cent of the children with disabilities reported that they were satisfied with the infrastructure at school, but a significant proportion (27 per cent) were not satisfied. 89 per cent of the children without disabilities being satisfied with the infrastructure. At the same time, 79 per cent of the children with disabilities found the number of teachers at their school to be adequate, compared to 86 per cent of the children without disabilities.

Just 58 per cent of the children with disabilities agreed that modern teaching/learning methods were being employed by teachers, while 32 per cent disagreed and 10 per cent were undecided. In the case of children without disabilities, 65 per cent agreed these methods were being applied at their school, 27 per cent disagreed and 9 per cent were undecided.

Similarly, only 63 per cent of the children with disabilities felt teaching was being adapted to the needs of the child, and 26 per cent did not agree. The proportion of those agreeing was slightly higher among children without disabilities (74 per cent), but this still underscores the children's perception of the remaining challenges in this regard.

#### **Quality of services**

When the parents/caregivers were asked if they had received any information or feedback from the school regarding how to assist their child's learning, results between both groups were similar: 56 per cent of those who have a child with disability and 54 per cent of those who have children without disabilities said no.

Likewise, 63 per cent of the parents of children with disabilities and 65 per cent of the parents of children without disabilities felt their child was receiving adequate attention at school. More than a quarter of the respondents in each category remained undecided.

More than 80 per cent of the parents across both categories said they were fully satisfied with the behaviour and attitude of teachers towards their children, and more than 90 per cent were satisfied with the services rendered by the school. However, when the parents were asked if student assessment was adapted to the learning needs of children with disabilities, 66 per cent of the parents/caregivers of these children and 65 per cent of the parents of children without disabilities disagreed. Similarly, more than 70 per cent of the parents/ caregivers across both categories stated that schools lacked infrastructure or teaching/learning materials to aid children with disabilities.



# ANNEX 10 ADDENDUM TO CHAPTER 8

This section is an addendum to the quantitative findings described in Chapter 8.

### Identification of disability and reported causes

#### Annex Table 10.1: Sources of information about the child's disability (%)

				, (/-/					
	Informed by:			the					
	Multi-disci- plinary Team	Doctor/ Psychologist	Nurse	Rural health service provider	Medical "quack"	Teacher	Family/ Community	ldentified by th	Total
Kachin	0%	34%	0%	0%	0%	0%	0%	66%	100%
Kayah	0%	24%	7%	0%	0%	2%	2%	66%	100%
Kayin	8%	19%	0%	4%	2%	0%	0%	68%	100%
Sagaing	0%	22%	0%	0%	2%	0%	0%	76%	100%
Tanintharyi	11%	30%	0%	4%	0%	2%	4%	49%	100%
Bago	1%	25%	5%	3%	0%	1%	0%	65%	100%
Magway	0%	42%	0%	2%	0%	0%	0%	56%	100%
Mandalay	7%	21%	1%	0%	1%	1%	1%	68%	100%
Mon	2%	71%	0%	0%	0%	2%	0%	25%	100%
Rakhine	0%	24%	0%	0%	0%	0%	0%	76%	100%
Yangon	2%	37%	3%	0%	3%	1%	1%	54%	100%
Shan	5%	28%	0%	1%	1%	2%	0%	63%	100%
Ayeyawady	1%	18%	0%	1%	0%	1%	3%	76%	100%
All	3%	28%	1%	1%	1%	1%	1%	64%	100%

# Visits to health facilities

The situation related to health care was studied against a number of parameters, including the frequency of visits to a health facility; the accessibility of a health facility; the availability of doctors; and the cost and quality of services. When asked why they rarely visited health facilities, 90 to 93 per cent of the respondents (for children with and without disabilities respectively) said they visited health facilities only when necessary.

# Type of health facility and practitioner visited

Among the children with and without disabilities to regularly visit a health facility, about half sought treatment at a private clinic (49 and 45 per cent respectively). This was followed by public health clinics, which were visited by 42 per cent of the children with disabilities and 43 per cent of the children without disabilities. A very small proportion of the respondents visited rural health service providers or other facilities.

Accessibility of the clinic and the quality of the services received were two of the most important considerations when availing of services from a particular facility for both groups. A total of 63 per cent of the children with disabilities and 66 per cent of the children without disabilities went for services from a particular clinic because it was easily accessible, while 65 and 63 per cent respectively did so because of the quality of the services rendered. Meanwhile, 40 per cent of the children with disabilities reportedly went to a particular clinic because they found it affordable.

