Harmonising Assistive Technology Assessment Data: A Case Study in Nepal

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Abstract

Background: There is a practical demand to maximise existing data to understand and meet the assistive technology (AT) needs in dynamic populations. Harmonisation can generate new insight by integrating multiple datasets that were not previously comparable into a single longitudinal dataset.

Method: We harmonised AT assessment data from three population-based surveys collected several years apart in Nepal: the Living Conditions of Persons with Disabilities (2014-2015), the Multiple Indicator Cluster Survey (2019), and the rapid Assistive Technology Assessment (2022).

Results: The harmonised dataset demonstrates a method that can be used for unifying AT surveys in other settings and conducting trend analyses that are necessary for monitoring a population's dynamic AT needs.

Conclusion: We set out to explore AT data's potential for harmonisation, and learned there is indeed value in this approach for situating disparate datasets, though the methodology proposed will need further validation.

Introduction

Assistive technology (AT) includes products like hearing aids and glasses, and their essential services. AT is critical in supporting independence and wellness for people with disabilities and at older ages.[1–3] Yet access to AT between and within countries is often inadequate and inequitable, with highly fragmented efforts to monitor coverage,[4–6] which further inhibit evidence-based decision-making. Improving data in this sector is a high priority to expand access to AT, which has been greatly advanced by the deployment of population-based surveys that focus all or in part on specific assistive products (APs). As APs and their essential services gain a presence on national health agendas, many countries have also added functioning and AP need modules to routine data collection efforts.[7,8] However, these are relatively recent additions to the global coherence of AT evidence, which is still characterised by country-level gaps and discordant datasets. A practical, urgent need remains to maximise existing data to inform evidence-based policy. The Global Disability Innovation Hub (GDI Hub) are mapping these and other datasets[4,7] and developing compatible methods to learn more from what is currently available.

The recent publication of the Global Report on Assistive Technology demonstrated the necessity and power of population-level data.[5] Sparse data inhibit evidence-based decision-making, and while data collection efforts grow globally, many existing datasets are too discordant to link, or go unused altogether.[4,7] Data harmonisation is the process of cleaning and adjusting multiple datasets so they can exist in a single dataset, constituting a method that is growing in importance as the volume and need to share existing data explodes.[9,10] Harmonisation explores how data derived from several different surveys can be integrated and considered together. This method can be especially useful where data collection may have been funded from different sources and for different purposes, which is a common challenge in the AT data space.[11] Well-defined methods can be applicable to many contexts where similar surveys have been done, while harmonised datasets are useful in and of themselves for further analyses. Overall, the process can even identify opportunities to improve data collection. However, there must be some existing similarity between the datasets so that key variables can be universally defined and applied. To test this method's potential with AT data, GDI Hub sought countries with three or more population-based surveys, conducted several years apart to examine change over time, that each included questions on disability/functioning and assistive products. Currently, three population-based surveys have included similar modules on assistive products (APs) in Nepal: the rapid assistive technology assessment tool (rATA)[12] administered by the WHO and other AP assessment surveys including modules on APs, such as the Living Conditions Studies (LCS)[13] administered by SINTEF and the Multiple Indicator Cluster Surveys (MICS)[14] by the UNICEF. Given GDI Hub's existing work and partnerships in-country, and the availability of multiple population-based surveys, Nepal was therefore chosen for the initial case study.

To provide context for this setting, Nepal introduced a National Policy and Plan of Action (2007) for the provision of access to AT services for people with disabilities. Yet access to AT is still very limited, with the LCS report published in 2016 finding only 1 in 8 people with disabilities having access to AT.[15] Nepal is a multi-lingual, multi-cultural, multi-religious, multi-ethnic country with a diverse geography, consisting of mountains, hills and terai,[16] with most of the population living in rural areas (79.8%), although the urban population is gradually increasing.[17] People with disabilities in Nepal are one of the 'most vulnerable and deprived' sectors of the population.[18,19] The 2011 census conducted by the Government of Nepal reported that 1.94% (513,301) of the total population lives with some kind of disability. This figure is almost certainly underestimated considering the global average estimate from the WHO of around 16%.[20] Indeed, as Karki et al describe: "anecdotal evidence suggests that the Maoist insurgency from 1996 to 2006,[21] the 2015 earthquake,[22] high incidence of natural disasters every year,[23,24] increased traffic accidents,[25] fall injuries,[26] and deafness[27] have contributed to a higher prevalence of disabilities in Nepal compared to some other low/middle-income countries (LMICs)."[21] This strongly suggests a need for more complete datasets on Nepal if the population's AT needs are to be more fully understood.

