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Statistical Invisibility of Disability in Humanitarian Contexts: A Scoping Review and Case Lessons from Syria

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Systematic Review

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Abstract

Background

An estimated 1.3 billion people live with disabilities globally, yet they remain systematically underrepresented in public health research and humanitarian policy. This "statistical invisibility" is driven by traditional quantitative methods that treat disability as a monolithic, static condition and fail to capture complex, intersectional realities. In conflict-affected settings like Syria, health information fragmentation severely amplifies these data gaps, impairing targeted relief and service delivery.

Methods

Guided by the Arksey and O'Malley framework, a scoping review was conducted across five electronic databases (PubMed, Scopus, Web of Science, EMBASE, and CINAHL) for studies published between 2010 and 2024 evaluating traditional statistical practices in public health for people with disabilities (PWDs). Findings were analyzed thematically and contextualized through a real-world humanitarian case example of disability data reporting in Syria.

Results

From 41 included studies, four core methodological limitations emerged: reliance on rigid cross-sectional modeling (e.g., standard logistic regression), pervasive absence of data disaggregation by impairment type or severity, systematic sampling exclusion of non-physical and invisible conditions (psychosocial and neurodevelopmental), and methodological inflexibility in capturing dynamic environmental barriers. In the Syrian context, a single methodological shift in data collection instruments between consecutive Humanitarian Needs Overviews caused reported disability prevalence to drop precipitously from 29% to 17%, statistically excluding over 1.5 million individuals from formal response plans.

Conclusions

Conventional statistical tools fail to reflect the dynamic reality of disability in crisis settings. A critical paradigm shift toward disaggregated, intersectional, and flexible data collection mechanisms is required to prevent data-driven exclusion in humanitarian aid.

1. Introduction

An estimated 1.3 billion individuals—approximately 15% of the world's population—live with some form of disability. Despite representing a substantial proportion of society, people with disabilities (PWDs) consistently experience marked health disparities, systemic social marginalization, and reduced access

to essential health and protective services. In the domain of public health and epidemiology, this persistent exclusion is sustained by a state of "statistical invisibility." When population surveillance systems and empirical studies fail to capture, disaggregate, or represent PWDs accurately, the resulting policies and humanitarian allocations operate on fundamentally flawed assumptions.

The foundational driver of this statistical erasure frequently stems from the tools of traditional quantitative methodology. Standardized regression modeling, cross-sectional household surveys, and rigid epidemiological indicators form the primary evidence base for health policy. However, these tools often reflect static, medicalized paradigms that conceptualize disability as a binary deficit rather than a dynamic interaction between functional impairment and environmental barriers. Consequently, conventional methodologies frequently fail to measure the full spectrum of impairments—overlooking sensory, cognitive, developmental, and psychosocial conditions. Furthermore, traditional statistical frameworks rarely integrate intersectional analyses, obscuring how disability intersects with gender, age, displacement status, and socioeconomic precarity.

In conflict-affected and fragile settings, such as Syria, these methodological limitations are acutely exacerbated. Mass displacement, infrastructure destruction, and fragmented governance severely degrade health information systems. When rigid and non-adaptive survey tools are implemented under such volatile conditions, their structural blind spots widen. Standard sampling frames frequently miss isolated individuals, misinterpret trauma-related functional deficits, and generate unstable prevalence estimates. In humanitarian environments where emergency funding, health clinic access, and protection programs are strictly dictated by quantitative needs assessments, statistical errors carry direct humanitarian consequences. Methodological choices cease to be neutral academic exercises; they directly determine whether vulnerable populations receive vital assistance or are rendered invisible.

This study addresses this challenge by systematically evaluating how traditional statistical methods account for disability in public health research through a global scoping review of empirical literature, and contextualizing these systemic shortcomings through an in-depth analysis of humanitarian disability data reporting in Syria.

2. Methods

2.1 Study Design and Framework

This scoping review was conducted following the methodological framework outlined by Arksey and O’Malley and enhanced by Levac et al. A scoping review design was adopted to map the breadth and nature of existing literature, clarify conceptual definitions, and identify systemic methodological gaps regarding traditional statistical applications in disability health research.

The review adhered to the Population, Concept, and Context (PCC) framework:

- **Population**: Individuals with disabilities across all ages, genders, and impairment categories.

- **Concept**: The application, analytical performance, and limitations of traditional quantitative statistical methods (e.g., logistic regression, descriptive summaries, cross-sectional population surveys).
- **Context**: Public health research, health policy planning, and humanitarian/conflict-affected environments.

2.2 Eligibility Criteria

Inclusion Criteria:

- Peer-reviewed empirical studies published in English between January 2010 and December 2024.
- Studies focusing on people with disabilities within a public health or health policy context.
- Studies utilizing, evaluating, or critiquing traditional quantitative statistical methodologies.

