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Persons with Disabilities in Rakhine State, Myanmar, a Needs Assessment Study

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Needs Assessment, Persons with Disabilities, Rakhine State, Myanmar



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June 2016



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Abstract

A needs assessment study was conducted including the participation of over 400 persons in three districts of Rakhine State, Myanmar. The study was composed of a representative quantitative survey of 334 persons with disabilities, and a qualitative study including eight focus group discussions and 20 key informant in-depth interviews. Persons with disabilities were identified through snowball sampling stratified by age and sex using a reference population with disabilities. No study had ever been conducted on people with disabilities in this State.

A majority (55%) of the respondents had a severe disability (could 'not do at all') and 99% 'had a lot of difficulties' to do at least one of the six categories of the Washington Group short set of questions to assess the type and the severity of the disability. The most frequent severe functional impairment was mobility (36% of the respondents). Higher psychological distress scores were detected in respondents under 50 years old, from Sittwe and having no access to bathroom facilities. Despite a primary health service coverage of 69%, the proportion of persons with disabilities who reported unmet needs in medical services was 75% (95%CI 69%-81%) and related to a lack of financial resources, expensive medical services, availability and distance. The persons with the most recent onset of disabilities and severe hearing impairment were the most at risks for not receiving appropriate medical care. In persons with some mobility impairment, 78% were not using any assistive device.

In respondents aged of 15 years old or more, the unemployment rate was 78% and higher in females, persons with severe disability,

and from Myauk-U district. Only 3% received a vocational training and they were 4 fold times more likely to currently work compared to other persons with disabilities. Only 3% of the persons with disabilities were receiving a pension, principally males over 50 years old. Overall, 81% (95%CI 77%-85%) of the respondents did not receive any assistance or social service within the last two years in particular in Myauk-U and Thandwe districts. The most frequent assistive devices or services needed to improve the function of the respondent were related to mobility (46%), physiotherapy, glasses, and hearing aids. The highest priorities reported for improving the living conditions were engaging in business, micro-credit, employment, physical rehabilitation and medication.

In a context of extreme poverty and high unmet social needs and where females were the most vulnerable, forthcoming interventions should focus on persons with the most recent onset of disabilities as they have the most acute health and rehabilitation needs, access to bathrooms and clean water, food aid, inclusive vocational training programs and livelihood opportunities.

Study context

Rakhine State is believed to be one of the poorest regions of the Republic of the Union of Myanmar (Myanmar) and is marked by historical and ethno-political tensions. The development of Rakhine State has long lagged behind much of the rest of the country, leading to a situation in which both the local Rakhine and other ethnic minority communities have considerable unaddressed health and socio-economic needs. The 2012 inter-communal violence, resulting in the segregation between the Rakhine and Muslim communities, has an ongoing negative impact on the local political and economic situation and has aggravated the condition of the most vulnerable populations particularly persons with disabilities.

During the census conducted in Myanmar in 2014, the estimated prevalence rate of people with disabilities in Rakhine State was 5.3%, greater than the national average of 4.6%. However, a considerable segment of the population was left out of the exercise and was not enumerated because of ethno-political tensions and the demand of many local people to self-identify as Rohingya not conceded by the local authorities (UN, 2015).

So far, no study, assessment, or situational analysis had ever been conducted on persons with disabilities in Rakhine State. The limited knowledge about the situation and the needs of people with disabilities has prevented the implementation of inclusive interventions and/or targeted services.

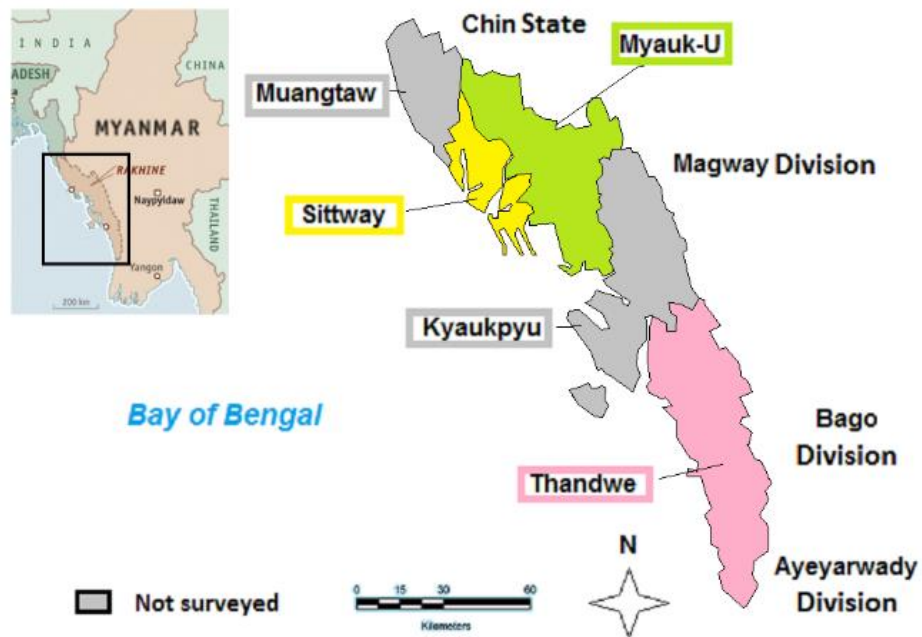
As a result, there is a lack of advocacy initiatives addressed to policy makers, international donors, and humanitarian and development agencies to develop inclusive policies and programs for persons with disabilities in humanitarian and development actions.

