#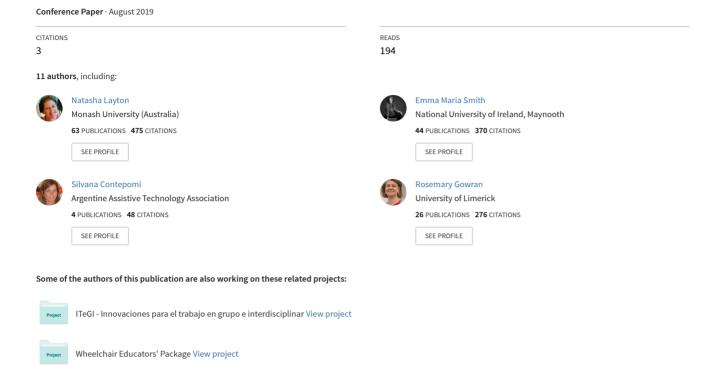 Measuring met and unmet assistive technology needs at the national level: Comparing national database collection tools across eight case countries

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Measuring met and unmet assistive technology needs at the national level: Comparing national database collection tools across eight case countries

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Abstract

The development and implementation of assistive technology policy that meets the needs of citizens is dependent on accurate data collection and reporting of assistive technology use and unmet needs on a national level. This study reviews the methodology from instruments intended to capture national statistics on assistive technology use across eight case countries from varying regions and income levels. Recommendations are provided, which highlight the need for mandatory, census level data collection according to international standards for data collection in the areas of disability and assistive technology.

Keywords

Assistive technology, epidemiology, database, census, data collection

Introduction

The World Health Organization (WHO) estimates there are approximately 1 billion individuals worldwide who require the use of assistive technology (AT) *(1)*. However, meeting individual needs is challenging given the diversity of contexts and commitment to AT provision *(2)*. Furthermore, AT provision is complex and the products prioritized in different settings will vary *(3)*. For example, some countries may experience a higher rate of

certain diseases which require specific AT (i.e. high rates of multiple sclerosis in the northern hemisphere) where other regions may be challenged to provide basic mobility equipment to address the needs of their citizens (i.e. high need for prosthetics and wheelchairs in conflict zones). In order to address these disparate needs on a global scale, it is important to have a full understanding of the current use and need for AT both on a national and a global level.

Accurate, comprehensive, and current data is required on both AT use and unmet need to justify systems investment in AT policy, programs, and spending *(2)*. Understanding prevalence of use, as well as prevalence of need, helps direct funds where they are most needed, and inform program decisions at a national level. Without reliable data on AT use, and unmet and projected needs, planning for and investing in appropriate and sustainable provision is compromised. Furthermore, it may be difficulty to develop systematic and context specific policies, guidelines, and standards with consideration for a systems thinking approach *(2,4)*. This may leave national governments vulnerable to the delivery of inefficient and ineffective services, resulting in poor quality and unaffordable AT. Improving available national statistics provides indicators for context specific planning, evidence for advocacy groups *(5)*, and opportunities to promote cost-effective national procurement methods through bulk purchasing for items of the greatest need *(3)*. These data may therefore enhance equitable access to AT required by all people with disabilities regardless of gender, age, race, or ethnic characteristics *(6)*. Regular data collection also promotes monitoring and reporting on progress of existing or new policies and programs by providing baseline and follow up data to complement additional evaluative measures *(4)*.

The use of data captured on a national level also helps to inform the understanding of regional and global trends. Understanding regional needs may help to promote the use of economies of scale, breadth in procurement programs, and deliver tailored education to the individuals who deliver services to enhance access to AT *(3,7)*. It is therefore necessary to explore some examples of national level AT data collection, to identify the strengths and limitations of existing methodologies, and make recommendations for the future.

Objectives

1. To compare national data collection tools and methods for understanding prevalence of AT use and unmet need statistics across eight case countries from varied regions and income levels.
2. To identify strengths and challenges in the collection of AT data based on the experiences across each of the case countries reviewed.
3. To provide recommendations on national data collection for AT use and unmet need statistics.

Methods

This methodological review compared methods used across eight case countries who have embarked on national data collection of AT use and unmet need statistics through a national census or health and disability database. Representatives who are familiar with

national datasets for each country reviewed and summarized the methodology used for data collection, availability of data, and commented on relevancy for the local population. They were also asked to identify strengths and limitations of the methodology used. Table 1 provides an overview of the topic areas addressed for each national dataset.