This case study, therefore, aims to contribute 1) a harmonised dataset for future research seeking to monitor and understand trends in AT outcomes over time and 2) a harmonisation logic for AT assessment questions that can be reused in other settings where AT data exist in previously incompatible forms. These contributions can significantly support dynamic understanding of country-specific AT need.

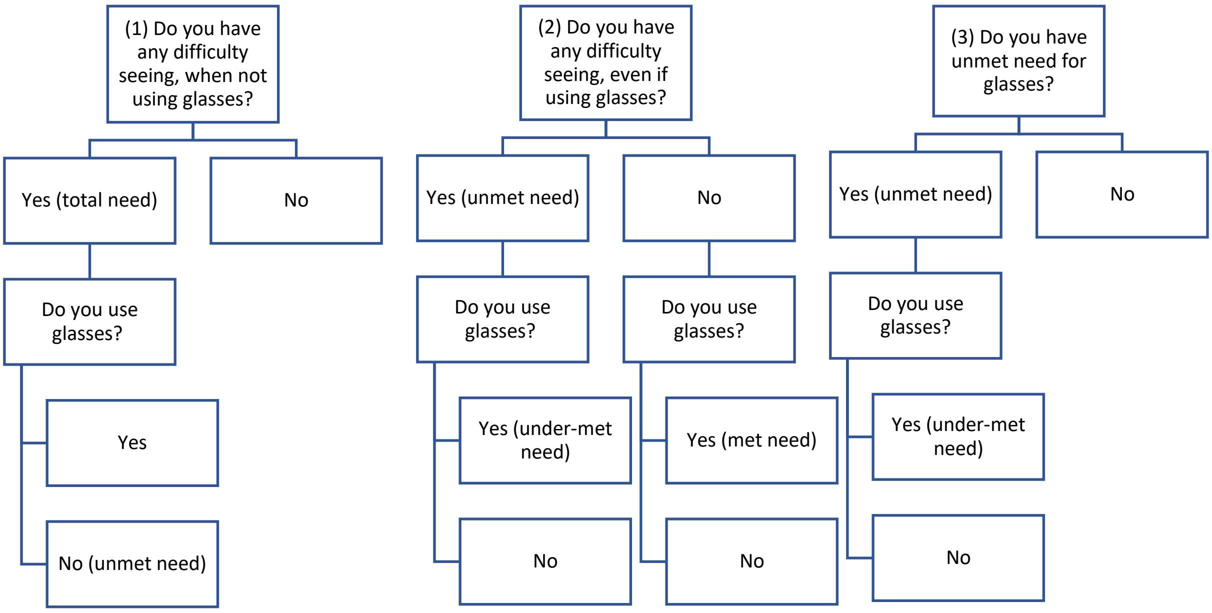
Method

Data sources

An LCS (2015, n = 34,754), MICS (2019, n = 4123), and rATA (2022, n = 11,230) have been carried out in Nepal. Each of these surveys (listed with the year of data collection completion and sample size) utilise population-based sampling and the Washington Group Short Set[28] of functional assessment questions (or a similar, modified version), as well as direct questions on assistive product (AP) use.

Harmonisation

Based on the assessment strategies used by each dataset, variables for AP outcomes were defined to be applied uniformly. Three AP outcome variables were defined: total (potential) need, under-met need, and unmet need. Figure 1 uses glasses to illustrate how these definitions were applied across each survey's specific approach to calculate these common outcome variables. We considered an individual to potentially have need for the AP if they had any functional difficulty, regardless of any AP use. This estimate of total need can also be calculated by adding met and unmet need, which is necessary in approach 2. Under-met need was defined as an individual with potential need that used an AP inadequate to address their need, i.e., experiencing difficulty even when using their AP, or reporting use as well as unmet need for the same AP. Unmet need was considered an individual with potential need that did not use any AP, or used an inadequate AP. Therefore, unmet need is inclusive of under-met need.



[1]

Figure 1: AT outcome variables in survey logic

To explore trends over time, the proportions of respondents using APs and with unmet need for APs were taken out of the total respondents with need, for each wave of the harmonised dataset. These estimates are provided with a 95% confidence interval (CI) based on the harmonised sample size in Figure 2.

