

“We bear it and accept our fate”

Perceptions of healthcare access from people with disabilities in Cox’s Bazar

J U L Y 2 0 2 2



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Summary

At any given time, multiple assessments are underway to inform the humanitarian response in Cox's Bazar, Bangladesh, where more than 929,000 Rohingya have sought refuge since 2017. However, data is lacking on the unique needs, preferences, and perceptions of persons with disabilities. A series of workshops with the Age and Disability Working Group (ADWG) identified the need to know how people with disabilities – both in camps and in host communities – feel about the response and their barriers to healthcare access. We hope to identify 'blind spots' in programming, help national and international actors deliver more equitable services, inform more inclusive performance indicators, and build trust.

In November 2021, Ground Truth Solutions (GTS) and the International Organisation for Migration's (IOM) Needs and Population Monitoring unit (NPM) conducted qualitative interviews with persons with mobility and vision impairments from Rohingya refugee and host community populations with the aim of better informing and supporting agencies in developing disability-inclusive programmes and engagement activities. In line with our findings that "who asks the questions" can bias responses,¹ NPM mobilised a Bangladeshi–Rohingya enumerator team. Three days of specialised training included input from ADWG technical experts on disability-inclusive communication.

This report's 'user journeys' involve seven composite personas - fictional characters derived from 33 semi-structured interviews - which help establish a narrative of people's lived experiences. Given available resources, the nature of this approach, and the prevalence of different types of disabilities, we focused on people with mobility and vision impairments.

Key findings

- People with disabilities face significant barriers in using feedback mechanisms. They worry that providing feedback will affect them negatively, or won't be considered.
- There is widespread confusion over aid eligibility requirements, support groups, and care options.
- Although Covid-19 messaging is widespread, dangerous rumours persist about what happens to those who seek treatment.
- Spirituality and traditional beliefs influence people's decision-making around healthcare. This highlights the importance of religious leaders in communication.
- Costs are prohibitive and facilities lack the reasonable accommodation and supplies necessary for people with disabilities or long-term illnesses.
- Precarious terrain is a barrier to healthcare access.

¹ Ground Truth Solutions. May 2021. "[For Rohingya, trust begins with who is asking the questions](#)".

Why user journeys?

Research often disaggregates data for persons with disabilities. But this does not present their unique experiences completely or accurately. People need and want space to talk, not simply to answer questions.

The user journey methodology builds on human-centred design principles. It facilitates service improvements by illustrating the perceptions and experiences of service users through their interaction with healthcare providers, from their self-care at home to choosing a health facility, traveling there, and receiving treatment.

To account for the nuanced experiences of the people we spoke with, we used individual rather than group interviews. We developed an interview guide emphasising narrative technique - in the Rohingya language and Bangla - in cooperation with the ADWG and NPM.

Perceptions provide contextual insight which can help develop appropriate, rather than generic, recommendations to improve services for both Rohingya and host communities. For the detailed methodology, please see Annex 1.

How to read this report

The seven "personas" illustrate the perceptions of a group of individuals. These stories combine verbatim quotes chosen based on demographic commonalities among the 33 people we interviewed. The accompanying illustrations recreate moments in their journeys and were shared with the community in workshops to ensure accurate representation.





Ramida

Woman, 70, living in host community with mobility impairment
Moddhom Holodia, Ukhiya, Cox's Bazar



My name is Ramida. We live with two of my daughters-in-law. Most of my sons, daughters, daughters-in-law, and grandsons live nearby. The people living around us – including my daughters-in-law – are good people, so we don't have any concerns living in this village. I have had this orthopaedic condition for around 13 years; it happened for no apparent reason. Only Almighty Allah knows why this happened to me.





“ After waking early, around 6 to 7 in the morning, I prepare for the day. Then I perform prayer, even though I find this physically difficult. I have my breakfast and take medicine, then rest for a while. I cannot move if the pain is severe. I spend my day sitting, lying, and hardly moving. If I have to walk or go anywhere, it is difficult and I rely on a walking stick. For example, if I have to urinate at night, I lean against the walls or my stick, holding a torch in my hand.

Once, my grandson dreamed that I went to a doctor for treatment and I got better. So, a few days ago, being unable to cope with the pain, I even took badujja oshudh.² But it made my head ache severely and I did not take it again.

Accessing healthcare is extremely difficult for numerous reasons. For example, lining up and waiting for a long time to receive a token, then for hours again in the waiting area before finally seeing a doctor. Patients with serious illnesses suffer tremendously.

Initially, I visited two doctors. One was nearby and the other was in Cox's Bazar. Then, I went to Chattogram by car. That was about 10 years ago. Recently, I went to another doctor, who prescribed two types of medicines. One alone costs 1,800 BDT and the other costs 950 BDT per dosage. I took two doses of the first one and only bought 40 doses of the second. How can I afford this expensive medicine? I go to the doctor optimistically hoping Almighty Allah will heal me afterwards. But I have not recovered.

“I still have much to complain about, but I do not know where to complain.”

I was informed of a highly experienced doctor in Cox's Bazar. Many people who had visited the doctor said he was very good and reliable so my sons took me to see him. My neighbours and relatives also advised me to visit the doctor when necessary. Sometimes, my husband and sons research information on experienced doctors when they go outside.

When I arrived, I had to wait for a short time but I did not have to stand in the queue; the hospital staff gave me a chair. We received a visiting slip which they collected. When my name was read out, I was taken in. They treated me politely; I had no concerns about them at all.

After the outbreak of Covid-19, the doctors only treated those who could afford a lot. If someone could not pay the required fee, they would neglect them. I was disappointed by the doctors after Covid-19 and unfortunately, there was no one to complain to. I still have much to complain about, but I do not know where to complain. When I complained to the doctors, they told me to seek better treatment with my own money.

Many people need treatment for serious conditions; I feel bad when I see them. And many people are not able to send their children with disabilities for medical treatment because they cannot afford it. I would like to suggest that doctors prescribe accurate medicine for patients. If the prescription is good, surely the patient will recover. Medical services and equipment should be standardised for better treatment. I just want the government's rules to be practiced as soon as possible. Many NGOs visit here to gather information about people with disabilities but they do not talk to us directly. They just talk to the caregivers.

² A traditional medicine that roughly translates to “monkey medicine.”



Hazera

Woman, 50, living in host community with vision impairment
Poschim Ratna Palong, Ukhiya, Cox's Bazar



My name is Hazera. My husband died 17 years ago, and I live with my children. There are nine members of our family: three sons, two daughters-in-law, three grandchildren, and myself. One of my sons is still unmarried.

My sons do not have businesses; they make a living as day labourers and I work as a maid. Although our income is insufficient for a family this size, we somehow manage with whatever I and my sons earn. I have done nothing exceptional in my life. However, I have done some needlework for my grandchildren's clothing, and I think I can be proud of that.





I wake up at 6am every morning. Shortly after getting up, I clean my house, perform ablution, then pray. Then I go for a walk with other women from the neighbouring homes, as it is good for my hip pain. After enjoying a walk outside, I return home for household chores like preparing meals and washing clothes. As a maid, I spend much of my time working in people's homes.