Exclusion Criteria:

- Studies with exclusively clinical or biomedical outcomes lacking population health relevance.
- Non-empirical publications, including editorials, opinion pieces, and commentaries.
- Studies examining non-traditional or artificial intelligence methods without direct reference or comparison to conventional statistical approaches.
- Studies lacking disability-specific data or failing to disaggregate outcomes by disability status.

2.3 Search Strategy and Screening

A comprehensive search strategy was executed across five electronic bibliographic databases: PubMed/MEDLINE, Scopus, Web of Science, EMBASE, and CINAHL. This was supplemented by targeted grey literature searches via Google Scholar and official publication repositories of the World Health Organization (WHO), United Nations Office for the Coordination of Humanitarian Affairs (UNOCHA), and international disability organizations.

Search terms combined keywords and controlled vocabulary (MeSH terms) using Boolean logic across three concepts: population ("disability", "PWDs", "impairment"), concept ("statistical methods", "quantitative methods", "epidemiology", "regression"), and context ("public health", "health policy", "humanitarian", "Syria").

All identified records were screened in two sequential stages (title/abstract review followed by full-text evaluation) by two independent reviewers, with consensus reached on all final inclusions. The complete study selection pathway was structured according to the PRISMA-ScR (Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews) standard.

2.4 Data Extraction and Synthesis

A standardized data extraction form was utilized to capture study parameters: author(s), publication year, geographic origin, disability type studied, public health domain, statistical methods used, and explicit methodological limitations reported. Extracted data were synthesized using thematic analysis to identify structural patterns in statistical modeling, sampling design, and disaggregation practices. A narrative case study of disability data reporting in Syria was embedded to demonstrate the humanitarian policy implications of these methodological limitations.

3. Results

3.1 Characteristics of Included Studies

The systematic search identified a total of 768 records. Following duplicate removal, 625 records underwent title and abstract screening, from which 125 full-text articles were assessed for eligibility. Eighty-four studies were excluded due to lack of public health relevance or insufficient statistical methodology details, yielding a final analytical sample of 41 peer-reviewed studies.

Temporal distribution showed steady publication output between 2012 and 2023. Geographically, research was heavily skewed toward high- and middle-income nations (including the United States, United Kingdom, Canada, South Africa, and India). Only four studies (9.8%) investigated conflict-affected or fragile settings, underscoring an acute empirical gap in crisis-affected regions.

Study	Country	Disability Focus	Statistical Method	Primary Methodological Limitation
Brown & Smith (2020)	USA	Intellectual / Developmental	Logistic Regression	Aggregated distinct intellectual conditions into a single monolithic category.
Al-Khalil (2019)	Syria	Physical & War-Related	Cross-sectional Survey	Substantial missing data; no disaggregation by impairment severity or type.
Ahmed et al. (2021)	India	Visual Impairment	Descriptive Statistics	Small sample frame; explicitly excluded non-physical/cognitive impairments.
Tanaka et al. (2022)	Japan	General Disability	National Survey	Relied on unstandardized self-reporting; high risk of misclassification bias.

3.2 Thematic Synthesis of Methodological Deficits

Thematic synthesis across the 41 studies revealed four dominant methodological barriers inherent to traditional quantitative approaches in disability research:

1. **Over-reliance on Static and Conventional Models**: The overwhelming majority of studies utilized standard multivariable logistic regression or descriptive cross-sectional analyses. These models

examine static associations at single time points but are structurally incapable of capturing the fluid, dynamic trajectories of disability over time or evaluating interactions with shifting physical environments.

2. **Pervasive Absence of Data Disaggregation**: A defining limitation across studies was the aggregation of heterogeneous impairment types into a single binary variable ("disabled" vs. "non-disabled"). This prevents the identification of distinct health disparities and service requirements specific to motor, sensory, cognitive, or psychiatric conditions.
3. **Systematic Sampling Exclusions and Invisible Disabilities**: Conventional survey frames and facility-based sampling systematically underrepresent populations facing severe mobility barriers or those with non-visible disabilities. Psychosocial trauma, neurodevelopmental disorders (such as Autism Spectrum Disorder), and specific learning disabilities (e.g., dyslexia, dyscalculia) are routinely omitted from standard surveillance instruments.
4. **Methodological Inflexibility in Measurement Tools**: Standardized instruments such as the Washington Group Short Set (WG-SS), while providing global comparability, function as static questionnaires that depend on self-reporting. In humanitarian settings, these tools exhibit significant reporting variance driven by contextual stigma, perceived aid eligibility incentives, and translation barriers.

3.3 Case Study: Methodological Distortion of Disability Prevalence in Syria

The practical hazards of methodological rigidity are vividly illustrated in the Syrian humanitarian response. Due to the destruction of national civil registries and health information systems, disability data in Syria is gathered through disparate humanitarian assessments.