Key demographic categories were also aligned during harmonisation, which included some recategorisation with the same value labels and the use of dummy variables as needed. For example, MICS youth and child questionnaires did not include questions that made the calculation of under-met need possible. Further adjustments were made to align these variables:

- The scale used for functional difficulty by LCS and MICS was adjusted for functional difficulty levels, with the 1-5 scale mapped/switched to a 0-3 scale, with 3 and 4 combined into ‘a lot of difficulty’, or ‘2’.

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[1] Approach 1 is used in the LCS, rATA, MICS youth (5-17) and child (0-4) questionnaires; approach 2 is used in the LCS and MICS adult (15-49) questionnaires. Approach 3 is included in the rATA questionnaire only, which asks respondents if they have unmet need for any APs and provides glasses as an option.

- Respondents aged <3 years or >49 years were removed from each dataset to align with the highest minimum and lowest maximum available across the three.
- For MICS and LCS, a 'don't know' option was included when asking about assistive product use, and those responses were recategorized as no use.
- All responses with missing data for any of the harmonised variables (except for MICS children and youth responses where calculation of under-met need was not possible) were removed.
- The rATA is the only survey offering gender options outside of male/female, but as no respondents identified with these options during the rATA survey in Nepal, no adjustment was needed based on gender.
- The only assistive products specifically mentioned across all waves were glasses and hearing aids. Questions on other APs or functional domains therefore could not included.

Results

After harmonising age groups, 39% of LCS, 11% of MICS, and 30% of rATA data were removed. Table 1 provides demographics and outcome estimates for each wave of the harmonised dataset. Table 2 stratifies the prevalence of vision and hearing functioning difficulty by level for each wave. Figure 2 depicts their age distributions.

Table 1: Wave demographics after harmonisation

Survey	Year of data collection completion	Respondents (n)	Female (%)	Vision difficulty (total need) (%)	Hearing difficulty (total need) (%)
LCS	2015	2551	48.8	9.5	17.7
MICS	2019	30993	64.7	8.2	3.3
rATA	2022	7842	53.5	11.7	3.8

The LCS wave identified exceptionally high hearing difficulty compared to the other two waves. The MICS also captured a higher percentage of female respondents. Vision difficulty is consistent across all three waves.

Table 2: Functional difficulty levels across harmonised waves

Survey	No difficulty seeing (%)	Some difficulty seeing (%)	A lot of difficulty seeing (%)	Cannot see (%)
LCS	90.5	6.1	2.5	0.9
MICS	91.8	7.6	0.5	0.1
rATA	88.3	9.9	1.6	0.2
Survey	**No difficulty hearing (%)**	**Some difficulty hearing (%)**	**A lot of difficulty hearing (%)**	**Cannot hear (%)**
LCS	82.3	10.4	4.5	2.7
MICS	96.7	3.0	0.3	0.04
rATA	96.2	2.4	1.0	0.4

The LCS estimated a higher overall prevalence of hearing difficulty, and therefore potential hearing aid need, particularly with respect to 'some' level of difficulty. However, all waves follow a similar trend of proportional decline in prevalence as severity of difficulty increases, for both vision and hearing.