Working is uncomfortable due to my many health problems: heart disease, hypertension, blurry vision, and weakness. My eyes give me the most problems. Everything is blurry and one eye itches a lot, which sometimes causes a headache. The problem with my vision is not congenital. It developed about two years ago. Continued stress and mourning over the death of my husband caused me several health issues and exacerbated the issue with my vision.

People advised me to see an eye specialist, but I had no money to cover the cost. Fortunately, some doctors visited our village recently, and I was able to see them. They tested my eyes and gave me these eyeglasses.

When I fall sick, I can rely on my children. Without them, I would have to knock on people's doors to seek help. Financial difficulties mean accessing healthcare has always been a problem. When I need medical treatment, I have to sell something. The last time I fell sick, my son had to sell the rice we had at home to afford my treatment. We do not have any organisations in the community that provide support to people.

However, at festive occasions, wealthy people donate money to poor people, ranging from 200 to 500 BDT.

“When I need medical treatment, I have to sell something.”

My last visit to the doctor was to treat high blood pressure. I fell down on the floor while praying due to high blood pressure, and my sons took me to the doctor by rickshaw. I normally go to the hospitals in Cox's Bazar for treatment. I have relatives-in-law in Cox's Bazar and they advise me about where to go and which doctor to visit for treatment. Last time, I accompanied one of my nephews to the hospital by rickshaw. The hospital was located at Panbazar in Cox's Bazar. It took several hours to go there and return home. When we arrived at the hospital, we had to wait a while before seeing the doctor. We left home at 3pm and returned at 8pm. It cost me a lot of money, including the 700 BDT doctor's fee.

When I entered the room for my heart test, the female staff there treated me with respect and helped me remove my burqa. The doctor understood my health problem well and I recovered after receiving the treatment. The doctor inquired if I took medicine regularly, and when I replied that I had been unable to take it for a few days, he urged my daughters to ensure I had the required medicine, even if they needed to starve for one day. He then jokingly asked my daughters what they would do if their mother died like their father.

Once, I went to Kutupalong to receive medication for Covid-19, but I returned home without visiting the centre because people there said that only a few paracetamols were being provided.

It would be helpful if the health facilities were nearer to us. When I went for the vaccine, I had to wait in a queue for a long time, which was difficult.



Golam

Man, 58, living in host community with mobility impairment
Purbo Ratna, Ratna Palong Union, Ukhiya, Cox's Bazar



My name is Golam. I have three little sons and a daughter, so my family has six members in total. Financial constraints make it very difficult for me to manage the family and educate my kids. I have a decent relationship with friends locally; some are like brothers to me, but not all. When we meet on the street, we chat – they do not visit my house regularly. They just come when I invite them, and vice versa. We also keep in touch by phone. I get along well with everyone in my family, including my wife. After waking up in the early morning, I clean my face and perform my prayer. Then I collect the trash from in front of my house. I spend my time sitting in a shop until I return home for afternoon prayer and food. Back at the shop, I spend the whole day talking with my friends. I am able to walk along the street by myself, but I have to stop now and then. As a result, for example, I managed no work yesterday. At home in the evening, I eat my dinner, then go to sleep.





My health problem started in 2011. I was suffering from a kidney problem and my legs had become swollen. First, the doctor gave me some medicine, but there was no improvement, so after two weeks, I saw a kidney specialist at a Chattogram hospital. I had my kidney tested and the result was really concerning. Since then, my health has never recovered; I have had various ongoing complications.

I am in serious financial trouble right now. I cannot get therapy for my throbbing legs. The healthcare clinics have no facilities. First, I was hospitalised in Chevron hospital in Cox's Bazar. After the treatment, I became very weak; my health had deteriorated so much that I could not even walk. As my condition deteriorated, my family suggested I go to a Chattogram hospital for better treatment. I went to a private hospital called Light Care in Chattogram. My family accompanied me so the visit was simple. But it was very difficult to return because my leg was more swollen and more painful.

“All praise be to Allah, I am quite strong right now. But only Allah knows the future.”

I had to pay 300 BDT for admission to the private hospital in Chattogram, but the prescribed medicines were too expensive. Transport from Cox's Bazar to Chattogram cost a lot as well. There were long queues in the hospital and I paid to put my name ahead of other patients. I could not even finish my treatment because later, I could not afford the medicine. Family and friends helped me cover my medical expenses. I have no income to support my family in covering all these expenditures. There are many other people with disabilities like me; they also lack income and face the same financial challenges in supporting their families.

The hospital doctors told me how to maintain my health when I returned home, and my family assists me. My wife takes very good care of me. Whoever I ask – not just my wife – they help immediately. All praise be to Allah, I am quite strong right now. But only Allah knows the future.

I have not noticed any difference in accessibility to healthcare since the pandemic; only wealthier people might notice this.

People's health conditions would be much better, in my view, if government hospitals and clinics had decent facilities, but we cannot access good medicines. If the government funds hospitals to deliver 10 BDT drugs, what we get is 5 BDT medicine. I think the government should pressure hospital administrations to eliminate corruption and offer the best possible care to patients. However, I must admit there has been improvement in recent years. There are now clinics for every ward.





Mohammad

Man, 48, living in host community with vision impairment
Poschim Ratna, Ratna Palong, Ukhiya, Cox's Bazar



My name is Mohammad. There are seven members of my family, and just one earner. My whole family lives together. I married off one of my daughters in Cox's Bazar, but she had to come back when she was three months pregnant. Her baby has a disability. We do not even know if her husband is alive. My younger daughter is not married yet. I drive a mini tomtom³ for a living. By the grace of Allah, I can support my family with what I earn.



3 A local small three-wheeler auto rickshaw.



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It has been over two years since I got this problem in my eyes. It is not a congenital defect. My vision is still not fully clear. I have a new prescription from the eye clinic, but I have not been able to get my glasses made yet. Even in daylight, I cannot see clearly; it is even worse in the evening.

I usually get up about 5 to 6 in the morning. After cleaning my face, I eat breakfast and then drive my mini tomtom to earn a living when I have no other duties.

Because of my visual condition, I am unable to continue driving my tomtom beyond 4pm. I had an accident and had to pay the police 25,000 BDT in compensation, which I had to borrow.

My wife and daughters-in-law help me maintain my health at home. My sons bring the medicine and other things I need, and also fetch medicine from the pharmacy.

Doctors see me at Sadar Hospital in Cox's Bazar, or Ukhia Hospital, and I have to buy medicine from the pharmacy. If there is a large crowd, the doctor cannot check on everyone, so I sometimes miss out despite waiting. The one thing that bothers me is being unable to visit a doctor on time and obtain treatment when I most need it. When I go to receive healthcare, it takes days. The main thing I do to maintain my health is pray to Allah. I want to die with my pure faith in Allah intact.

“Allah can take and give souls. It is up to him.”