#### **Quality of services**

While a strong majority of the children with disabilities (77 per cent) were satisfied with the verbal advice provided by the health professionals, 50 per cent were not satisfied with the written advice given. Again, these proportions were more or less the same for children without disabilities, as well as for boys and girls across the two categories of respondents.



Regarding the availability of the required services at the health facility, the respondents were asked if they received all, most, few or none of the services sought. In response, 50 per cent of the children with disabilities and 47 per cent of the children without disabilities reportedly received most of the services, whereas 29 and 26 per cent respectively received only a few of the services sought.

More than 90 per cent of the respondents in both categories said they were satisfied with the services received at health facilities and considered the doctors/health professionals considerate and understanding.

It would be pertinent to end this addendum with a word of caution: The proportions mentioned here must be considered in light of the fact that very few respondents were actually using health services regularly. Hence, the proportions noted are reflective of the opinion of these respondents only.

# ANNEX 11 ADDENDUM TO CHAPTER 10

This section is an addendum to the quantitative findings described in Chapter 10.

#### **Registration of children with disabilities**

It is critical for planners and programme managers to have an accurate number of the beneficiaries to be covered within the ambit of welfare services. One of the easiest ways of ensuring the accuracy of these numbers is to have a robust national birth/death registration system. Having such a system would also mean that any disability evident at birth would be readily recorded.

A comparison of children with disabilities by state who possess various kinds of registration documents shows considerable disparity with regard to birth registration. Magway was the only region with 100 per cent registration of births, followed by Mandalay (89 per cent), Mon (85 per cent), Kachin (81 per cent) and Sagaing (80 percent). Interestingly, Ayeyawady, which is among the most developed regions, recorded only 60 per cent of the children with disabilities with birth certificates. Tanintharyi, Rakhine and Kayin had even lower rates (around 50 per cent).

In terms of holding a national registration certificate, more than 3 in 4 of the 722 eligible respondents (76 per cent) did not have the certificate, and 12 per cent did not respond to the question. An overwhelming 98 per cent of the parents of children with disabilities said their children had no certification pertaining to disability.

Among the types of registration explored under the SitAn, a birth certificate stood out as the most commonly possessed document. However, a significant proportion of the children with disabilities lacked even that document, and far higher number of them did not have a national registration or disability certificate. However, these two documents could significantly assist government programme planners in tracking children with disabilities, thereby not only improving credible and real-time information on these children but also enhancing their fundamental rights.



# ANNEX 12 ADDENDUM TO CHAPTER 11

This section is an addendum to the quantitative findings described in Chapter 11.

# Seeing

During the fieldwork, no children in the age group 2-4 years were reported as having difficulty seeing in Meybon Township (Rakhine). However, this was not case for Hlaingtharya (Yangon), where 1.3 per cent of the children ages 2-4 years are estimated to have difficulty seeing. A much higher 3.3 per cent of the boys in this age group are estimated to have some difficulty.

For the children ages 5-17 years, the estimates of prevalence in difficulty seeing are 8.2 and 13.4 per cent for Meybon and Hlaingtharya respectively. For boys in this age bracket in Meybon, the estimated prevalence is 12.8 per cent, nearly three times higher than that for girls (4.4 per cent). At the same time, the opposite is found to be true in the case of Hlaingtharya Township, where among girls the prevalence is 16.3 per cent and for boys it is 7.4 per cent. One notable finding is that complete blindness was not found for any of the age groups in Mon State or among the 2- to 4-year-olds in the other two townships. However, for Meybon and Hlaingtharya, 1.7 and 2.7 per cent respectively of the boys aged 5-17 are estimated to be blind.

# Hearing

Among children ages 2-4 years in the comparison townships, no incidence of difficulty hearing was reported. However, 5.6 and 2.9 per cent of the older children are estimated to have such difficulty in Meybon and Hlaingtharya respectively. Overall, almost the same proportions (3.0 per cent) of girls and boys ages 5-17 years are estimated to have hearing issues, although a marked difference was seen in Meybon Township (7.0 per cent of the boys and 4.4 per cent of thegirls). In addition, the use of hearing aids for children was not found to be as common in these two control locations as in Mon State.