Moreover, there is a very limited understanding of the protection risks that are faced by girls, boys, women, and men with disabilities in Rakhine State, especially due to its unique socio-political situation. Therefore, a needs assessment study on persons with disabilities in Rakhine State was required.

Objectives

The overall aim of the study was to assess the situation of persons with disabilities, their needs in relationship to basic services and identify barriers to access these services in selected districts of the Rakhine State.

Figure 1: Map of the districts surveyed, Rakhine State, Myanmar



Legend: Three out of the five districts of the Rakhine State were included in the study: Sittwe, Myauk-U and Thandwe.

Methods

Sampling methodology and case finding

The needs assessment of persons with disabilities in Rakhine State was achieved by conducting a quantitative and qualitative population based assessment study. Given the large size of the State, 5% of the country (Figure 1), the anthropological approach and technical non-probabilistic snowball sampling was used for participant identification (Zwang and Garenne, 2008).

This technique enabled us to explore a network of relationships from one local community contact. Once the person with disabilities was identified in the field, the quantitative questionnaire was administered. As in the Myanmar Census 2014 (Department of Population Ministry of Immigration and Population, May 2015), the Washington Group (WG) short set of questions was used to identify and to assess the type and severity of the functional limitations of the respondent (CDC, 2010).

Sampling for the eight focus discussion groups and the 20 key informant in-depth interviews, using four different tools, were made from a network of community based organizations (CBO). Opting for CBOs was appropriate insofar as these organizations play a mediation and information supply role for person with disabilities. The interviews were carried out in Burmese, Rakhine, and local languages used by the Muslim population, recorded and transcribed verbatim. In order to ensure the representativeness of the quantitative survey, a randomized sample stratified by age and sex using a reference population was employed. An age profile analysis on 4 million persons with disabilities with censuses data from five ASEAN countries (Cambodia, Indonesia, Malaysia, Philippines and Vietnam), with disability data, (IPUMS international) was conducted to define the age and sex profile of the population to be surveyed. The Myanmar census 2014 disability prevalence rates was used to select the districts to be surveyed.

Statistical analysis

Continuous data were reported as mean (standard deviation) or median with range (minimum, maximum) for non-normally distributed data. Categorical data were compared using the chi-square or the Fisher exact test as appropriate. The risks of the persons with disabilities were analyzed using multivariate logistic regression presented as adjusted risks (AOR). Multivariate linear regression was used for analyzing continuous variables. Confidence intervals (CI) were calculated at 95% (95%CI) and comparisons considered significant when $p < 0.05$. Data were analyzed using Stata v13 (Stata corp.).

Ethics

Ethical approval for the study was sought and obtained from Handicap International's Technical Resource Department. Informed oral consent was obtained from all survey participants. Informed oral consent was obtained after explanation of the interview content. For people under 16 years old or those with intellectual impairment, consent was sought from a family member, who was present during all interviews. All interviews were anonymous and full names not recorded.