The last time I visited a doctor was in Cox's Bazar. I went alone by vehicle and came back on foot. I had to pay 500 BDT as a visiting fee and another 500 BDT for the medicine. Before then, a female doctor from Dhaka charged me 1,000 BDT. I visited her twice, and the tablets she prescribed cost 180 BDT each. Many friends contributed to the cost of my treatment. The total cost was 12,000 BDT, but my condition did not improve. But now, with a different female doctor treating me, my health is improving.

We regularly see on TV that we should maintain distance and always wear masks to protect ourselves from the virus. So that's what we are doing. We maintain distance on the streets and in the mosque. Since the lockdown, the situation has normalised somewhat. I am not worried about Covid-19. Allah can take and give souls. It is up to him. I think it would be difficult to receive treatment if I was infected. I would even need to travel to the cities, to Dhaka or Chattogram, for specialist hospitals.

We know that NGOs are working to improve healthcare in the area, but the local authorities grab most of the NGO assistance. Ultimately, just a little portion is allocated to the health sector. If you are entitled to 500 BDT relief, you will receive just 50 BDT. The rest is in the hands of the leaders, and not everyone receives something at all. People only receive assistance when NGOs come directly to our doors.

If an organisation from the area can make people's problems known to doctors and the public, I think people will receive better quality healthcare. Services would be much improved if the government built at least a small hospital in each village. People would be able to get emergency healthcare. Women in labour could receive care, and other emergency services could be easily available.



Nur

Woman, 22, living in Rohingya community with mobility impairment
Camp 11



My name is Nur, there are five people in my family, and we all live together. I have no friends here, but my relatives and neighbours live nearby. I live on a hillside and have difficulty going up and down.

All I do is perform prayer five times a day, and drink tea in my spare time. Aside from that I cannot do much. When I am depressed, I usually take a walk or visit my neighbours and sit there for a while. That is how I pass my days.





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I have suffered from hip pain since before we came here. I got the pain when fleeing Myanmar. As police were chasing us while we were fleeing, I jumped in a canal to escape arrest and it caused pain in my hip. When I heard that they were listing names for therapy, I gave mine. For the first two days they just did the paperwork, then the next day they showed us how to lay down and how to walk to recover from the pain. I thought they would take us somewhere for treatment and to provide medicine, but they did not.

I do not know how to look after my health and no one in my family can help me. My leg is not good; I want to fix it but I do not know if medicine or injections are good. I buy medicine from local shops for pain relief.

Last month, in order to afford treatment, I had to sell most of my ration, keeping only three kilograms of rice. And I still did not have enough money.

It is tough to get healthcare if I have to travel to a facility far away. I would say receiving healthcare is difficult for everyone in the camp, not just me. It is very difficult for us to climb up and down the hill without any proper steps.

“Even if I could complain, I would be unable to travel to the complaint centre.”

We have problems accessing healthcare because whenever we visit the health facilities, we have to wait a long time. For example, if we go in the morning, it will be evening before we are done and by then we will have no energy for the journey.

I went to Turkey's hospital last week. I chose to visit that hospital because I heard they provide good treatment. I walked there with my son because I cannot afford the transport, and I do not face any challenges travelling there. When I arrived, they gave me a token. Then I had to wait all afternoon, which is very hard because I cannot stand for long due to my back pain.

I felt safe with the doctor but sometimes the workers in the health post are very rude to us. Still, we bear with them and receive our treatment.

I have never complained about the healthcare system, even when disappointed, because I do not know how or where to complain. Even if I could complain, I would be unable to travel to the complaint centre because walking too much hurts.

There are no local individuals or organisations who help people with disabilities like me. If we urgently need money for treatment, we request older people from the community to collect a donation on Friday when people gather to pray.

Because of Covid-19, I need to take better care of myself to avoid contracting the coronavirus. This is quite difficult for a person with disabilities like myself. I receive information about Covid-19 from NGO volunteers who come to our area. I am not afraid of Covid-19 because only Allah can give us sickness and only he can decide whether we are going to die or not.

I believe that only Allah is capable of making me recover from my pain. The doctor can only prescribe medicine but the ability to make someone ill or well is in Allah's hands. So, if Allah wants me to die from this pain, I cannot prevent it.