# Walking

About 10.8 and 5.0 per cent of the children ages 5-17 years are estimated to have difficulty walking 500 metres on level ground in Meybon and Hlaingthraya respectively. Among these two control townships, higher values of difficulty in walking longer distances in Meybon is particularly noticeable (9.3 per cent of the girls and 12.7 per cent of the boys). Use of an assistive device for walking was not commonly observed in Meybon. In Hlaingtharya, however, 2.5 per cent of the children ages 5-17 years use some form of assistance.

#### Self-care

In Hlaingtharya, no respondent for a child ages 2-4 years reported that the child faced challenges in picking up small objects compared to others the same age. However, in Meybon 3.7 per cent of the children in this age group were estimated to have difficulties in this regard.

For children ages 5-17 years, the estimated incidence of difficulty in self-care activities (eating and dressing on their own) were much higher, 5.8 and 12.9 per cent for Meybon and Hlaingtharya Townships respectively. Similar to the gender-specific results in Mon State, the incidence of self-care difficulty among boys in Meybon in this age group was much higher than that for girls, 7.6 and 4.3 per cent respectively. For Hlaingtharya Township, however, the opposite was true (10.7 per cent of the boys and 14.0 per cent of the girls).

#### Communication

Less than 1 per cent of the children ages 2-4 years in Meybon are estimated to have difficulty understanding their mother/primary caregivers. In Hlaingtharya, the rate is much higher (2.8 per cent). At the same time, 8.4 per cent of the children in this age group in Meybon have difficulty being understood. A startling 24.8 per cent of all the children ages 2-4 in Hlaingtharya – or 1 in 4 – are estimated to have similar difficulties, with a higher prevalence among boys than girls.

In Meybon it is estimated that 4.7 per cent of all the children ages 5-17 years (5.0 per cent of the girls and 4.3 per cent of the boys) have difficulty being understood by other household members. In the case of Hlaingtharya, a much higher 11.3 per cent of all the children in this age bracket are reported to have similar difficulties, with little gender difference. Likewise, 4.8 and 11.5 per cent of the older children from Meybon and Hlaingtharya are reported to have difficulty making people from outside the household understand them when communicating.

# Learning

The estimated prevalence rates of difficulty learning among children ages 2-4 years are much higher for the two comparison townships than for Mon State: about 13.0 per cent for both Meybon and Hlaingtharya. However, in Meybon incidences of learning difficulties in this age group were reported for girls only, while in Hlaingtharya, 11.6 and 15.5 per cent of the girls and boys respectively are estimated to have learning difficulties.

Likewise, the estimated incidence rates for learning difficulties among children ages 5-17 years are very high for the two comparison townships, 14.9 per cent for Meybon and 19.5 per cent for Hlaingtharya. By gender, the prevalence in Meybon stands at 14.4 per cent for girls and 15.4 per cent for boys, while figures for Hlaingtharya are 19.2 and 19.9 per cent respectively.

### **Emotions**

In Meybon and Hlaingtharya, 12.3 and 5.6 per cent respectively of all the children ages 2-4 years are thought to have behavioural issues. In Meybon, gender differences were few. However, the prevalence of such behavioural traits in Hlaingtharya is estimated to be twice as high for girls (7.1 per cent) as compared to boys (3.3 per cent).

Among the 5- to 17-year-olds in Meybon, it is estimate that 17.5 of the children feel anxious/ worried/nervous at least once a month, and a significant 36.5 per cent are seen as being depressed/sad at least once a month. These results are exponentially higher than the results found in Hlaingtharya (5.8 and 7.6 per cent respectively). In terms of



controlling their behaviour, 3.9 per cent of the children ages 5-17 in Meybon and 7.8 per cent in.Hlaingtharya are estimated to have difficulties.

Lastly, the children ages 5-17 in Meybon face difficulties in (1) focusing on activities they enjoy (9.0 per cent), (2) accepting changes in routine (14.1 per cent), and (3) making friends (5.0 per cent). For Hlaingtharya, the prevalence rates were higher, 12.8, 16.2 and 9.2 per cent respectively.