Results

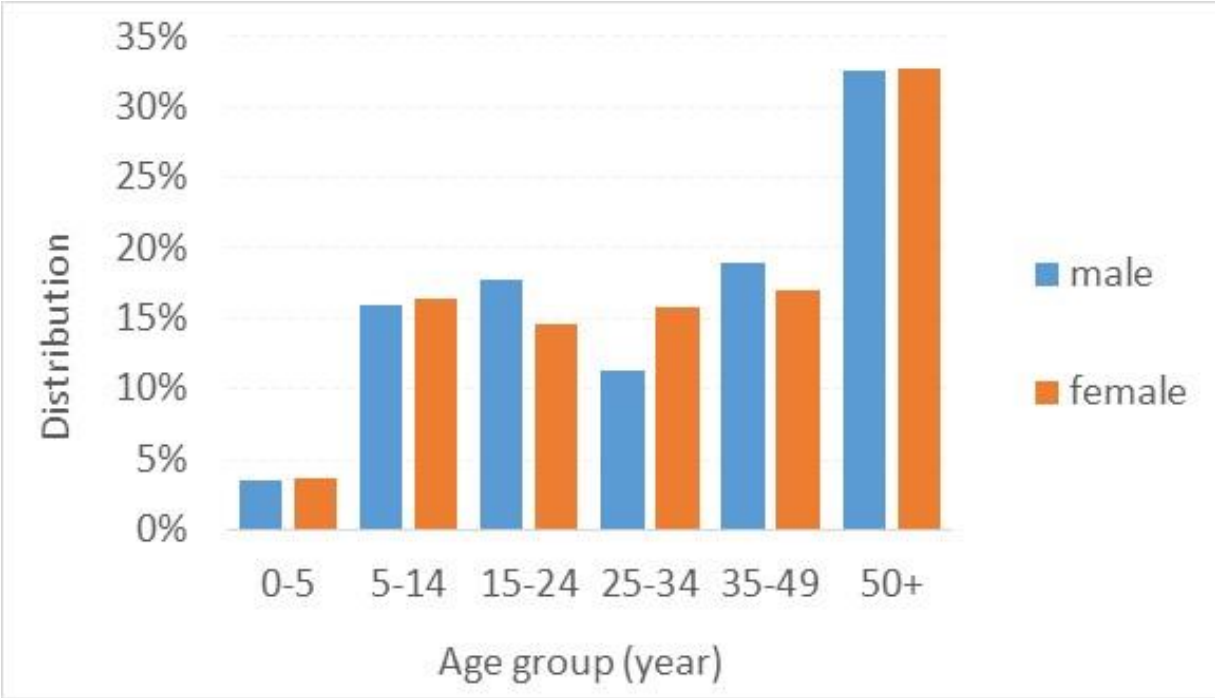
Location

Three out of the five districts of the Rakhine State were surveyed (Figure 1). Overall, 31 Rakhine villages and 3 cities in each district were surveyed (70% of the respondents). Muslim communities customarily stay in the north of the Rakhine State and were interviewed (30% of the respondents) in 2 villages in Sittwe and 2 villages in Myauk-U districts and in one internally displaced persons (IDP) camp in Sittwe.

Respondents characteristics

The study, including training and data collection, was conducted between March and May 2016. The number of persons interviewed and included in the quantitative survey was 334 of whom 144 were from Sittwe district (43%), 124 from Myauk-U (37%), and 66 from Thandwe (20%). The total number of male was 169 and of female 165, resulting in a sex ratio (male/female) of 1.02 (Figure 2). The mean age of the population interviewed was 37 years ranging from 3 to 98 years old; without differentiation between sexes ($p=0.849$).

Figure 2: Respondents' age group distribution by sex



As a result, the age distribution of the population with disabilities interviewed in each district was not different from the pre-defined target age distribution (in Sittwe, $p=0.150$; in Myauk U, $p=0.996$; and in Thandwe, $p=0.341$) except in the IDP camp ($p=0.049$, 7% of the sample) where people with disabilities were slightly younger and the age distribution different.

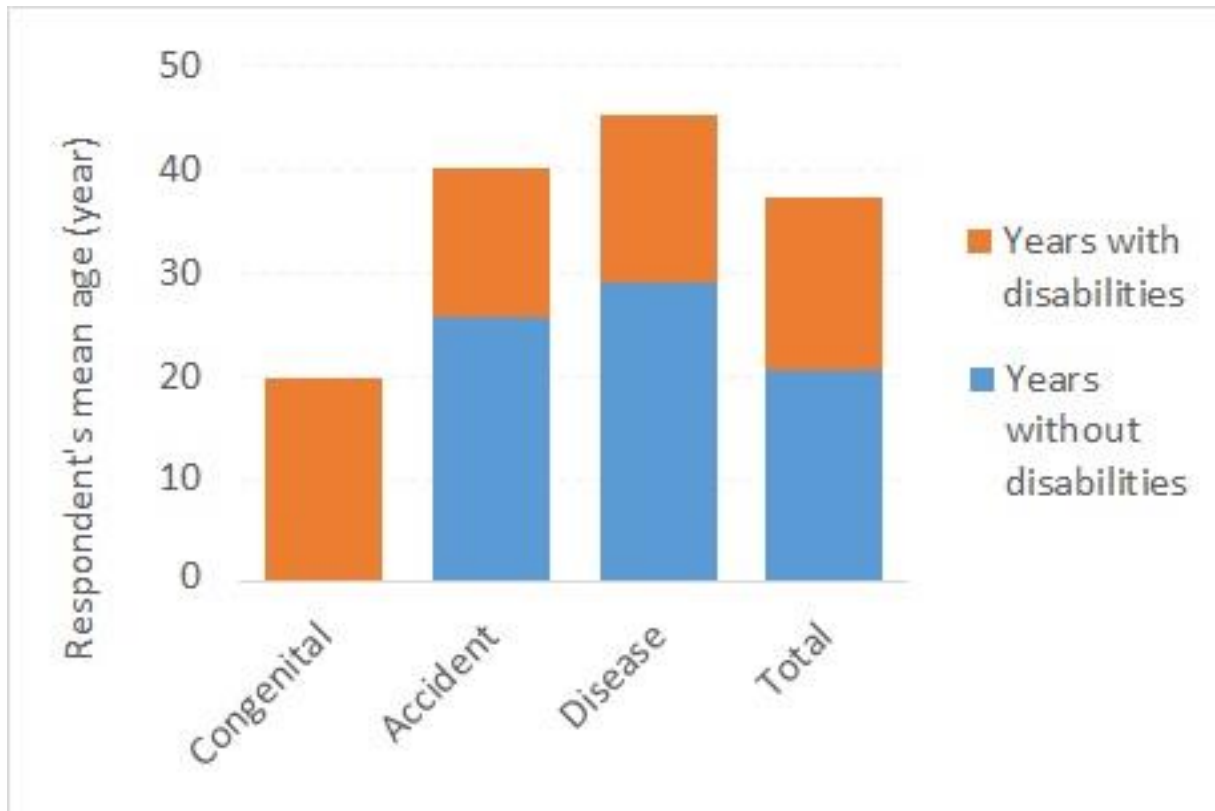
Overall (excluding the IDP camp), the age distribution of the sample was representative of the population with disabilities in Rakhine State ($p=0.210$). The overall sex ratio ($p=0.717$) was not different from the target nor was the place of residence (86% surveyed from rural area compared to 83% targeted, $p=0.350$).