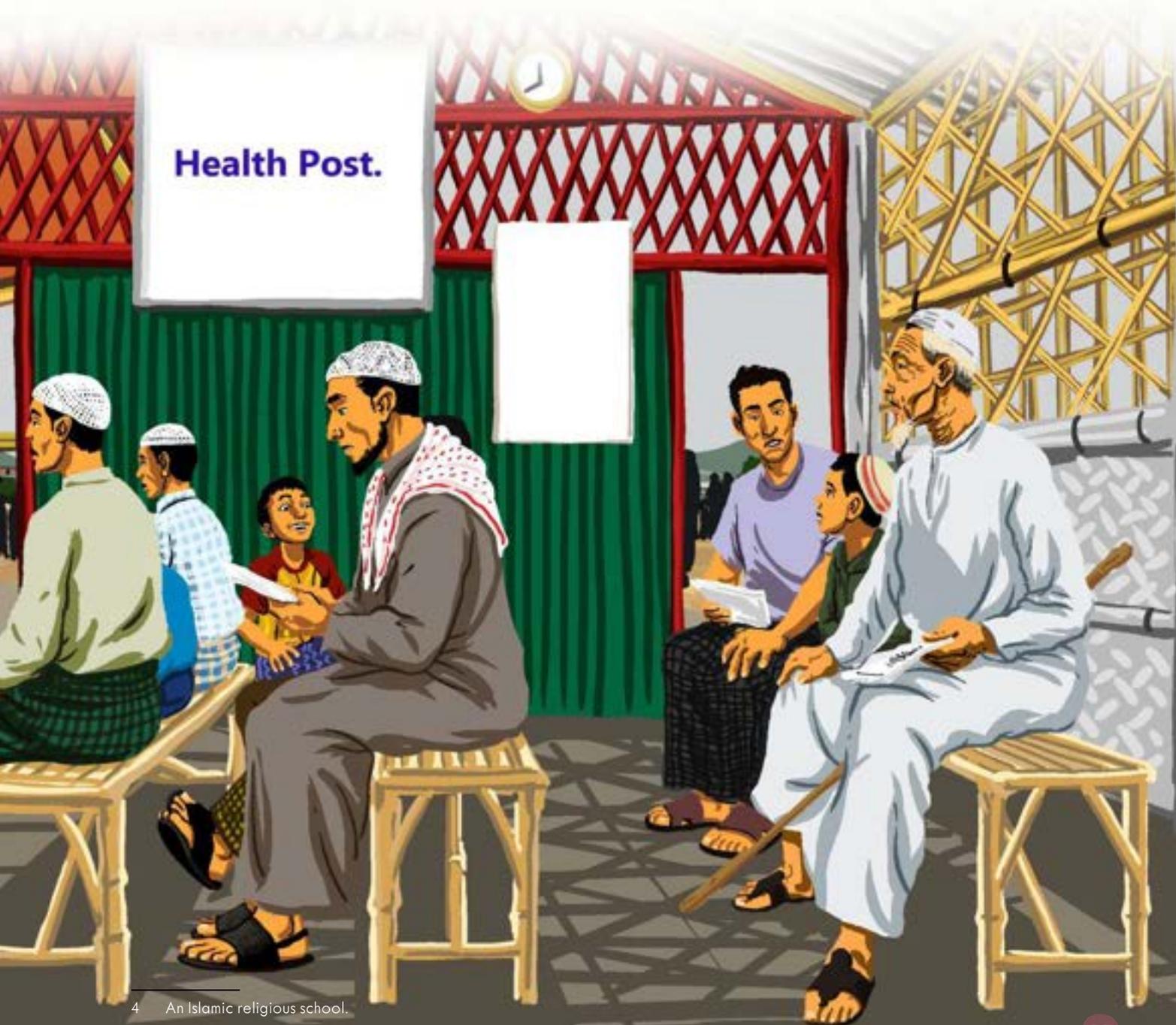


Osman

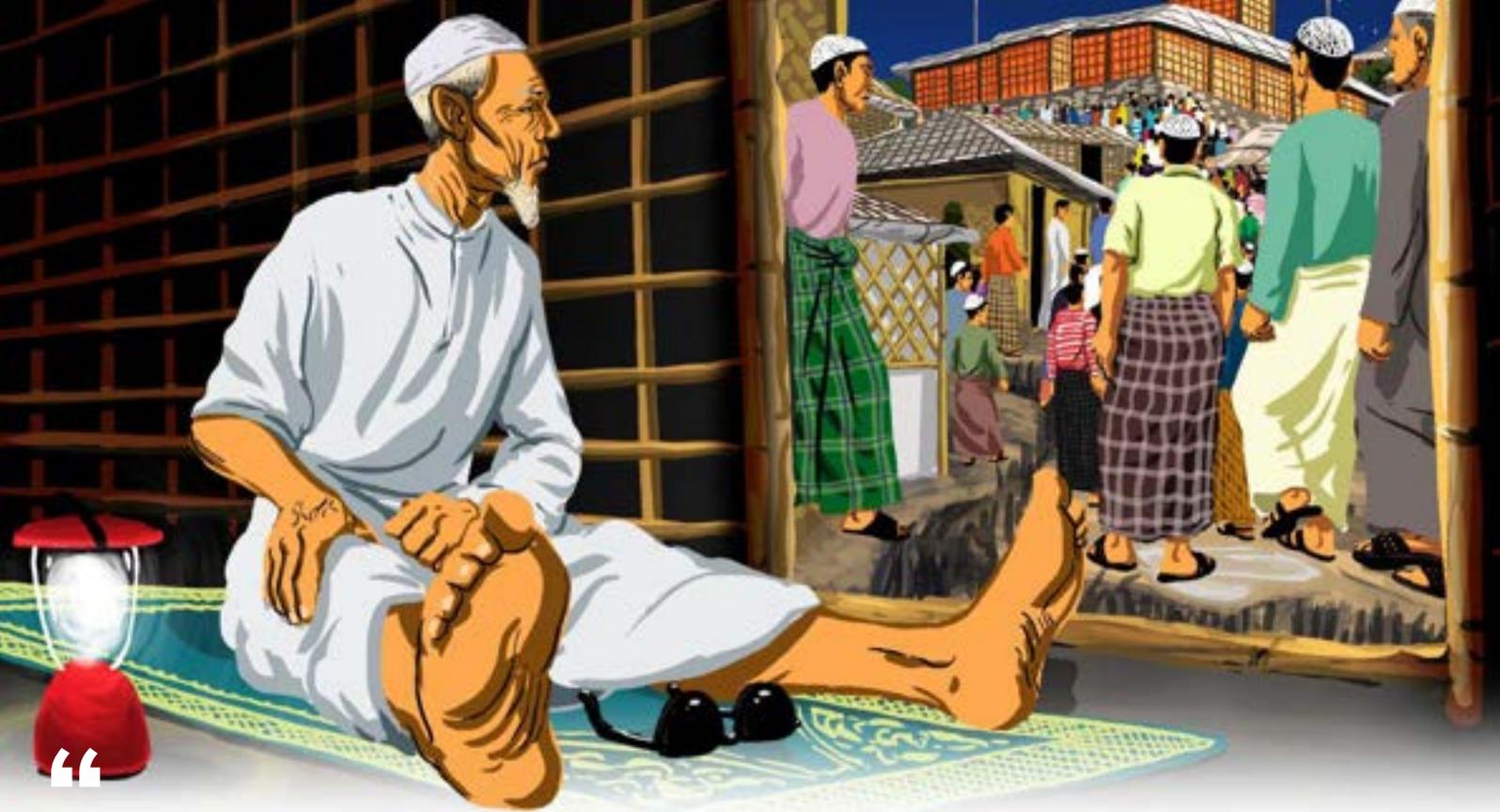
Man, 62, living in Rohingya community with vision impairment
Camp 13



My name is Osman. There are seven people in my family, and we all live together except for one of my sons, who is admitted to the Madrasa.⁴ Everyone is good in my family. My shelter is beside the mosque, and there are two more shelters next to ours. As I am a disabled person, I have spent a lot of money and visited many hospitals for my disease but so far, it has not improved. I take medicine and injections for my health. My family help me with everything, like cooking food and providing warm water.



⁴ An Islamic religious school.



It is difficult for me to go out as I have issues with my knees and vision. On top of that, the roads are bumpy and the solar lights in the street have been damaged. I cannot clearly see at night, so going out is very hard and I only go out to pray Salah⁵ at the mosque. We were living happily in our country. Our main goal is to go back. Here, we cannot move freely, we are not allowed to leave the camp. Sometimes I visit my friends and sometimes they visit me. We go to the mosque together and pray.

In the early morning, I go to the mosque for Fajr prayer.⁶ Then I come home at around 10am, take a nap, then have my lunch. By then, it's Zuhr⁷ prayer time, and I go to the mosque to pray. Sometimes I go to the market to buy groceries. I also have to go to receive rations.

“After consulting the doctor, they just gave me a few paracetamols, as always.”

I visited an IOM-supported health clinic near us 15 days ago. I went there because it is nearby and easy to reach. I went alone because it is nearby. I had no challenges travelling there. When I reached the clinic, I had to wait one hour in the waiting area to receive a token. After receiving the token, I had to wait two more hours to finally see the doctor. The staff at the health clinic never treat us with respect. We are irritated that we have to wait in line for so long when we visit a health post.

After consulting the doctor, they just gave me a few paracetamols, as always. I assume the doctor understood my illness, and yet they do not provide me with what I need. Now I am planning to visit another hospital because they provide better healthcare. I do not get proper treatment in the camp hospitals as the medicine for my disease is not available. I feel like the doctors are not capable of treating us properly because they never provide us with the correct treatment for our illnesses. Even one of the assisting staff who works there suggested I should visit Turkey's hospital because they provide decent healthcare.

I do not know about any local organisations that supports people with disabilities. And there is no one rich in our camp to help other people.

I usually do not complain because there is no one to listen to our complaints. Also nothing changes, no matter how many times we complain. I think it is better to stay silent and complain to Allah because he is the only one who can change the impossible.