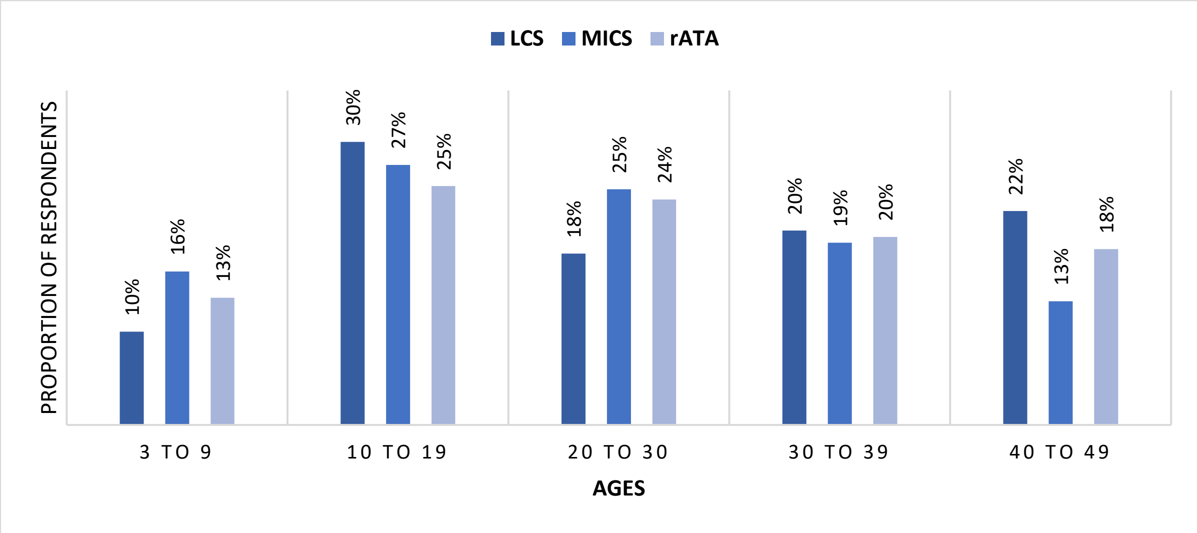

Figure 2: Age distribution of harmonised waves

Trends in AP outcomes were also explored over time. Figure 3 shows estimates for use and unmet need with 95% CIs for glasses and hearing aids, out of the total with need in the specific functional domain.

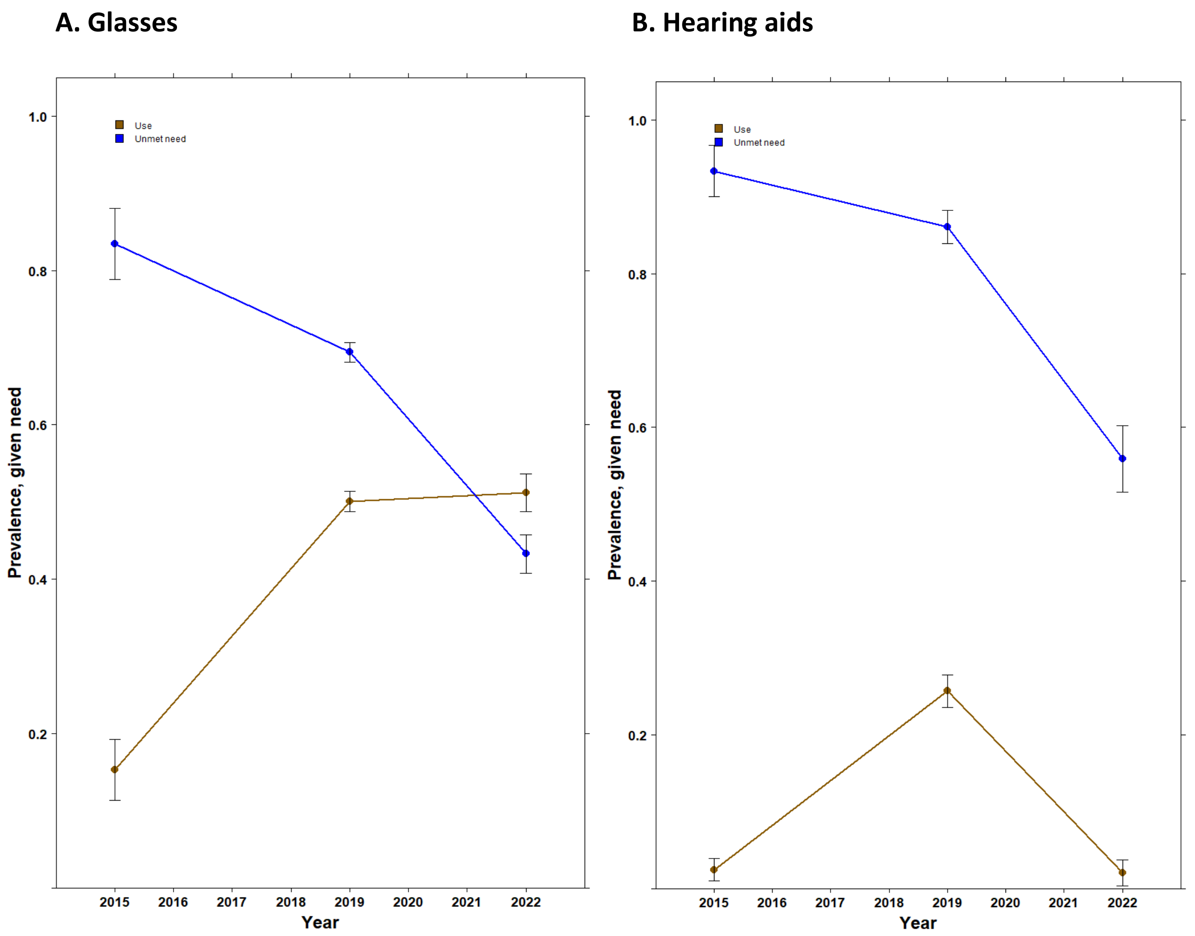

Figure 3: Use and unmet need, among respondents with need for A. Glasses (left) and B. Hearing aids (right).