The eight focus group discussions (FGD), included groups with representation of persons with all types of impairment as well groups with specific criteria. One FGD was conducted with persons with visual impairment, one with people with mobility impairment, one in an IPD camp, two FGD were held in Myauk-U with one group representing the Rakhine community and one group representing the Muslim community and two FGD in Rakhine villages in Sittwe district. All FGD were gender balanced except one specific FGD held with women only. The 20 in-depth interviews were conducted in key informants from Non-governmental Organizations (NGO), schools, and social action and health services.

Type and onset of disabilities

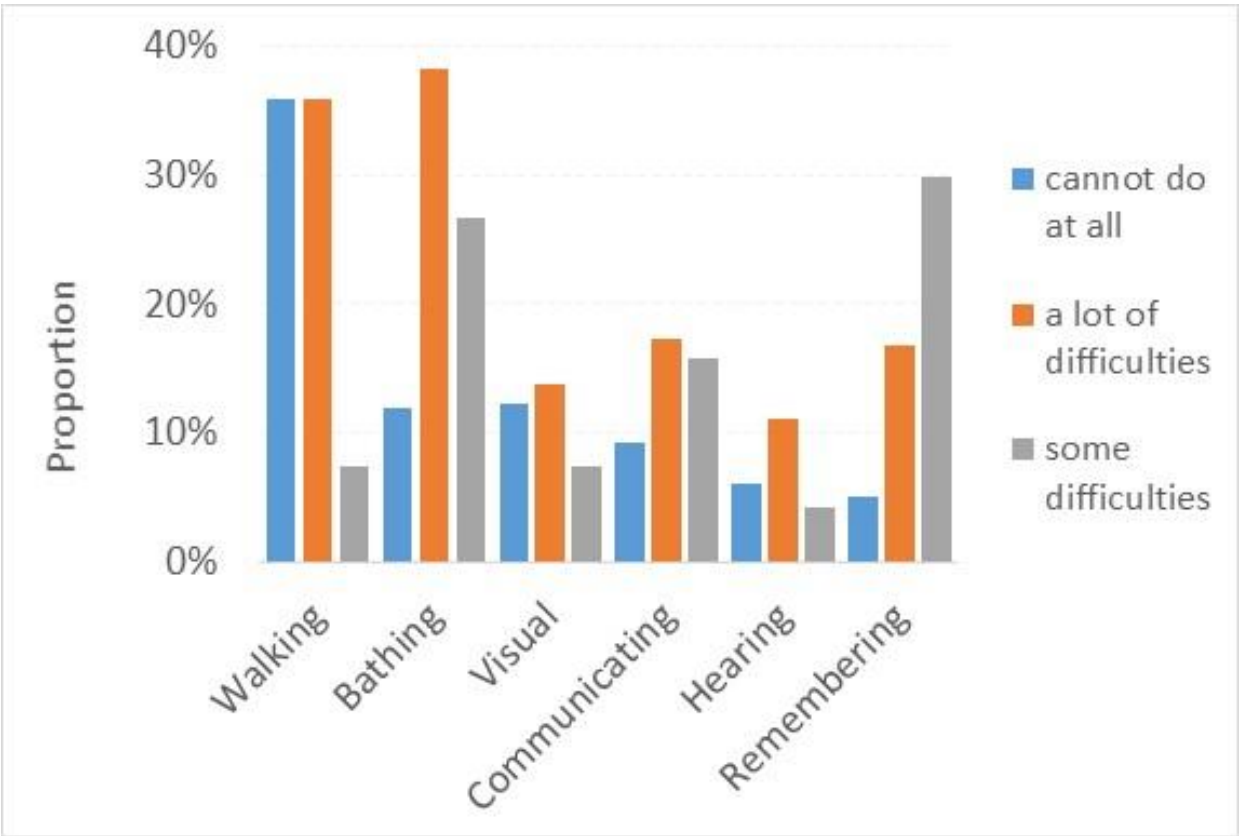
The mean age at onset of disability was 16 years old and the mean duration of disabilities was 21 years (Figure 3). The breakdown by cause of disability was disease (46%), congenital (27%), accident (21%), other (4%) and don't know (1%). No differentiation between sexes was detected ($p=0.569$). The proportion of respondents with chronic disease was 22% with no differentiation between sexes ($p=0.803$).