I do not know anything about Covid-19 because I never paid attention to anything related to it. Yes, there were some announcements through loudspeakers, and women from BRAC also used to come to educate us about it. I have never been afraid of Covid-19 because we always stay clean and safe and I have faith in Allah. I always tell people not to be afraid of it and to have faith in Allah.

5 Salah is a set of five daily prayers.

6 Fajr prayer is one of the five mandatory salah.

7 Zuhr is one of the five mandatory salah.



Baitus

Man, 82, living in Rohingya community with mobility impairment
Camp 11



My name is Baitus, I have a family of four. My son and his wife live in a separate house; my wife and I live together and sometimes my grandsons stay with me. My relatives also live nearby. I have four or five friends who live close by, so when I am upset, I go out to talk to them, and then I feel better. It makes me happy when I can talk to someone who is more knowledgeable than me and can give me advice.





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I have difficulties with everyday tasks because one half of my body is paralysed. I try to walk twice a day, in the morning and in the evening. I wake up early in the morning, perform morning prayer and then sleep again. After a few hours of sleep, I eat breakfast and go to the market to buy groceries. After returning from the market, I spend some time sitting at a nearby shop, gossiping with friends. I have lunch, go to the mosque for noon prayer, and return home until afternoon prayer. Having performed afternoon prayer, I go for a walk and hang out for a while. And after evening prayer, I attend a sermon in the mosque, return home, have dinner, take a rest, perform night prayer, and then go to bed.

People are sad that we have no hospital nearby to provide treatment and medicine. It is difficult to go to hospitals that are too far away. I do not complain about anyone, even if I do not get the treatment I need or someone from the health centre treats me badly, because I'm afraid that they would treat me even worse next time I visit.

“The doctor told me to keep taking the medicine but I cannot afford to buy them.”

My relatives help me with money and I have visited doctors in Palongkhali and Kutupalong because I heard these doctors are good at treating orthopaedic diseases. I went by bus and my relatives helped me to get on the bus. In the Turkish hospital, the doctor provided me with some medicine and told me to go to Cox's Bazar if the medicine does not cure my disease. However, I do not have money to go to Cox's Bazar. The doctor in Palongkhali also said that my disease can only be cured in the Cox's Bazar or Chattogram hospitals. They do not have advanced medical instruments to treat my disease. As they said, the medicine from the Turkish hospital did not cure my disease. Now, I have to buy painkillers from a local pharmacy. Standing in the line for a long time is difficult for patients. There are older people, children, and people with severe diseases that have to stand in the waiting area until their number is called.

The doctor is a very good person. He is religious, he prays five times a day, and he respects me. He talks with me very well. He gave me instructions on how to use the medicine, which I followed. The people in the clinic near us, where I do physical exercise, also treat me respectfully because I am an older person in the community. After returning home, I use balm, kerosene, and warm water for pain relief. The doctor told me to keep taking the medicine but I cannot afford to buy them.

It is easy to receive treatment from NGO-supported hospitals, but these facilities do not provide treatment for all kinds of medical conditions. For example, if someone has a cut, they do not receive a tetanus vaccine as it is not available in these facilities. Also, people are not provided with a full course of medication. They provide some prescribed medicine and people have to buy the rest from private drugstores.

I received all the information about Covid-19 from NGO volunteers who visited our home and area to announce it by loudspeaker. I was not worried about contracting Covid-19 because I had faith in Allah, but I was afraid to go to a health centre during the pandemic because people who did not even have Covid-19 symptoms would be kept in a quarantine facility for around 15 days.

Healthcare access: Key areas for improvement

The experiences of Ramida, Hazera, Golam, Mohammad, Nur, Osman, and Baitus⁸ illustrate several key areas for improvement.

Persons with disabilities face significant barriers using feedback mechanisms for health complaints

Bangladeshi and Rohingya people both noted challenges accessing complaint and feedback mechanisms. When people had feedback to share, they either did not know how, hesitated in the belief their impairments would restrict them, or simply did not believe they would be listened to. A few Rohingya people feared complaining would make them targets for worse treatment. Our previous survey of the wider population of aid recipients revealed that people with disabilities are slightly less likely to give feedback.⁹

“I don’t complain about healthcare workers because I’m afraid that if I visit again, they’ll treat me even worse. I don’t even know where to complain about all of the problems we face.”

Rohingya woman, 65 years old

Consultations with the Rohingya disability support committee¹⁰ indicated that people prefer face-to-face feedback, and that complaints are more reliably sought by humanitarians through household visits. Even then, Rohingya do not always feel comfortable sharing honest feedback, especially when speaking to Bangladeshi volunteers. They also mentioned discomfort voicing complaints with helpdesks and said language barriers prevented them using hotlines.

Of the 33 people we interviewed, very few mentioned ever having complained about health treatment, despite their negative experiences. A GTS survey in 2021 showed feedback mechanisms are well used among the general refugee population: 57% of Rohingya used feedback mechanisms in the month before the survey.¹¹ Agencies must consider accessibility for persons with disabilities and stay aware of rumours or attitudes that may deter feedback. However, people will not provide feedback if they do not believe their concerns will be addressed. Previous research has highlighted this and it remains a concern.¹²

Recommended action

The humanitarian community must collectively ensure people with disabilities can access feedback mechanisms and understand fears and rumours that prevent people coming forward, as well as ensure that feedback is properly responded to. Actions that respond to feedback should be regularly communicated in order to build trust.

People likely want to give health-specific feedback at health facilities, rather than through general humanitarian “feedback mechanisms,” so healthcare facilities should support staff to proactively seek feedback. Exit interviews and even informal conversations could help to better understand when reality falls short of people’s expectations.

⁸ All names are fictional and not taken from any respondents.

⁹ Ground Truth Solutions. October 2021. [“Balancing act between health and livelihoods in Cox’s Bazar”](#).

¹⁰ The disability support committee was formed by the Centre for Disability in Development (CDD) and CBM Global for people with disabilities to support each other and share information and resources to access help services, rations and other necessary information.

¹¹ Ground Truth Solutions. October 2021. [“Balancing act between health and livelihoods in Cox’s Bazar”](#).

¹² REACH. May 2021. [“Age and disability inclusion needs assessment”](#).

Confusion over eligibility and levels of care

Some members of the host community expressed confusion about where they could go for treatment. Some were disrespected by security guards and turned away without care due to being “locals.” In response to these findings, health representatives said no policies restrict host community access to healthcare facilities and suggested that eligibility requirements are misunderstood by frontline teams and that communication may have broken down between healthcare providers and visitors.

Clear health sector guidance exists on services available at different facilities for the camps and nearby host communities, but people do not always know this. Primary healthcare facilities should be constantly accessible to provide basic services including curative care, standard triage, maternal and child health, gender-based violence support, nutrition, communicable and non-communicable disease treatment, and psychosocial health support. Health posts, by contrast, only operate during business hours, six days per week, and provide more limited services.¹³ Secondary care facilities that are equipped to handle specialised treatments, surgeries, or medical imaging typically require a referral from a primary health facility.