# ANNEX 13 NGOS PERSPECTIVES

Mili	The Myanmar Independent Living Initiative (MILI) operates out of Yangon. One of the few DPOs in the country, MILI reports that in the last few years there has been an increase in the number of DPOs in the country, including outside of Yangon. According to MILI, it has been difficult for persons with disabilities to be included in the development process, although marked improvements have been observed in the last decade.
	According to MILI, persons with disabilities are still looked at as charity cases and beneficiaries, not as rights holders. For the most part, NGOs (and some DPOs) do not include children with disabilities in their programming. Likewise, many in the disability community believe that government planning, policy development and/or mechanisms of implementation related to persons with disabilities do not include DPOs (although the findings of this study refute this claim).
	Currently, MILI engages with local and community entities, state/regional organizations, line ministries and the DSW, as well as Parliament, although there is little cross-sectoral work related to children with disabilities in Myanmar. Coordination among and between the DPOs is difficult and consensus is difficult to reach as many organizations function simply as special interest organizations, without taking into consideration a wider focus.
EDEN	The Eden Centre for Disabled Children, an organization for persons with disabil- ities, has operated in Myanmar since the year 2000. They operate a daycare centre for children with disabilities and provide special education and rehabili- tation. They also collaborate with other organizations at the community level. The Eden Centre provides several trainings to strengthen NGOs and schools and special education trainings for staff from the schools as well as mainstream teachers. Since 2007, the Eden Centre has provided inclusive education related work, disability awareness training to parents, community leaders and students through financial support from Welthungerhilfe(WHH).
	Eden's daycare centre in Yangon serves around 170 children with disabilities, ages 0 to 18 years old. In addition, the centre provides assessment support, designs rehabilitation programs, and offers parent training and counselling to children who are not from Yangon and cannot attend daily. In addition, the centre has run two ECI classrooms (46 children and 3 staff members) since 2007, and it will start a small-scale 18-month ECI project in the Yangon region with financial support from the Finish embassy in early 2016.

TLMM	The Leprosy Mission Myanmar (TLMM) has been active in Myanmar since 2003. Although leprosy has been eradicated, they work with people affected by leprosy and children and adults with disabilities due to other causes through disability resource centres (DRC). They provide a variety of services similar to those found in CBR programmes such as physiotherapy, occupational therapy, assistive technology support, training for parents, livelihood support, and awareness raising. Currently, TLMM works in 17 townships in Yangon, Ayeyarwaddy, Bago, Mandalay, Sagaing and Magway Regions and in Mon State. Approximately one-third of all TLMM clients are children with disabilities, although they do not have any funding that is earmarked for children with disabil- ities. Much of the work at the field level is done by volunteers trained by their field staff. TLMM works collaboratively with UNICEF on issues related to early childhood intervention and with the DSW at the state/regional level. Further- more, although there are no memorandums of understanding, TLMM also works with the MoE and the MoH at the field level.
HI	<ul> <li>Handicap International (HI) has been present in Myanmar for almost two years.</li> <li>Part of their country plan is dedicated to promoting inclusive education. Handicap International is now working on developing a training on inclusive education, which is to be delivered by a national partner and to include practical advice and guidance for teachers.</li> <li>According to Handicap International, the NGO and DPO landscape in Myanmar is very fragmented and no coordinating mechanisms are available. Handicap International has provided funding for an international expert to conduct ECD workshops with a disability component, and plans to establish agreements with national NGOs aimed at developing work related to inclusive education, which will incorporate ECI and the establishment of a training unit. However, Handicap International is very conscious that various layers of training are necessary, from foundational to policy-making.</li> </ul>
MLRC	According to the Myanmar Literacy Resource Centre (MLRC) there is a long tradition of children with disabilities being accepted at regular schools. There is also some experience related to having children with disabilities living in institutions and attending regular schools in the neighbourhood. However, there are also many difficulties related to the lack of technical capacity in regular schools as well as stigma associated with disability that prevents parents from enroling children with disabilities in regular schools.
	After 2004, the MoE expressed a great deal of interest in inclusive education, and the concept and its principles have been discussed ever since. The MLRC has developed training materials related to inclusive education, developed a set of guidelines for accommodation (including a peer-to-peer support system), produced materials to be included in the teacher preparation curriculum, translated the UNESCO "Embracing Diversity" Toolkit and provided some training to teachers in collaboration with another NGO.

i The Lancet Series on Maternal and Child Undernutrition, 2008 and 2013



unite for children

# **Unicef Myanmar**

23-A, Inya Myaing Road, Shwe Taung Gyar Ward 2 Bahan Township (P.O Box 1435) Yangon 11201 Tel: (95 1) 230 5960 to 69 Email: yangon@unicef.org Website: www.unicef.org/myanmar