Figure 3: Lifespan with disabilities by type of impairment



Overall, 55% of the respondents could 'not do at all' and 99% 'had a lot of difficulties' to do at least one of 6 categories of the Washington Group set of questions to assess the type and severity of the disability. No differentiation between sexes was detected ($p=0.846$, $p=0.119$, respectively).

Figure 4: Proportion of respondents with functional impairment by type and severity



Respondents from Thandwe district were at lower risk for any severe disability (AOR 0.14) compared to other districts. Severe functional impairment ('cannot do at all') was 36% for walking, 12% for bathing, 12% for visual, 9% for communicating, 6% for hearing and 5% for remembering (Figure 4). Persons with poliomyelitis were at higher risks (AOR 2.69) for walking impairment. There was no difference observed in children under five years old compared to older respondents (p=0.395).

Female (AOR 2.31) compared to male and respondent over 35 years old (AOR 4.92) were significantly more at risk for severe visual impairment. No difference was detected for the other types of functional impairment.

Individuals' characteristics

In the 15 years old or more population, 52% of the respondents were married, no differentiation between sexes detected ($p=0.801$) and 47% were not able to read or write. Female (AOR 2.04) compared to male, persons with congenital disabilities (AOR 2.47) and persons with severe hearing impairment (AOR 2.05) were at higher risks for illiteracy.

Female, 27: I never attended school. My parents did not want me to go to school because they thought I could not walk properly and the school was located far away.

Livelihood

The average household size was 5 persons and the median monthly income of a household with a person with a disability was 45,000 MMK (around 38 USD) ranging from 0 to 200,000

MMK. As a result, the average income per person was 8 USD a month.

A large majority of the respondents did not know what the monthly income was (85%) probably because most of the persons with disabilities do not work and do not generate income. Moreover, most of the household workers have casual work (farming) subject to seasonal variability or small scale activities for basic self-sustainability.

In a list of 22 basic items in a household (air conditioner, bank account, bicycle, car, cattle, cellphone, chicken, couch, electricity, fan, fridge, internet connection, land, motorbike, landline phone, radio, rice cooker, solar power system, sewing machine, stove, table and chairs, TV), the mean number of items owned by the household was 3.4, ranging from 0.8 in the IDP camp, 1.8 in Myauk-U and, 3.8 in Sittwe to 6.6 in Thandwe.

While 100% in the IDP camp had access to clean water, 34% (95%CI 29%-39%) of the other respondents did not have access to clean water; the most at risk were female (AOR 2.41), as well as respondents from Thandwe (AOR, 8.81) and Myauk-U (AOR 27.26) compared to Sittwe district.

51% (95%CI 45%-56%) of the respondents did not have access to a bathroom with the most at risk were female (AOR 1.58) and residents from Myauk-U (AOR 2.14).

15% (95%CI 11%-19%) of the respondents were sometimes (3 times a month or more) not able to eat for 24 hours within the last month, the risks being higher in children under 15 years old (AOR 2.02) and persons with severe disabilities (AOR 4.21).

78% of the persons with disabilities aged of 15 years or more did not currently work. The most at risk for unemployment were the persons with a severe disability (AOR 4.27), female (AOR 2.04) and those from Myauk-U district (AOR 2.09).

3% of the respondent aged of 15 years or more received a vocational training and they were almost 4 times more likely to currently work compared to those who never received vocational training (71% vs. 20%, respectively).

Female, 22: I am interested in vocational training but I don't know what kind of vocational training is suitable for me.

50% of the respondents aged of 15 years or more could not engage in any household activities by themselves, in particular persons with severe disability (AOR 1.94) and from Myauk-U (AOR 2.01).

3% of the respondents receive a pension; in particular male (AOR 10.05) and respondents over 50 years old (AOR 21.40) compared to other groups.

81% (95%CI 77%-85%) of the respondents have not received any assistance or social service within the last two years. The persons the most in need of assistance were female (AOR 1.82), from Myauk-U (AOR 4.87) or Thandwe (AOR 5.71) as well as persons with less severe (AOR 2.49) compared to those with severe disability. 100% of the persons from the IDP camp are receiving a monthly ration of rice.

Psychological impact

Asking questions about five different types of psychological distress using a score ranging from never (0) to very often (4), the mean score was 5.5 ranging from 0 to 19. Respondents under 50 years old ($p=0.005$), from Sittwe ($p=0.001$) and persons having no access to a bathroom ($p=0.001$) had a significant higher psychological distress score compared to other groups.

94% of the respondents have never received any psychological support to deal with their current life situation. 2% received support from an NGO, 1% from a social worker, 1% from a peer support group and the other 2% from family, neighbors, psychologist or local organization for people with disabilities. Persons with severe disability were more likely to receive any kind of support (AOR 3.26).

The main system to cope with disability was the family (51%), 'had no other option' (18%), 'overcame the situation alone' (16%) and 'my spirituality' (9%).