“A few days ago, I went to a doctor to receive phototherapy of my legs. But it didn’t affect me at all. Tears started flowing out of my eyes because I didn’t understand anything about the treatment.”

Host community woman, 55 years old

Accessibility barriers and broken information pathways leave communities uninformed of the differences between these levels of care and how the referral system works. This causes dissatisfaction with lower-level facilities and a tendency to bypass primary care. People expressed widespread frustration at receiving paracetamol when they expected more advanced treatment. Rohingya perceptions commonly saw the Turkish and Malaysian¹⁴ hospitals – both secondary care providers – to deliver better services than others.

Many people also expressed confusion about their medication. To reduce anxiety and produce better health outcomes, health services should clearly explain the purpose and benefits of prescribed medication and at-home treatment.¹⁵

“Before Covid-19 started, there was a hospital near our house where treatment and medicine would be provided. But, since Covid-19, the doctor does not come to that hospital and the hospital no longer provides services; it just lies empty. Now, people with disabilities go there to do physical exercises.”

Rohingya man, 58 years old

Recommended action

To avoid confusion, manage expectations, and support community members to make informed choices, patients need clearer communication about eligibility requirements, when they should access various levels of care, and what to expect from facilities and community health workers. Communication should align with the preferences of persons with disabilities and consider their specific challenges. Pictures can help to demonstrate symptoms and recommended actions. Healthcare facilities should help individuals understand their treatment more comprehensively.

13 Health Sector Cox’s Bazar. February 2020. [“Minimum package of essential health services for primary care facilities in the FDMN/Refugee camps”](#).

14 It should be noted that according to health representatives, the Malaysian hospital is no longer in operation, though many respondents mentioned it while explaining past experiences of visiting.

15 Paterick, Patel, Tajik, and Chandrasekaran. January 2017. [“Improving health outcomes through patient education and partnerships with patients”](#).

Spirituality and beliefs influence decision-making about healthcare

Most people - particularly women – described their daily routines as revolving around prayer. Within both refugee and host communities, spirituality guides decision-making about personal health, including the facilitation of home remedies. Traditional healing practices are not yet well understood by humanitarians.¹⁶ Healers are not recognised and registered by government and thus operate in secret.^{17 18}

“Whenever I get sick I call a traditional healer who lives near me; he heals me by calling the Adhan.”¹⁸

Rohingya man 53 years old

Some in the Rohingya community believe disabilities are caused by jinn, or spirits/demons, which leads people with disabilities and their caregivers to seek health advice from spiritual healers and religious leaders.¹⁹ One host community member consulted a spiritual healer to address her health concerns; another took traditional medicine rather than seeking healthcare outside the home. A BBC Media Action study found that many Rohingya believe they will recover faster when treated by traditional healers.²⁰

People described interactions with doctors at health facilities positively. Whereas doctors made them feel comfortable and respected, other staff were rude or disrespectful. Whether doctors and staff members were religious was important to a few participants in making them comfortable, especially as in relation to privacy for women.

Many were less concerned about their health because of their faith. For some, their faith removed concerns about Covid-19, while for others it provided comfort when they did not understand what was happening or could not access treatment. The heavy role of religion in both communities underscores the importance of involving religious leaders in community messaging. Leaders are regularly approached in the camps for information about Covid-19, although research indicates that the advice they provide is not always accurate.²¹

Recommended action

Given the importance of spirituality and traditional medicine, better understanding cultural beliefs and practices that influence health choices, including working with traditional healers, would help humanitarians minimise risk to communities and improve health outcomes. The humanitarian community should consult traditional healers and inform them about the referral system so they can refer cases to other facilities when necessary. Communication about health facilities – such as which facilities to visit for specific issues – should leverage spiritual leaders as a trusted source of information for persons with disabilities.

Facilities lack reasonable accommodation and supplies

Most people, when they were even able to reach a clinic, had waited for hours to be seen, some returning home without treatment due to the sheer number of people. BBC Media Action and ACAPS similarly reported that at NGO-run hospitals and other facilities in the camps, long waiting times are common and cause great discomfort.²² For those with disabilities, this can mean standing in pain or distress, sometimes in the hot sun or rain.²³

16 The New Humanitarian. July 2018. [“In Rohingya camps, traditional healers fill a gap in helping refugees overcome trauma”](#).

17 ACAPS. February 2021. [“Bangladesh: Considering age and disability in the Rohingya response”](#). February 2021

18 Adhan is the Islamic call to prayer recited by a muezzin at prescribed times of the day.

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19 ACAPS. February 2021. [“Bangladesh: Considering age and disability in the Rohingya response”](#).

20 BBC Media Action. November 2020. [“Rohingya community concerns over health services in the camps”](#)

21 BBC Media Action. July 2020. [“Covid-19 information reaching many, but not all: Some community and religious leaders need more information”](#).

22 BBC Media Action. November 2020. [“Rohingya community concerns over health services in the camps”](#); ACAPS and IOM. May 2020. “Covid-19 Explained: Edition 6”.

23 ACAPS. February 2021. [“Bangladesh: Considering age and disability in the Rohingya response”](#).

Facilities are not equipped to meet the requirements of persons with disabilities. Only one host community member had visited a clinic with a specific waiting area for people with disabilities, which was more physically accessible. At a different hospital, the same person had to be carried up the stairs because there was no wheelchair ramp for her to access the doctor's office. She was involved in a disability support group, and thus had access to a network and resources that others did not mention.

Many, especially Rohingya people, felt public hospitals lacked the supplies to treat chronic conditions and disabilities. This was also clear in BBC research, which reported many people travelling to a different camp for treatment.²⁴ There is a widespread belief that facilities outside the camps – including private hospitals – provide better treatment. This feeds another common belief, that money is a prerequisite for adequate care. This is not without evidence. One host community member had bribed a staff member to move their name up the waiting list.²⁵

“I had to queue for almost six hours before my turn; I was so worried that I would return without seeing the doctor, but I stayed patient. I did not feel comfortable as I had to wait for a long time.”

Host community woman, 67 years old

Recommended action

Health providers should systematically communicate facilities' capacity for the day to manage expectations and reduce waiting times and discomfort. They should provide specialised training for staff on working with persons with disabilities.

Providers should make reasonable adaptations to existing health facilities to enable people with disabilities to access services with dignity, including adding seats and otherwise improving waiting conditions – especially considering rain, storms, and very hot and sunny weather.

Allegations of misconduct must be taken seriously. The government's zero-tolerance stance should be strictly enforced. Feedback mechanisms should reflect social desirability bias, particularly within the Rohingya community, and ensure that affected communities feel safe to provide feedback on sensitive issues.

Health messaging is widespread but dangerous rumours persist

People shared worrying rumours about what might happen to those who seek treatment or test positive for Covid-19, including being taken away by authorities or being killed while in hospital. These rumours were also noted in a collaborative GTS study with the Bangladesh Red Crescent Society in 2020.²⁶ Whether these rumours are still common in the wider community or are more limited to people with disabilities – who tend to be more isolated – was not examined in this study.

Many said they believe their faith protects them from the virus and take comfort in the belief that virus infection is determined by destiny.