Table 1. Topic Areas for Data Collection

Sample Selection	Level (population vs. sample) of data collection. Voluntary or mandatory response. Respondent recruitment/selection. Inclusion of vulnerable groups.
Data Collection	Methodology used. Strengths and limitations for country context. Demographic and socio-economic indicators collected.
Assistive Technology Analyses	Level of analysis for specific assistive products. Relevance of assistive products to in-country requirements. Data collected on assistive product use and unmet need, including reasons for use or unmet need, and barriers to obtaining AT.
Availability of Data	Researcher access to data and process to obtain. Data available to the public and process to obtain.
Strengths and Limitations	Strengths of the methodology. Limitations of the methodology specific to in-country requirements.

Analyses

Country representatives were provided with a set of questions corresponding to the topic areas outlined above and asked to provide information on each of the topic areas. Where multiple datasets were identified, a single primary dataset was identified which was national in scope, with preference given to population level datasets. In the case where no national survey was identified, a dataset of individuals with disabilities was used in lieu. Additional datasets, including other national databases, are identified in the results. Relevant methodological data were collated and reviewed for common and differing approaches, strengths, and limitations. Narrative data provided were reviewed and summarized, providing national examples to illustrate common strengths and limitations. Results are presented by topic area.

Results

Representatives of eight case countries reviewed and provided information on their national datasets. Table 2 provides an overview of the datasets reviewed for this paper, including the name of the data collection tool, agency, population, and AT use and unmet need data. In many cases, additional tools or datasets were identified which are not reported in the table; preference for analyses was given to national datasets which included assistive products in the analyses, or datasets which would provide more robust national data. Additional details regarding the results are presented by topic area. To illustrate key themes or concepts in the results, case countries may be used as examples.

Sample Selection

The majority of datasets report on a sample of the population, with approximately half reporting voluntary responses. Samples were largely selected geographically by household or dwelling. In Canada, the sample was selected based on those who identified an activity limitation in a national census *(8)*. In Argentina, the sample was selected only from households in urban areas of 5000 or more *(9)*. Data from Ireland is presented from an opt-in database of individuals with disabilities *(10)*.

Data Collection

In all cases, methodology included in person (door to door or telephone) interviews guided by a questionnaire or computer assisted data collection tool. In countries where results were not linked to a national census which includes demographic indicators, basic demographic data was captured including gender, age, and education. Varying levels of information were collected regarding disability status or activity limitation; in Colombia, Brazil, and Zimbabwe these data were guided by the Washington Group on Disability Statistics short set of questions, while the Telangana Disability Study in India *(16)* (not reported in Table 2) used the Washington Group extended set *(17)*. The Disability Certification database which is currently being implemented in Colombia (not reported in Table 2) bases activity limitation questions on the International Classification on Disability, Functioning, and Health *(18)*, while the Assistive Technology Bank database, also in Colombia uses the ISO9999:2016 classification *(6)*.

Assistive Technology Analyses

The level of analyses for AT related data varies widely, from no data collected at all regarding the use of AT (Argentina) to over 70 named assistive products across areas of activity limitation (Canada). In general, the categories of AT reflected are broad, without specific mention of individual products, or limited in scope with only a few products mentioned. Reasons for use are identified in the majority of data collection tools which identify AT use. Of those datasets reviewed, very few addresses unmet need for AT, or the reasons for unmet need. Table 2 provides additional details.

Table 2: National Data Collection Tools

Country	Name of Tool* (Date)	Agency Responsible*	Population/Sample; Mandatory/Voluntary; Description (n)**	AT Use Data Collected	AT Unmet Need Data Collected
Argentina	National Study of Profiles of Persons with Disabilities *(9)* (2018)	National Institute of Statistics and Census	Sample; Voluntary; Individuals living in homes in urban areas with over 5000 inhabitants (n=4100)	No.	No.
Australia	Survey on Disability, Ageing, and Carers *(11)* (2015)	Australian Bureau of Statistics	Sample; Mandatory; Individuals living in private dwellings, cared accommodations (n=25 555 households, 1 009 caring establishments)	Type of aid used and reason for use for: hearing aids, mobility aids (specific), guide dogs, orthoses and orthotics, lifts, apps, and communication aids (computer and non-computer based).	Partial: Broad questions on reasons for unmet need, not linked to specific AT.
Brazil	National Health Survey *(12)* (2013)	Brazilian Ministry of Health and Brazilian Institute of Geography and Statistics	Sample; Voluntary; All households (n=63 000 households responding)	Whether AT used for mobility (canes, crutches, wheelchairs, walkers, other), hearing (hearing aids), or vision (glasses, lenses etc.). No specific AT named. Linked to perceived difficulties and activity limitations requiring use.	Partial: Difficulties when using/not using AT.
Canada	Canadian Survey on Disability *(8)* (2017)	Statistics Canada	Sample; Voluntary; Individuals self-identifying with activity limitation in National Household Survey (Census) (n=50 000)	Type of AT used: Over 70 specific AT named in areas of hearing, seeing, moving/bending/reaching/fine motor, learning difficulties, and other. Reasons for use linked to activity limitation.	Yes: AT "need but not have" and reasons recorded.
Colombia	National Population	National Statistics	Population; Mandatory; All individuals (n= unavailable)	Use of specific types of AT: glasses, lenses, magnifiers, canes,	No.