Female, 22: I feel depressed sometimes when I cannot do what I want. But when it happens my family usually encourages me.

Access to services

The proportion of person with disabilities reporting there was a school in their community was 81% (95%CI 77%-85%) at an estimated average 30 minutes distance; the proportion was 69% (95%CI 65%-74%) for primary health services at an estimated average of 40 minutes distance; 13% for social services at an estimated average 40 minutes distance; 8% for traditional healers at an estimated average one hour distance; 3% for psychological support at an estimated average more than one hour distance; 2% for vocational services at an estimated average 30 minutes distances and 0% for rehabilitation service.

Male, 15: I think that the medical service is not good for us and our Rakhine state is very poor.

The proportion of respondents in need of general health practitioners was 68% but access was limited by a lack of financial resource (32%), the availability of the service (24%) or the distance (19%). The need for medication was 64%, limited by a lack of financial resource (29%), availability (28%) or distance (13%); and the need for specialists was 55%, limited by the availability (52%), a lack of financial resource (23%) or the distance (13%).

Male, 17: According to doctors, my leg would be in a better situation if I was under regular medical care but because of financial difficulties my family cannot afford to follow the physician's recommendations.

The need for vocational training was 46%, restricted by the availability (52%) and because access was refused due to the impairment of the person (31%).

The need for school was 38% but the access was mainly refused because of the impairment of the respondents (73%).

Health services and rehabilitation

Overall, 75% (95%CI 69%-81%) of the persons with disabilities who needed any health facilities could not go there as much as needed. These unmet needs were composed of persons who could not attend at all any health facility and others that should have gone more often. 43% of the respondents went to any health facilities while 36% needed to go more often. Of the 57% of the respondents who did not go, 68% needed to attend a service.

The respondents most at risks for unmet needs in health facilities or to 'see the doctor' within the last 2 years were those with recent onset of disabilities (under 3 years, AOR 2.20; from 4 to 6 years, AOR 1.83) compared to those with longer onset, and those with severe hearing impairment (AOR 2.87), no other significant risks factors were detected.

Female, 65: Once I met a man at the bank and I received financial charity aid from him. With this money I bought a hearing aid from a shop. I never received anything from the hospital for my ears.

The most frequent assistive devices or services needed to improve the functional abilities of the respondent were related

to mobility. 46% of respondents needed a cane, wheelchair, crutches or prostheses.

In persons with mobility impairment, 78% were not using any assistive device. Among those using a device (usually homemade), 65% used a cane, 22% used crutches, 7% used prostheses and one person used a wheel chair. The most at risk for not using any assistive device were female (AOR 2.14), aged below 50 years old (AOR 3.24) and persons living in Myauk-U (AOR 5.07) or Thandwe (AOR 3.48).

Female, 33: I think that the quality of medical care is not good. I have never heard that there is a rehabilitation center for people with disabilities.

The needs for a physiotherapist (35%), prostheses (24%), and social services (29%) were all mainly restricted by the availability (86%, 62%, and 78%, respectively).

Male, 52: We have difficulty to access the hospital as it is far away. Before, we could not go to the hospital because of the conflict but after some time, we were allowed to go with permission of the authorities but it is still a burden.

Community participation

64% (95%CI 59%-69%) of the persons with disabilities felt abandoned or hated by their by their community and that life is harder compared to others because they cannot do things like before. The most at risk for these opinions were persons between 25 to 34 years of age (AOR 3.13), living in Sittwe (AOR 1.80), with severe disability (AOR 2.91), with a higher psychological distress score (AOR 1.20) and those who have unmet needs in health services (AOR 2.05).

The proportion of respondents who feel like other people look at them differently due to their impairment was 59%. The most at risk for this perception were under 35 years old (AOR 2.08) and with a higher psychological distress score (AOR 1.12).

Female, 33: Our community does not have superstitious beliefs anymore about persons with disabilities but my neighbors gossip about me and insult me because I am a woman with disabilities and I want to get married.

31% (95%CI 26%-36%) of the respondents reported that people use pejorative terms to refer to them because of their impairment. The most frequently discriminated persons were under 50 years old (AOR 2.60), from Sittwe (AOR 4.21) or the IDP

camp (AOR 5.74) or with a higher psychological distress score (AOR 1.12).

Male, 48: I feel depressed when people make fun of me when I go out of my house. Sometimes, I want to give up my life.

In a list of four different types of community participation (family visits, community festivities, shopping at the market, and worshipping), the proportion of persons with disabilities never participating in any of all the four community events was 28% (95%CI 24%-33%). Persons with severe disabilities (AOR 7.13), aged of 25 years old or more (AOR 1.77) and females (AOR 1.95) were more at risk of never attending any of these community activities.

Female, 33: I never go to the festival with my husband because I am afraid that he will lose face when we walk together.

The proportion of respondents who ever had a leader role in the community was 16%. Females (AOR 7.81) and persons with congenital disabilities (AOR 2.45), compared to other type of disabilities, were less likely to have a role in the community. For

those who never had a leader role, a majority (51%) thought they would never become a community leader.

