

Understanding The Disability Related Needs in Pithakaity Char Island (Morigaon District, Assam) – Results of An Investigation

19-20 February 2016

BRIEF REPORT

Dr Sunil Deepak, Mobility India North-East

INTRODUCTION

Centre for North-East Studies (C-NES) is providing primary health care services focusing on mother and child care through boat clinics to around 3 million persons living in the river islands of 13 districts of Assam.

Mobility India (MI) is an organisation active in service provision and training in the areas of rehabilitation and assistive devices for persons with disabilities since 1994. In April 2015, MI has initiated a regional office (MI-NE) for the north-east of India in Guwahati.

In February 2016, C-NES and MI-NE collaborated to conduct a **Pilot Survey** on persons with disabilities in one of the river islands in Morigaon district of Assam. This brief report provides information about this survey and its results.



Morigaon Boat clinic team with Dr Sunil Deepak (MI-NE)

SURVEY OBJECTIVE

This survey was a preliminary step to gain general understanding about disability issues in the river islands. The main objective of the survey was to understand if there are persons with disabilities living in one of the river islands and the kind of problems they face.

SURVEY METHODOLOGY

One island (Pithakaity) in Brahmaputra river in Morigaon district was identified for the survey. This island can be divided into 3 areas (Pithakaity Char 1, Pithakaity Char

2 and East Kalair Char), where C-NES boat clinic team from Morigaon conducts once monthly primary health care clinics.

The survey was organised in four steps – (1) Community awareness (2) Training of the survey staff (3) Survey conduction (4) Data entry and analysis.

Community awareness: On 19 February, one day before the survey, community health volunteers (ASHA workers) of the island were asked to inform the island population that on 20 February 2016 there will be a team to look at persons who have any difficulties related to hearing, seeing, moving, learning and memory. The community health volunteers asked these persons to come to the C-NES clinic in Pithakaity Char for a check-up.

Training of the survey staff: A one day training course on how to collect information from persons regarding their functional difficulties was conducted by Dr Sunil Deepak of MI-NE in collaboration with Dr C. R. Hira and Mr Ashok Rao of C-NES, on 19 February 2016 at the District hospital of Morigaon. About 25 persons including boat clinic team of C-NES as well as persons from district health services and Sarva Shiksha Abhiyaan (universal education campaign) took part in this training.

Conducting the survey: A simple 2 page questionnaire in Assamese language based on the questions recommended by Washington Group on Disabilities was prepared for the survey. For all the questions (for example – Do you have difficulty in seeing even if you wear eye glasses), three options were provided – some times, often and all the time. Only the persons who answered “often” or “all the time” were to be considered as persons with disabilities.

The survey was conducted in one site (Pithkaity Char 1) for all the three areas of the island. All the persons who had come voluntarily to the boat clinic site were interviewed by one of the Boat clinic staff.

Data entry and analysis: All the completed survey forms were entered in an excel sheet by Dr Deepak, who analysed the data and prepared this report.

CONDUCTING SURVEY AND DATA COLLECTION

On 20 February 2016, Dr Deepak accompanied the C-NES boat clinic team from Morigaon to Pithakaity island. The list of C-NES team members is provided in **Annex 1**. Three persons from the C-NES team (Dr Islam, Dr Akhtar and Mr Rahman) conducted the survey.

While the disability survey was carried out, the remaining staff of the Boat clinic carried out their monthly clinic activities focusing on pregnant women and women with young children.

RESULTS

A total of 36 persons were identified as persons with disabilities. The total population of the whole island is 2,622 persons, therefore the persons with disabilities identified during the survey constitute 1.3% of the population.

Annex 2 provides a list of the persons, their sex, age and disabilities. Some details like names and village name have been removed for issues of privacy.

Among the 36 persons with disabilities, 21 were female (58%) and 15 were male (42%). Among the 36 persons with disabilities, 12 were children equal to or less than 15 years (33%), while the remaining were 16 years or older. Among the older persons, 5 persons had more than 60 years (14%).