Country	Name of Tool* (Date)	Agency Responsible*	Population/Sample; Mandatory/Voluntary; Description (n)**	AT Use Data Collected	AT Unmet Need Data Collected
	Census (13) (2018)	Administrative Department		wheelchairs, cochlear implants, other. AT not linked to specific activity limitation.	
India	Survey of Persons with Disabilities (14) (National Sample Survey 76th Round Schedule 26; 2018)	National Sample Survey Organization, Ministry of Statistics	Sample; Voluntary; Stratified sampling identifying villages, urban blocks, and households (n=Approximately 384 000)	Partial: Whether AT was advised/prescribed, type of aid, current use. Reasons for use: locomotor, visual, hearing, speech and language, intellectual disability, mental illness, other. List of AT not comprehensive.	Partial: Whether indicated aids acquired.
Ireland	National Physical and Sensory Disability Database (10) (2017)	Health Research Board	Population; voluntary; Opt-in database based on service use/need (n=20 676)	Partial: AT used which is funded by the government is coded. Privately funded AT is not captured.	Partial: Needs captured for funded AT only.
Zimbabwe	Living Conditions Among People with Disability in Zimbabwe (15) (2013)	Ministry of Health and Child Care and Zimbabwe Statistical Agency	Sample; voluntary; Stratified cluster sampling in private households (n= 64 300)	Use and working condition of assistive devices, how device was obtained, training and maintenance, device satisfaction.	Partial: Access needs to AT related social services

Notes: *Names of data collection tools and agencies translated into English where necessary. **Sample sizes may be approximate, based on publicly available data.

Availability of Data

Data is available (or is anticipated) for researchers to access in all countries reviewed. In those countries where data is currently available to researchers, the majority must apply for access to the microdata for analyses through a partnership with a university or a national statistics organization. General data is made available to the population as high-level analyses, as published by the organization who has collected the data. Generally, AT specific data are not included in these high-level analyses.

Strengths and Limitations

The national scope of datasets was identified as the primary strength. When comparing all tools, we identified the lack of consistency of data collection, as a key limitation. Other limitations identified included inadequate sampling and the use of voluntary samples, self-identification of disability status, and inadequate specificity on AT use and unmet needs, including barriers to obtaining AT. We expect substantial variation in data collection methods and available data on AT use and unmet need statistics.

Discussion

In this report, we have compared eight national data collection tools for AT across varying income levels and regions. Overall, we found survey tools to be largely sample driven in lieu of population based approaches. This may lead to sampling frames which are inadequate for specific vulnerable groups, with a higher potential for the resulting dataset to present an incomplete picture of the population. For example, the use of sampling frames often excludes individuals living in group living environments including residential care facilities, where potential AT users, including individuals with disabilities or older adults may be living. Systematically excluding these individuals from data analyses may result in underestimating the prevalence of AT use. This is the case in Canada, where the sampling frame only includes those living in private dwellings. This excludes the estimated 270 000 individuals living in residential care or alternative levels of care, who may be more likely to use assistive technologies associated with functional limitations due to ageing or severe disability *(19)*. Given the increase in use of assistive products with ageing *(20,21)*, excluding these populations likely results in underreporting of AT use. Other surveyed countries, including Colombia, specifically include these groups in the National Census.

In addition to the use of sampling frames which exclude groups based on type of residence, we also found evidence of sampling frames which exclude individuals living in rural or remote areas. For example, the National Study of Profiles of Persons with Disabilities in Argentina included only those living in communities of 5000 individuals or more *(9)*. In some cases, this has been addressed through the use of regional surveys, which may be better suited to capturing the needs in rural and remote areas. In India, the Kerala State Disability Survey was a mandatory census of an entire region, specifically addressing disability and associated needs, both for individuals living in private dwellings, and for those in institutions *(22)*. Regional surveys which capture the entire population may be better suited to

understanding specific needs of the population where a larger national sample is more difficult to obtain.

Sampling frames may also be problematic if they exclude certain vulnerable groups. For example, Australia excludes individuals living in distinct Indigenous or Torres Strait Islander communities. This is concerning as recent statistics suggest nearly half of the individuals in these communities (45.1%) experience a disability and require assistance with activities of daily living *(23)*. Canada also excludes indigenous populations living in reservations. Previous research has found indigenous people in Canada may experience disability at twice the rate as non-Indigenous Canadians *(24)*. Excluding these individuals results in a lack of understanding of the needs of individuals in these areas and may impact service delivery to these vulnerable communities.