Awareness about rights

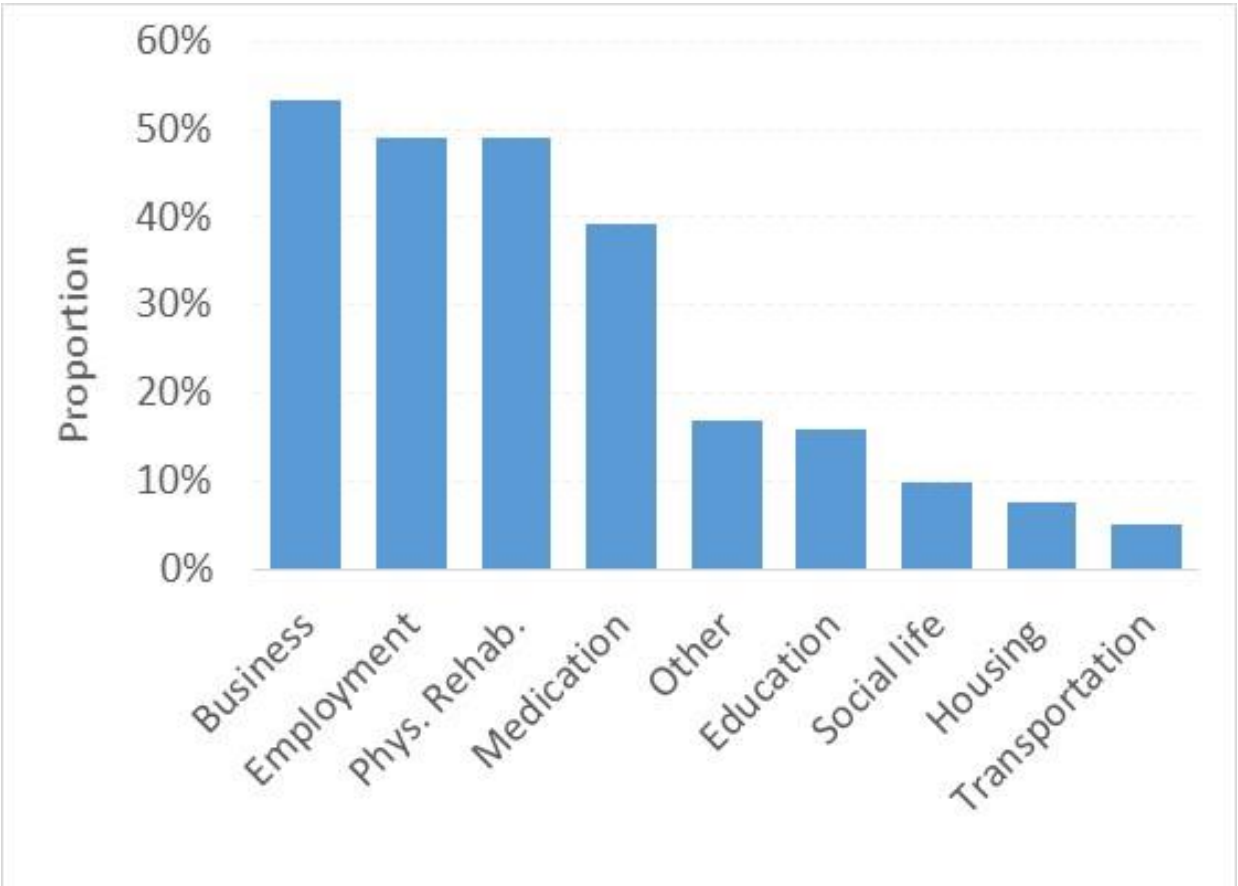
In Rakhine State, 94% of the persons with disabilities had never heard about laws for persons with disabilities and 94% had never heard about the Convention on the Rights of Persons with Disabilities (CRPD).

Female, 25: It would be very good for us if we had a meeting place to talk together once a year.

The proportion of respondents who were member of an organization for people with disabilities for one year or more was 2%. However, the proportion increased to 38% for persons who were members less than one year, with the average membership duration being two weeks. This finding can be attributed to study participants deciding to register with the local disabled persons' organization and study partner, after being identified but prior to being interviewed for the study.

Priorities to improve living conditions

Figure 5: Priorities to improve living conditions, persons with disabilities, Rakhine State, Myanmar



The most frequent answers of the persons with disabilities for improving their living conditions were business or micro-credit (53%), employment (49%), physical rehabilitation (49%), medication (39%), others (mainly financial support, 17%) and education (16%).

Male, 43: I wish I had a permanent job, to stand on my own feet without relying on others. I feel having little value. I am depressed because I only do casual work.

Conclusions and recommendations

The needs assessment study of persons with disabilities in Rakhine State, Myanmar, used a representative sample stratified on sex and age with snowball sampling to identify persons with disabilities for a sample of over 400 persons (including both quantitative and qualitative surveys). The study design was also designed to identify and include persons with severe disabilities. The unmet needs in health and social services and high unemployment rate indicated that the persons with disabilities are prone to extreme poverty in Rakhine State.