Validation

Harmonisation and validation methods vary based on the data types. In this case, two opportunities were possible to assess our specific definitions.

The LCS is the only survey to include approaches 1 and 2 (Figure 1) as separate questions used to assess total need: 'Do you have any difficulty, without using the AP?' and 'Do you have any difficulty, even when using the AP?' (in combination with 'Do you use the AP?'). Using each approach, unmet need is estimated at 206 and 202 for vision, and 440 and 421 for hearing, out of the total with functional difficulty in each domain.

Based on the unmet need question specified in the rATA, unmet need for glasses and hearing aids is estimated at 60% and 90% of those with vision and hearing functioning difficulty, respectively. Unmet need was also defined in this analysis as having functional difficulty, but not using the AP. By this definition, unmet need in the harmonised rATA wave is 52% for glasses and 98% for hearing aids, of the total with any functional difficulty for each. In each case, the variation is <10%.

Discussion

The harmonised dataset indicated emerging trends for vision and hearing difficulty as well as AT outcomes. Glasses use increased over time, but hearing aid use was far more limited. The surveys also found considerably high rates of disability, particularly hearing difficulty, given the harmonised population are under 50 years old; hearing impairment have been estimated globally at 1.4% for children aged 5-14, and 9.8% and 12.2% for women and men respectively, aged >15.[29] The high prevalence of hearing difficulty identified in the LCS wave and described in the organisation's report,[15] may be an effect of its administration by a hearing aid company (SINTEF). Yet the LCS used self-reported screening questions were similar or identical to those used in the other surveys, which found substantially lower prevalences of hearing difficulty, and within 0.3% of each other. However, all waves produced the same overall trends when stratifying vision and hearing difficulty by level and age group.

Surveys with multiple questions on AT allow for some internal validation for AT outcome definitions. The close estimates in the validation checks indicate that approaches 1 and 2 may be used to estimate unmet need with reliable results and demonstrates their utility for further harmonisation work, where similarly discordant data exist. Applying different definitions within the same dataset also demonstrates where variation may be related to the specific AP or functional domain, if a definition does not consistently produce over/underestimates. Including more comprehensive modules on AT will allow more precision in estimates, as well as more opportunities to connect with previous datasets that may be more limited. For example, with the inclusion of a question dedicated to unmet need, the rATA survey can generate more AT outcomes with fewer, or no adjustments necessary.

Though our study is not without limitations, it can contribute to many avenues of future work. We are equating functional difficulty of any level with need for the specific assistive product, which assumes all participants with any difficulty would benefit from the AP. As individuals may not want the AP for personal reasons, or the AP may not address some conditions, this definition may overestimate true need. However, relying on an estimate of potential need is necessary when more nuanced data are not available, and our definition of need for this case study is based on the most inclusive WHO definition of need included in the rATA survey.[12] This definition showed consistency when situating AT outcomes, all of which can be useful harmonising other countries' surveys that use these AT questions. Working with secondary data, we are unable to explain anomalies such as the high hearing difficulty prevalence identified in the LCS. This gap highlights a need for a central space for harmonising data and sharing insights, so anomalies can be identified amongst the coherence of AT research, and investigators can further interrogate their data to understand why. Apart from policymakers planning for population health needs, harmonised datasets can be extremely useful to innovators. If for example the hearing need is shown to be significant or increasing, there is opportunity for innovators to address the market and demonstrate a potentially high demand for hearing products to funders.

Conclusion

The AT sector is characterised by disparate, sparse data, and harmonisation has great potential to address this issue in many contexts. Our investigation tested this potential in Nepal, linking three surveys to be directly compared by the same outcomes and allow some internal validation. More work is necessary to dive deeper into this dataset and test this method in other settings. Yet overall, these efforts will contribute further to the sector-wide call to unify and maximise existing data, to understand population-level needs and gaps, and expand access to AT.

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