We also found samples were largely voluntary throughout the majority of our data collection tools or required self-identification of disability status in order to trigger inclusion in the sample. There is evidence that voluntary samples exclude individuals in marginalized communities, and certain vulnerable groups. To illustrate this, we might consider the evidence that voluntary samples have been demonstrated to underreport data from individuals with lower socio-economic status *(25,26)*. Further, individuals who have poorer health status have been shown to be underrepresented in voluntary health surveys *(25)*. Given the likelihood that individuals who require the use of assistive technologies experience poorer health status than the general population *(27,28)*, and the evidence demonstrating income inequality for individuals with disabilities *(29)*, it is reasonable to assume that the use of voluntary surveys may systematically underrepresent this population.

Registries or databases may provide opportunities for ongoing monitoring and data collection, where national surveys do not meet the need. In Colombia, several databases exist which record and classify individuals with disabilities, and those who have received AT services *(30,31)*. These allow for an ongoing record of individuals who are using or need assistive products and may be a more reliable source of data from groups who might otherwise be excluded from national samples. The same is true in Ireland, where the National Physical and Sensory Disability Database maintains data on individuals who are identified as experiencing a disability *(10)*. However, there are limitations to these databases. First, individuals must have been identified as requiring or seeking services related to their disability. Second, this does not include those individuals who may benefit from the use of assistive products however do not meet the stringent criteria for disability classification. Furthermore, these databases often include only those products which are procured through national insurance schemes, and do not include those products purchased or created by the individual privately.

When considering the AT content in the cases we reviewed, we found a varying level of specificity to identify the types of AT used. In many cases, there were either limited lists of potential AT products, or the categories were so broad as to not provide enough detail to

inform future research or policy. In Zimbabwe, data were collected using open questions across 7 device categories including availability, utilisation, training, maintenance, and satisfaction. This appears to be among the most complex analyses of AT and related services among the countries reviewed. However, very few of the tools addressed details regarding unmet needs and the reasons for unmet need. These are critical components to understand when developing policy and implementation plans, and for advocates in the community.

Finally, we found an effort to use standardized terms and agreements in a number of the tools, including the Washington Group on Disability Statistics questions *(17)*, however there was no universal use of a single framework. As a result, there is little ability to compare data from one country to the next, and in some cases, from one survey to the next, when the frameworks are not used universally across all tools, or in each subsequent survey. The use of a single framework would enhance comparability of the data on a national, regional, and global level.

Limitations

This study was not intended to provide an exhaustive review of all data collection tools used globally to assess use and unmet need for AT. Rather, we used a sample of countries representing varying income levels, government systems, and regions to highlight some of the challenges and successes in national AT statistic collection. We acknowledge the limitations of a sample in this case.

We may also have neglected to include relevant sources of data, including surveys which did not specifically address health and assistive technologies, and information from the military or veterans' organizations which may have differing health coverage.

Recommendations

Based on our analysis, there are several recommendations which we would propose to enhance the collection of national statistics in the area of AT:

1. Data is ideally collected at the population level, within or secondary to a mandatory national census. If secondary to a national census, it is important the data can be linked to demographic and socio-economic indicators collected during the census. Population level statistics are inclusive of all members of society and would acknowledge the use of AT as a universal experience for all individuals at all ages.
2. Where sampling frames are used in lieu of population level data, sampling should not rely on self-identification as a person with a disability and should apply methods or tools which are representative of the population as a whole. Sampling frames must also carefully consider the potential for underrepresentation of marginalized and vulnerable groups and take steps to ensure these groups are accurately represented.
3. Global alignment with a minimum set of questions, including a single classification system for assistive products, would enhance comparability of data. Alignment with the Washington Group on Disability Statistics should be considered, with modifications to the AT related questions to align with the WHO Global Cooperation on Assistive

Technology (GATE) initiative list of the 50 priority assistive products *(1)*. Specifically, an amended set of questions in the Washington Group Expanded Question Set should reflect the variety of AT used across all impairment categories, with notable changes in the areas of communication and cognition.

4. Where possible, researchers should endeavour to gain access to the microdata which does exist in order to publish the data on AT use and unmet need, and clearly identify strengths and limitations within the dataset in their published material. Analysis of microdata allows researchers to identify inequities in the AT provision process, contributing to rationale for adjustment of policies regulating funding and provision models.

Conclusions

National level AT use and unmet need information is not adequately captured by existing data collection tools in the case countries we reviewed. Addressing sampling strategies to ensure the inclusion of vulnerable or marginalized groups and adhering to an international standard for disability and AT related questions will improve our national, regional, and global understanding of the current use and unmet needs for AT. Researchers should also endeavour to make use of the data which does currently exist, by requesting access to microdata to identify trends and inequities in service provision, and ensure this data is available to advocates and policy makers. Increased understanding will contribute to more robust and sustainable policy making and implementation.

Acknowledgements

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