Overall, awareness raising on the study results and subsequent training on disability inclusive development, with State level authorities (district, township and village) is recommended, especially as it relates to livelihoods and the access and inclusion of persons with disabilities in educational and health programs.

Extreme poverty

The livelihood score of the persons with disabilities (in a list of basic items owned by the person with disabilities' household) and an average income per person of 8 USD a month revealed very low living conditions associated with no access to clean water (31%) or a bathroom (51%).

Regarding food aid for persons with severe food shortage (15%), interventions should focus on children (under 15 years old) and persons with a severe disability.

The study showed that business, micro-credit and/or employment are the first priorities for the persons with disabilities from Rakhine State.

The development of an inclusive action plan fostering inclusive initiatives based on study results should be implemented with Department of Social Welfare (DSW), disabled peoples organizations (DPO), and community based organizations (CBO) to improve the quality of life of persons with disabilities, at the state, district, township and village level. Additional workshops with local authorities, NGO, DPO, and CBO on target interventions identified by the study should be implemented.

Unmet service needs

In Rakhine State, the unmet needs rate in health services for persons with disabilities was 75%. The persons most in need or not receiving appropriate medical care were those with recent disabilities and with severe hearing impairment.

The training of DSW workers on disability identification and the needs of the most recently impaired persons, basic psychosocial support, cares and referral mechanisms should be implemented. Moreover, taking into consideration that persons with severe hearing impairment were at higher risk for illiteracy, DSW workers should be trained for sign language and access to education and accessible communication formats/languages is recommended.

Despite a primary health services coverage of 69%, access to a general practitioner, specialist, medication, physiotherapist, or vocational training were restricted by a lack of financial resources, availability of the service and distance (most of the services are only available in Yangon for the whole country).

81% of the respondents did not receive any assistance or social service within the last two years. Upcoming assistance strategies should focus on women and persons living in Myauk-U or Thandwe districts where the aid was more scarce.

Water, sanitation, hygiene (WASH)

Half of the persons with disabilities did not have access to a bathroom and the study showed that persons without access were at higher risk for psychological distress. In order to decrease psychological distress, and increase access to bathrooms, further sanitation strategies should be implemented with a focus on females and respondents living in Myauk-U district. Additionally, toilet, water points, and bathing areas must be physically accessible for persons with disabilities, especially those persons with mobility issues, assistive devices, and visual impairments.

Vocational training

While the persons with disabilities were almost 4 times more likely to currently work if they had vocational training, the need for vocational training is high but restricted by availability. The access to vocational training was also frequently refused because of the individual's disability. Forthcoming interventions should focus on awareness raising and inclusive policies for persons with disabilities in vocational training programs in particular those with a severe disability, female, and residing in Myauk-U district where the employment rate was the lowest.

Gender issues

Overall, females with disabilities were more vulnerable than male with disabilities. They were at higher risks for illiteracy, unemployment, access to clean water, access to a bathroom, not receiving any assistance, lower community participation, not using assistive device, and having more financial difficulties to access medical services compared to male with disabilities. Focus on enabling women and girls to access services is recommended for all service providers, including Government, NGOs and CBOs.

Awareness

The study showed very low awareness about rights of people with disabilities (6%) and low affiliation to a CBO or DPO.

The creation and strengthening of self-help groups (SHG) should be applied to increase social cohesion, dissemination of information, and awareness-raising on the rights of persons with disabilities.

Mapping of available services within the State and regionally is recommended. Information campaigns on access to services would be an asset for persons with disabilities to promote access to health, rehabilitation, economic and education services.

Persons with disabilities must be included in the provision of services, especially services essential to basic needs (primary healthcare, food distribution, WASH). This includes the consideration of persons with disabilities in a humanitarian crisis. Physical and communication accessibility must also be considered.

The recent increase in the proportion of members from an organization for persons with disabilities was a direct result of the study design using snowball sampling technique. This indicates a high desire to engage with one's peers and participate in a social organization. Emphasis on creating greater social opportunities for persons with disabilities is recommended.

Community differences

The mean age of persons with disabilities in the IDP camp was significantly lower compared to other people with disabilities. Further studies should be conducted to explain this difference.

While people with disabilities from the IDP camp had a lower livelihood condition (lower item score) compared to others, they had better access to clean water, a bathroom, and food aid compared to other persons with disabilities in the Rakhine State. Muslim communities were at higher risks for illiteracy, and

Muslims from the villages had a higher need for mobility assistive devices.

Study limitations

Despite a randomization under age and sex constraint, the snowball sampling technique might have detection limits for people with sensorial and intellectual impairments. Without any robust population reference distribution by type of disabilities, it is difficult to distinguish whether the technique used here underestimated some types of disabilities or not. Therefore, the snowball sampling technique might be influenced by the community perception to identify persons with disabilities, and physical impairment related to mobility might have been overrated compared to sensorial and intellectual impairments.

Further analysis on the distribution by type of impairment should be conducted to further define the population with disabilities according to age, sex, and the local environment.

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