Nearly every Rohingya person we spoke with noted they had received information on Covid-19 from NGO volunteers using loudspeakers, but not all had understood it. It is unclear how Covid-19 messaging and other risk communication reaches people with hearing impairments.²⁷ Previous surveys have confirmed that pictorial and other visual communication methods are not widespread, although they may be preferred by people who are unable to follow loudspeaker announcements.²⁸

“I heard that we might contract Covid-19 if we touch dogs. That is why we should not touch dogs with bare hands.”

Host community man, 75 years old

24 BBC Media Action. November 2020. [“Rohingya community concerns over health services in the camps”](#).

25 ACAPS & IOM. April 2021. [“Añárar Báfana, Our Thoughts: Rohingya share their experiences and recommendations”](#).

26 Ground Truth Solutions. January 2021. [“COVID-19 takes social and financial toll on Cox's Bazar camp communities”](#).

27 While GTS consulted an international expert in qualitative research with people with hearing impairments as part of the research design phase, resource constraints inclusion of individuals with hearing impairments in this study.

28 BBC Media Action. November 2020 [“Rohingya community concerns over health services in the camps,”](#)

Few people had opinions on whether healthcare had improved or worsened since the pandemic, although some felt uncomfortable with the social distancing required in clinics or did not understand why some clinics were closed. Discomfort with these measures stemmed from not understanding why people were being isolated. This highlights concerns about the comprehension of Covid-19 messaging. Anxiety also stems from rumours about what happens to people who test positive.²⁹

Recommended action

The success of messaging campaigns – whether on Covid-19 or other key topics – should not only be measured by the number of people reached but also on comprehension and behaviour change, especially for groups that are harder to access, such as persons with disabilities. Messaging should be distributed through different formats for different communities.

Religious leaders and influencers in the community should be better engaged to spread health messaging and dispel rumours but should firstly be highly educated and trained on these matters. Caregivers and others with close contact to vulnerable communities should receive specialised education on the risks posed.

Healthcare costs cause stress and prevent access to treatment

Both communities referred to the lack of funds as a chief barrier to quality healthcare. People cannot afford full cycles of prescribed medication or ongoing treatment for chronic conditions, nor can they follow up on referrals for further treatment or surgery. To do so, they mentioned selling their rations, collecting donations from wealthier neighbours on religious holidays, and taking loans that they struggle to pay back.

When choosing a healthcare facility, many had to carefully weigh the costs and benefits of public or private clinics and were heavily influenced by other community members concerning where to seek healthcare. One man, who had recently arrived in Cox's Bazar, remarked that when he needed healthcare, it took him a few days to figure out where the hospital was. This suggests that information about local facilities is not readily accessible to those without a peer network for recommendations and resources.

“A few days ago, I was telling my wife that I want to take a pack of glucose as my body was shaking and I wasn't feeling good. She said I couldn't take one because a pack of glucose costs around 800 BDT, which our sons can't afford.”

Rohingya man, 53 years old.

Recommended action

Bangladesh is now the fifth year of crisis. Health services must find long-term solutions to meet the needs of people with disabilities and chronic conditions that require frequent and ongoing treatment. This requires greater coordination between NGO-run and government facilities. Scaling existing disability support and self-help groups and investing in additional community support systems may help to fill the gap in services and support existing systems.

Notoriously difficult terrain is a barrier for persons with disabilities

Accessing a healthcare facility can be arduous for people with disabilities, even in the best weather. But Cox's Bazar's muddy and hilly terrain, combined with the lack of assistive devices, can be near-impossible to traverse. People we spoke with have walked, been carried by family, taken buses and tomtoms, but some simply could not access facilities and sent family members in their place. Others borrowed money for public transport or were escorted to clinics.

²⁹ BBC Media Action, “[Covid-19 information reaching many, but not all: Some community and religious leaders need more information](#),” July 2020

Consultations with disability-focused organisations revealed that although mobile support services are available, they can only operate in limited areas due to funding constraints. People often do not know when these services will be in their area, so they miss out. These services are also less available to the host community due to insufficient funding for specialised services.

“Our shelters are on slopes where there are no proper steps for people to climb up and down, making it extremely difficult for us to go down for water... A few days ago, I fell and injured my knees. And when it rains, we cannot go down at all because the ground becomes so slippery.”

Rohingya woman, 43 years old

Recommended action

Persons with disabilities urgently need more physical support through transport or mobile services. Advance communication of when mobile teams will visit specific camps or areas is essential to help people with disabilities receive care without having to travel to a health post or primary or secondary care facility. These services should also be available more regularly to the host community. People need financial support for transport to essential services.

People do not know about specialised support organisations

People we spoke with in both communities were unaware of local organisations that support persons with disabilities. Most people’s networks were limited to family, friends, and religious communities. A “self-help” group exists for host community members with disabilities and there is a similar “disability support committee” for Rohingya, but only one person mentioned these.

Mobile teams from disability-specific organisations like the CBM Global Disability Inclusion (CBM Global) and the Centre for Disability in Development (CDD) had visited some people, who were satisfied with services like physiotherapy and training on how to care for themselves at home. However, funding limits mean these organisations only operate in certain camps, so they are out of reach for many.

Most people we interviewed could not identify any community-led organisations or structures that support people with disabilities, but many noted family as their principle social resource. Families assume responsibilities including building latrines onto their shelter, fetching supplies from pharmacies, and accompanying or even physically carrying people to health clinics. When medication was necessary for fever or common illnesses, some people reported sending family to local shops. The need for around-the-clock care from family can impact a household’s ability to engage in paid work, compounding vulnerabilities and further reducing access to resources for adequate healthcare,³⁰ as well as disproportionately affecting women, who take on most of the caregiving work.

“My wife helps me get ready in the morning, then she helps me have breakfast, and when I finish breakfast, she moves me from my bed to another place where I can get some fresh air and see the sunlight”

Rohingya man, 80 years old

With limited interaction in the wider community and limited knowledge of local groups from which to seek support, persons with disabilities have expressed feelings of rejection, exclusion, and sadness.³¹ Supporting people with disabilities and their caregivers to strengthen their community-based support networks may help them to advocate for their own rights, improve access to services, and address concerns related to both emotional and physical well-being. Although this study did not explore the intersectionality of these issues, existing research does point to the necessity of additional qualitative work to examine the double discrimination faced by women with disabilities.

30 ACAPS, “[Bangladesh: Considering age and disability in the Rohingya response](#),” February 2021

31 *ibid*

Recommended action

The response should help people with disabilities and caregivers to form their own support structures and advocate for their own needs and priorities. Rehabilitation should be more widely available and integrated into primary healthcare provision.

Humanitarians should provide better support for caregivers to address the economic vulnerability of households with disabilities. This can involve increasing income-generating activities for both caregivers and people with disabilities, which can be done inside the home, and prioritising households with disabilities for work opportunities, as well as equipping organisations with resources to provide mobile health services or static health centres.

