Disability: Measurement, dynamics, and population implications

Results of cognitive interviews to test the translation of international disability measures into three Zambian local languages

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To address to the pressing global need for reliable and comparable disability statistics for both policy and research, the Washington Group on Disability Statistics (WG) has developed a standardized short set of questions (abbreviated as WG-SS) to measure disability, focusing on the functioning in six domains: seeing, hearing, walking, cognition, self-care, and communication (Madans et al. 2011). However, only nine officially validated translations of these WG-SS questions are available on the official website – none of which covers a local African language.

Previous research has compared results from different, nationally representative population surveys in Cameroon that lead to different prevalence levels of disability (Simo Fotso et al. 2019). The nature of the term used (i.e. “disability” vs “handicap”) and the conditions of the interview explain a part of the discrepancy but differences may also result from translation issues from the French or the English versions, the two official languages.

To test the quality of international disability measures, we have translated the WG-SS into three Zambian local languages (Bemba, Chewa/Nyanja, Nsenga) and tested their local validity through 60 cognitive interviews obtained via a quota convenience sample. Cognitive interviewing employs techniques such as probing and thinking aloud to uncover the respondents’ cognitive processes in responding and to identify potential misunderstandings connected to translation. The results of the cognitive interviews will not only inform a survey experiment on the effect of on-the-fly translation on survey data quality, but also provide insights into necessary adaptations for the Zambian context.

What goes behind the 1.4% disability prevalence in Indonesia? An investigation into the perspectives of survey commissioners

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The Indonesian 2020 population census estimated that 1.4% of the population is disabled. This figure is substantially lower than the WHO’s 2022 estimates, which stated that 16.0% of the world’s population lived with some form of disability. (WHO, 2022). This study aims to understand the mechanism behind Indonesian disability statistics through exploring the rationale behind the existing approach to disability measurement, including the instrument used and who commissions disability data collection. Given the limited information available through literature reviews and secondary data analysis, this study examines the perspectives of government institutions responsible for collecting population data through censuses and surveys and for producing official population statistics.

A reflexive thematic analysis was performed on seven key informant interviews from the BPS-Statistics Indonesia (BPS) and the Ministry of Health Indonesia (KEMENKES). This study discusses three themes identified through the analysis: (1) disability as a low-priority and non-central agenda, (2) negotiating power, inclusion and responsibility in disability data collection, and (3) systematic barriers lead to underrepresentation.

This study concludes that disability data collected alongside population and health indicators is a marginal indicator. The inclusion of a disability module across population censuses and surveys aims only to produce disaggregated population data by disability status, reflecting a binary approach to disability. This created greater challenges for researchers and policymakers to understand the disabled population and create programs that target the needs of disabled individuals, since such data is unavailable. This creates a vicious cycle: low disability figures lead to low national priority, which in turn results in poor data collection and further underestimation.

Feasibility research into using administrative data and predictive modelling to produce disability status estimates for England

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Official estimates of population by disability status for England and Wales are produced as part of the decennial census, but there is pressing user need for more frequent, robust disability statistics. This presentation outlines ongoing novel research responding to that challenge by examining the feasibility of producing population-level estimates for disability status in England using a predictive model applied to a suite of linked administrative data.

We have linked several administrative data sources from different government departments, including benefits, education, employment and health datasets. The de-identified data are linked via a population spine – England-based residents on the Office for National Statistics' Statistical Population Dataset.

Machine learning algorithms were used to train a model on a subsample of data from 2021. The outcome variable was Census 2021 disability status. Predictor variables included age, sex, geography and various administrative data variables. The performance of the model was tested and evaluated on a different subsample of the data to that on which the model was trained. Various evaluation metrics were employed to assess model performance, along with predicted and observed disability prevalence rates by socio-demographic characteristics.

Using Spark Machine Learning Library functions and several linked administrative data sources presents a challenge in measuring uncertainty around our predictions. We have explored methods to calculate confidence intervals and provide an indication of the levels of uncertainty. The performance of the predictive model will need to be assessed regularly and to do so we aim to make use of social survey data in non-census years.

Neurodevelopmental disability and child abuse: Evidence from a population-based school survey

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Background: Child abuse is a major societal challenge. Research shows that abuse is unevenly distributed, and children with neurodevelopmental disorders (NDDs) are at elevated risk. However, little is known about exposure in neurodiverse subgroups. Aims: This study (1) assesses victimization among neurodiverse youth compared to non neurodiverse peers and (2) differentiates between specific NDDs. Methods: A population-based sample of 6,721 Norwegian youth (12–16 years; M = 14) completed a digital child victimization survey during school hours and reported whether they had received a NDD diagnosis. Attention deficit/hyperactivity disorder (ADHD; n = 560) and autism spectrum disorder (ASD; n = 109) were identified. The survey covered physical abuse and neglect at home, other victimization (e.g., harassment, psychological abuse), and sexual abuse, offline and online. Fisher's exact test (one tailed) was used to test group differences. Results: Adolescents with self reported NDDs were overexposed to victimization at home and outside the home across most violence and abuse categories. ADHD and ASD were associated with distinct exposure patterns. Youth with ASD (11%) reported less sexual victimization by peers than youth with ADHD (21%), and less online sexual abuse (2%) than adolescents with ADHD (7%) and non neurodiverse adolescents (4%). A similar pattern was observed for less severe physical abuse at home (9% ASD vs. 21% ADHD vs. 20% none). All tests reached statistical significance ($p < .05$). Conclusions: The study adds knowledge about differential exposure to child abuse in specific NDD groups. Future research should reach a broader spectrum of neurodiverse youth with greater functional impairment.