



Including and engaging people with disabilities in research: experiences and reflections from Myanmar

Background

- In 2019, 13% of Myanmar's population (5.9 million people) was living with a disability (see fig 1).
 - Health care service delivery has been halted due to the current conflict and instability. People with disabilities (PWD) are disproportionately affected.
 - There is limited data and research on PWD, especially in fragile and conflict-affected settings such as Myanmar and particularly with regards to health.
- This poster reflects on Burnet Institute's experience of including PWD as participants in research in Myanmar, and shares the challenges and lessons learned during data collection for the institute's adolescent mental health project.**

What we did

- A quantitative approach, collecting data using surveys administered by a trained enumerator.
- 322 participants aged 15-24 were selected from a township in Yangon Region and another in Magway Region.
- As PWD are more likely to have mental health problems than non-disabled people, we purposefully included PWD in this study. 26 out of 322 participants were PWD.

What we learned

- **Recruitment:** Recruiting PWD was challenging, especially during active conflict. The PWD support network can help recruit the hard-to-reach PWD population, however, in conflict settings most organizations kept low profiles because of safety and security concerns, and it was hard to communicate with them.
- **Approach:** The research team has worked with stakeholders in the study sites for many years, so it was feasible to recruit PWD to the study through local networks. The team also ensured suitable transportation to the study site for the PWD and their accompanying support people.
- **Adjustments:** Researchers and enumerators need to understand participants' disabilities, going beyond a general description such as 'physical or intellectual disabilities'. This ensures appropriate recruitment and data collection arrangements are put in place for all participants. These can range from a larger font for people with visual disabilities to hiring a sign language specialist to better communicate with participants with hearing loss.
- **Location, duration and set-up:** Consideration should be given to the location and duration of interviews with PWD. The research team observed that PWD were more relaxed and comfortable during interviews when accompanied by friends they could hear or see (non-disabled participants normally preferred a private space).
- **Other logistics:** Enumerators noted PWD sometimes needed further adjustments, e.g. more time to complete a survey. An accompanying support person may also need to be accommodated. These adjustments need to be considered from the outset to allow logistical and financial accommodation.

Fig 1: Disability prevalence in Myanmar by disability (% population and estimated total in 2019) Source: UNFPA

Disability	ANY	Seeing	Walking/ Climbing Stairs	Remembering/ Concentrating	Hearing	Inability to Self Care	Communication
At least one							
Millions of people affected	13% 5.9M	6% 2.9M	5% 2.5M	4% 2.0M	2% 1.1M	2% 1.0M	2% 0.7M

Conclusion

Identifying the entry point to connect with PWD networks and secure their active engagement and participation in research is important, especially in a conflict setting. Including PWD in research requires careful preparation, not only for data collection but also to ensure their safety and accessibility needs are met. Again, this is especially important in conflict-affected settings.