Conclusion

Communication breakdowns complicate healthcare access across the response, causing fear and confusion and disempowering persons with disabilities, leading to negative perceptions of humanitarians and health workers. The voices and perspectives of people with diverse needs are often missing in decision-making, making it harder to programme effectively, address rumours, ensure people have the information they need, and build trust.

More effort is needed to first understand the Rohingya community – their support networks, fears, and traditional approaches to health issues – and then to engage spiritual healers and other trusted community members to ensure that people are referred to the correct facilities when advanced care is needed.

As the Rohingya crisis moves into its fifth year, the humanitarian community must prioritise long-term solutions. Meeting the needs of those with disabilities and chronic conditions, as well as addressing longstanding social cohesion issues, requires more than emergency solutions. This calls for the expansion of disability services such as rehabilitation and investment in community support systems.

Annex 1: Methodology

Inception phase

The inception phase began with an assessment to identify key gaps in information within the response and priorities for humanitarian actors to strengthen services to affected persons with disabilities. Key informants encouraged GTS to focus on a single sector to produce more targeted recommendations.

After identifying access to health as an issue of concern, GTS facilitated a series of workshops with ADWG members to define the research scope. Participants agreed to focus on physical barriers to healthcare access, as well as invisible barriers such as economic restraints and stigmas, and how these challenges have evolved during the Covid-19 pandemic. They also identified a need to better understand the experiences of the Bangladeshi host community. This aligns with recent research that indicates that the unique priorities and challenges of the host community are under-explored due to sensitivity around data collection outside the camps and a general emphasis on the Rohingya, who are almost entirely dependent on humanitarian aid to meet their basic needs.³²

Persons with disabilities from the affected communities were not consulted during the inception phase due to camp access restrictions. Strengthening capacity within the response to conduct research among and with persons with disabilities should however be a priority and is a challenge that will be considered in future research.

After defining the scope of the research, GTS hosted a co-design workshop with the ADWG to develop the research sample and tools, while additional enumerators were recruited by NPM to ensure a balanced Bangladeshi–Rohingya team. Training on quantitative and qualitative research techniques and inclusive communication was provided separately to the Bangladeshi and Rohingya enumerator teams, followed by a pilot phase to test the translated tools.

User journey interviews

The IOM NPM team of Bangladeshi and Rohingya interviewers conducted a total of 33 in-depth, semi-structured interviews throughout November 2021, with interviewees sampled according to draft profiles determined during the inception workshops with the ADWG. In total, 19 interviews were completed with Rohingya people, and 14 with host community members, according to the demographics below:

Disability type	Rohingya: Female	Rohingya: Male	Host Community: Female	Host Community: Male
Visual impairment	2	3	3	3
Mobility impairment	6	7	4	3

Host community interviews were conducted in Ukhia, Cox's Bazar in the following locations: Bazar Para, Poschim Ratna Palong, Shikder Para, Purbo Ratna Garam, Anowar Para, Purbo Balokia Palong, Moddhom Holodia, Holodia Palong, Holodiya Patabari. Rohingya interviews were conducted in camps A1, 8W, 11, 13, 14, 18, and 20. Interviews were structured around the journey experienced by each respondent. Interviewees provided detailed accounts of their personal situation, their experience accessing healthcare and caring for their health at home, changes since the onset of the pandemic, and how they receive information about Covid-19. They were asked to reflect on positive and negative aspects of their experience and on how the whole process could be improved. To draw out these key points, the interviews used directed storytelling, a narrative inquiry technique that allows researchers to explore recent experiences through a series of

32 ACAPS, "[BANGLADESH COX'S BAZAR – BANGLADESH Rohingya refugee response: Information and analysis ecosystem](#)," November 2021

prompts and guiding questions. Each interview was recorded, transcribed, and analysed using MAXQDA qualitative coding software. Participants were identified with the support of ADWG partners.

Personas

The seven personas presented in this report are a composite of experiences based on qualitative data that express the needs, goals, drivers, and behaviours of a group of individuals. Each of the seven personas provide tangible identities that represent the characteristics of different kinds of user. They make it possible to explore different combinations of characteristics and how they impact respondents' experiences. Despite being fictitious, the personas of Ramida, Hazera, Golam, Mohammad, Nur, Osman, and Baitus (all fictional names) are synthesised characters based on commonalities derived from the transcripts of the qualitative interviews. All quotes are taken verbatim from translated interview transcripts and edited for clarity. Personas were developed through a preliminary data analysis after data collection had concluded and were then discussed in workshops with the ADWG and disability support groups in both communities to ensure they accurately represent people's experiences.

User journeys are a valuable method of highlighting experiences that are commonly overlooked by traditional monitoring and evaluation efforts. However, they cannot be considered an evaluation. The user journeys included in this report do not reflect average experiences but are rather based on the self-reported accounts of 33 purposively sampled interviewees. The usefulness of the personas should not be limited to this report. They can and should guide decision-making to ensure that future changes to healthcare access and information in the Rohingya camps and host community areas are effective and accessible for all.

Validation workshops

After concluding data collection and analysing the interviews using MAXQDA software, preliminary findings were identified and discussed in workshops with the ADWG to identify where findings resonated with what they already knew, where findings were surprising, and what was currently being done in response to some of the issues identified. Similar workshops were held with the CBM Global Disability Inclusion (CBM Global), the Centre for Disability in Development (CDD), HelpAge International, Humanity & Inclusion, and the health sector to gather their perspectives and identify how their current and planned activities address these findings.

Workshops were also conducted with 11 members of the host community "self-help" group (a support system for people with disabilities to access information and resources) and 11 people in the disability support committee for Rohingya in the camps. Both groups were formed by CBM Global in partnership with CDD. IOM NPM also led post-data collection workshops with the Bangladeshi and Rohingya enumerators to debrief, explore their perspectives on the findings, and address what could be improved when working with people with disabilities in future.

Limitations

Given the resources available at the time, the targeted nature of the user journey approach, and the prevalence of different types of disabilities in the context, the study focused on people with mobility and vision impairments. This means that conclusions and analysis from this research should not be generalised to those with auditory, speech, psychosocial, or intellectual impairments. Additionally, while effort was made to mobilise a peer-to-peer approach, it was difficult to identify qualified enumerators that identified as having a disability to assist the NPM team. This highlights the need to source and train people with disabilities as enumerators and to better understand the accommodations needed to empower them to participate in knowledge-generation for the response.

While this study was designed in collaboration with the ADWG, it was not co-designed with the disability community. This limitation should be addressed in future research through an expanded timeline for the design phase and by allocating resources to engage members of the disability community at all stages. Enumerators also faced difficulty in physically locating interviewees, given that personal addresses are not always systematically documented. Due to this limitation, the minimum three interviews needed to create a composite persona representing the experiences of Rohingya women with a visual impairment was not completed. However, information from the two interviews that were conducted was incorporated into the key findings and analysis.

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This work was conducted in partnership with the IOM Needs and Population Monitoring (NPM) unit and with support of the Australian Department of Foreign Affairs and Trade (DFAT). Ground Truth Solutions will continue to collect surveys on a regular basis to inform response planning and programme adjustments. To see our previous reports on feedback from Rohingya and host communities, visit our [website](#).

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