In terms of kinds of disabilities, 31 persons had a single area of functional difficulty while 5 persons had more than one areas of functional difficulties. The representation of different disabilities was as follows – hearing difficulty 14 persons (39%), seeing difficulty 10 persons (28%), locomotor difficulties 6 persons (17%), learning and memory difficulties 6 persons (17%) and chronic mental illness 2 persons (5%). (Note: Since 5 persons, had more than one kind of functional difficulty, the total of percentages of the different disabilities is more than 100%)

An English translation of the questionnaire is provided in **Annex 3**.

COMMENTS

In the 2011 National Census, a house to house survey in Assam state had shown a prevalence of persons with disabilities as 1.54%. In this survey no house to house visits were carried out. This survey included only some community awareness and asking persons to come to the clinic voluntarily. Therefore, finding 1.3% of persons with disabilities through voluntary reporting in Pithakaity island is highly significant. It means that the total number of persons with disabilities in the island may be much higher, with many more persons who have significant functional difficulties.



Dr A. Islam from C-NES Boat clinic team explains the survey in Pithakaity Char 1

During the survey, the C-NES boat clinic team was surprised that though they had been coming to the island regularly since 2008, and they believed to know all the inhabitants, they had never seen most of the children and adults with significant disabilities.

Boat clinics focus on mother and child care. For this reason, majority of the persons attending the health clinics run by C-NES in the river islands are women, especially pregnant women and women with small children. Usually in all disability surveys, number of men is much higher than women. However, in this survey the number of women and girls was much higher. Therefore it is possible that there can be many more men with disabilities among the island population, who did not or could not come for the survey.

Usually persons with locomotor difficulties are the largest group of persons with disabilities in a community, often more than 40% of all disabled persons. However, in this survey their number was very small. This may have been due to conducting of the survey in an area far from Pithakaity Char 1 village and at even more distance from other villages. Therefore it is possible that there can be many more persons with locomotor difficulties among the island population, who did not or could not come for the survey.

There were no persons with some specific disabilities such as cerebral palsy among those who had come for the survey. This can also mean that there may be more hidden children and adults with disabilities in the island population.

Dr Deepak personally examined 22 persons with disabilities identified during the survey. Among these there were 3 blind persons (2 children), 1 child with very low vision, a child with cleft lip and palate, a 3 months old baby with myelomeningocele, a baby with a missing ear, a boy with serious kyphosis with consequent hip deformity and a child with a leg amputation. None of the persons examined had received a disability certificate and most had no idea about the different Government schemes related to persons with disabilities. Many of them who need specialized services, had never seen a specialist. Most persons had been seen by local doctors (?) in the near by village on the mainland while a small number had been to the district hospital in Morigaon.

There was no one among the 36 persons with disabilities who had a hearing aid or eye glasses or any other assistive devices. Most of the persons including children had limited or no education.

Middle ear infection with pus discharge from one or both ears was a common complaint including in most persons who had difficulty in hearing.

CONCLUSIONS AND SUGGESTIONS

The voluntary reporting survey on persons with significant functional difficulties carried out in a river island in Morigaon district has shown a significant number of adults and children with these problems. It is likely that a house to house survey will bring out many more such persons. The survey also showed that many of these persons require specialist support, some require surgical interventions, and some require assistive devices.

It will be important for C-NES to consider providing some of these support services to island populations through the local referral services. In collaboration with the office of Assam State Disability Commissioner, Sarva Shiksha Abhiyaan, district

health services and NGOs like Swabalambi and Shishu Sarothi, C-NES can also prepare an information sheet about different Government schemes and referral centres for distribution to needy families.

Mobility India is in the process of setting up a centre for producing assistive devices in Guwahati. In future, MI can also provide practical collaboration to C-NES in this area.

Dr Deepak expresses his thanks to all the team of C-NES that collaborated for this survey including Mr Ashok Rao, Dr C. R. Hira, Dr Ashraf Islam, Dr Aziz Akhtar and very specially Mr Shyamjit.



Some members of the C-NES boat clinic team at Pithakaity Char 1 with Dr Deepak

Annexes

1. List of C-NES Morigaon boat clinic team members and their roles
2. List of the persons with disabilities identified during the survey, their age, sex and kind of functional difficulties
3. The English translation of the questionnaire used for the survey