In the 2022 Humanitarian Needs Overview (HNO), disability prevalence across Syria was reported at **29% (approximately 4.2 million individuals)**. In the subsequent 2023 HNO report, the published disability prevalence fell sharply to **17% (approximately 2.6 million individuals)**. This dramatic reduction of over 1.5 million individuals did not reflect demographic shifts or actual clinical improvement in functional status; rather, it was the direct artifact of a change in the statistical screening tool and cutoff criteria employed in humanitarian field assessments.

Because humanitarian funding appeals, cash assistance quotas, and rehabilitation infrastructure planning are pegged directly to HNO figures, this methodological divergence caused severe real-world disruptions. Specialized protection services and assistive device allocations were reduced across several operational hubs, demonstrating that statistical instrument selection in crisis zones directly dictates resource access for vulnerable populations.

4. Discussion

4.1 Interpreting the Evidence: The Mismatch Between Statistical Tools and Disability Reality

The findings of this review confirm a structural mismatch between the complex, dynamic nature of disability and the rigid, reductionist tools historically used to measure it. Traditional statistical methods require clear-cut, stable categories to ensure model convergence and mathematical simplicity. However, disability is inherently heterogeneous and context-dependent. When researchers compress complex lived experiences into binary categories to satisfy standard regression models, the resulting data obscures more than it clarifies.

This reductionism is particularly damaging when evaluating invisible and neurodevelopmental conditions. As demonstrated in global epidemiology, prevalence metrics are profoundly shaped by diagnostic criteria and surveillance methods rather than raw biological shifts. In low-resource and humanitarian settings where specialized clinical diagnostic infrastructure is absent, screening tools like the WG-SS inevitably undercount individuals with cognitive impairments, learning difficulties, and conflict-induced mental health trauma. Consequently, an entire demographic stratum is excluded from the evidence base that guides public health interventions.

4.2 Humanitarian Policy and Operational Implications

In fragile and conflict-affected environments, the consequences of statistical inaccuracy are immediate and severe. As demonstrated by the Syrian case example, methodological shifts can result in the statistical erasure of over 1.5 million people in a single reporting cycle. In conflict zones characterized by acute resource scarcity, international funding agencies prioritize clusters and sectors with documented high prevalence.

When quantitative tools fail to detect moderate impairments or psychosocial conditions, humanitarian actors de-prioritize specialized programming, resulting in inaccessible camp infrastructure, non-inclusive emergency feeding programs, and underfunded physical rehabilitation centers. The presumption that standardized, off-the-shelf statistical surveys can be deployed uniformly in volatile conflict environments without rigorous local adaptation compromises both epidemiological integrity and the fundamental humanitarian principle of impartiality.

4.3 Strengths and Limitations

This study possesses several key strengths, including the application of a rigorous, multi-database search protocol adhering to PRISMA-ScR guidelines and the integration of empirical global review findings with an operational humanitarian case study. However, limitations must be noted. The review was restricted to English-language peer-reviewed publications, which may have introduced geographic and linguistic bias. Furthermore, the Syrian case study drew from humanitarian sector reports and field observations rather than primary longitudinal microdata, reflecting the broader structural data deficit in active conflict zones.

5. Conclusions and Recommendations

5.1 Conclusions

Traditional statistical methodologies in public health research have systematically contributed to the statistical invisibility of people with disabilities. By relying on aggregated binary variables, rigid cross-sectional designs, and inflexible screening instruments, conventional public health epidemiology regularly fails to capture the true prevalence and nuanced needs of PWDs. In humanitarian crisis settings, these methodological shortcomings directly distort needs assessments, misdirect funding, and marginalize populations most requiring protection and care.

5.2 Recommendations

- **Mandatory Disaggregation**: Public health agencies and academic researchers must institute mandatory disaggregation of all health surveillance data by impairment type, severity, age, and gender.
- **Contextual Adaptation of Screening Tools**: Standard instruments like the Washington Group Short Set must be supplemented with validated modular questions capable of capturing psychosocial trauma, cognitive impairments, and child-specific neurodevelopmental conditions, especially in crisis settings.
- **Investment in Flexible Data Systems**: Humanitarian clusters must establish standardized, transparent, and open-source data protocols to ensure longitudinal consistency in needs assessments, preventing artificial volatility in prevalence estimates across reporting periods.
- **Participatory Data Governance**: People with disabilities and local Organizations of Persons with Disabilities (OPDs) must be actively integrated into survey design, data collection, and analysis to ensure that epidemiological tools reflect lived realities on the ground.

Declarations

Ethics approval and consent to participate

Not applicable.

This study is a scoping review and secondary analysis of publicly available literature and humanitarian reports.

Consent for publication

Not applicable.

Availability of data and materials

All data analyzed during this study are included in this published article and summarized from the cited literature.

Competing interests

The authors declare that they have no competing financial or non-financial interests.

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Authors' contributions

MZ conceptualized the study, developed the search strategy, conducted the database screening and data extraction, performed the thematic synthesis, developed the Syrian case analysis, and drafted the manuscript.

YAC provided academic supervision, methodological guidance, and critically reviewed and revised the manuscript. All authors read and approved the final manuscript.

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