Disability and Assistive Technology in Population-Based Data

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Summary

This article aims to describe the data types and accompanying methods that are commonly-used to estimate disability prevalence in a population. These estimates are often commissioned by policymakers to scale supportive measures, and innovators to describe addressable markets to funders. To represent a population (as well as smaller sub-groups that comprise it), data are collected from thousands of individuals. Given the time and cost of collecting population-based data, surveys will use simplified, quantitative measures to approximate more complex social and health statuses. These data are by necessity reductive, which has implications for their use, particularly when informing decision-making that affects people with disabilities. Understanding the limitations and uses of these data types is crucial for situating and comparing evidence, and not over- or misinterpreting research employing data that incompletely represents the population in question.

Each data type has its uses and limitations in estimating disability prevalences, particularly in the study of healthy aging. To employ them most effectively, they should be used as directly as possible, and in connection with each other. To estimate how many people in a country are simply ‘disabled,’ an investigator will have many compromises to make. Perceiving disability prevalence from health record and registry data employ a medical model of disability, described as the presence or absence of specific conditions, or further interpreted into weighted disability-adjusted life-years (DALYs) and healthy life expectancies (HLEs). Data collected from wearable sensors, or digital AT, can also have representation pitfalls with respect to adoption, particularly in low-resource settings. Functional assessments draw more from the social model by allowing space for the individual to self-report difficulties and barriers in-context. Disability identity must further be studied separately, and considered with how disability is being discussed in evidence.

In any case, existing biases in resource allocation decisions and perception of disability will be amplified by inconsiderate application of AI and datasets that are not contextualised, misrepresentative, or misinterpreted. Population-based assistive technology (AT) data provide a useful entry point to more directly estimate support needs for a population without necessitating a blanket disability estimate or assuming individual needs from a specific diagnosis. Forecasting with these data further support aging populations, which have dynamic needs that must be anticipated to be met. Improving evidence to this aim will necessitate identifying and collating existing population-based AT datasets; harmonising surveys to create multi-wave datasets to observe trends; identifying factors associated with transitions to need for AT; and producing forecasts that maximise different data types, with consideration for the limitations associated with each, to further evidence-based decision-making to expand access to AT. Reframing research to move away from monolithic disability prevalence estimates towards (for example) the timing of certain needs in the life-course, or sociodemographic factors associated with unmet needs, will improve the precision, utility, and meaning of evidence in this space.

I. Disability and aging

The global increase in disability prevalence is substantially driven by population aging.[1] Populations initially age as fertility levels slow and decline, and the proportion of working-age and eventually older individuals increases, while further population aging is driven by more people living longer lives.[2] Longer life expectancies are themselves associated with increases in prevalences of disability due to the onset of age-related comorbidities.[1,2] The concept of 'healthy aging' focuses on maintaining functional ability and preventing or delaying disability onset with aging. In these terms, disability is often equated to health and defined by clinical assessments, with the magnitude of age-related, chronic diseases frequently defined in terms of 'years of health and life lost'[3] in population health research. These concepts are related, but not transposable. How disability is estimated and understood in a public health context will vary by data collection method, source, and assumptions/thresholds applied by investigators.

Individuals experience aging and disability very differently. Disability at older ages is not evenly distributed, for example women tend to live longer than men and experience a greater prevalence of morbidity and disability,[2] as personal behaviours and environmental exposures that are gendered, such as diet and employment type contribute to this variation.[4] Disability prevalence is also bidirectionally related to socioeconomic status (SES),[5,6] with prevalence variation shown across household economic status/income[7,8] and education.[9–11] Supportive measures at older ages are also unequally distributed. For example, the complex relationship between gender, disability, and socioeconomic support is intensified where women's labour force participation rate remains below that of men, women generally receive lower pension benefits in most countries.[2,9] Further, gender and socioeconomic inequalities in accessing health care[12,13] and using assistive technology[14] are also present globally and impact these associations.

Disability prevalence estimates are used to scale support needs for a population, evaluate policies and interventions, and understand the changing demand for products or services. However, presence or absence of disability is inferred from a variety of data types, thresholds, and assumptions, which are often insufficient to reach these aims, especially when used in isolation. These data types originate from different understandings of disability, namely medical and social models, which affect how disability is conceptualised and effectively treated in discussion. To appropriately support populations with dynamic needs, disability representation in population-based datasets must be better understood and contextualised.

II. Perceived measures

Perceived measures are applied to a population by an investigator. These measures typically rely on the clinically assessed presence of a specific condition or pathology, or a threshold for a critical level of disability, to assign disability in a population. Population-level datasets using perceived measures of disability are based in a medical model of disability, wherein disability and health are mutually exclusive concepts, the avoidance of disability is a desirable outcome, and that disability should be 'fixed.'

Health record data can inform on the prevalence of certain disabling conditions. However, disability prevalence estimates based on these data are subject to diagnosis availability and result in ascertainment bias; in settings where diagnostic services are sparse, individuals are less likely to engage with health institutions, or facilities are inaccessible, reported prevalences will be lower. Support needs are often approximated from these data alone, which does not consider individual environmental and social contexts, which can make a supportive intervention ineffectual.

Registries for disabling conditions are also used to inform perceived measures of disability prevalence.[15,16] Registries often exist where individuals must be signified as disabled to receive specialised support,[17] but registering can be prohibitively difficult and requires individuals to acknowledge their own support need as significant. Importantly, registry data have also been used to surveil and discriminate against marginalised groups, fostering well-founded concern about modern registries, exacerbated by data privacy violations.[18,19] All of these factors will bias estimates based on registry data towards underestimating the true prevalence of many disabling conditions, especially where impairments are less severe,[20] or stigma is widespread.

Perceived measures are applied to data from these sources to approximate the 'burden' of disabling conditions. Disability-adjusted life years (DALYs) quantify 'years of healthy life lost to disability,' while quality-adjusted life years (QUALYs), a complimentary concept, denote the 'years of healthy life lived.'[21] Both measures are widely used to make resource allocation decisions. Each state of health is assigned a weighted value from 0 (perfect health) to 1 (death), with pathology-specific weighting. The weighting is determined by a panel of 'experts'[22] using two trade-off questions to allocate resources. The Global Burden of Disease report describes how a disability weight is derived in part from the first question:[22]

> *"…if the [panellist] judges that 1000 healthy people would have an equal claim on the resources as 8000 people with some severe disability, the weight assigned to that particular disability is equal to 1 minus 1000 divided by 8000, or 0.875."*[22]

The second question asks the panellist how many people cured of a certain disability to be equal to prolonging the lives of 1000 people. Arnesen et Nord provide an example, and point out the issue of forced constancy across these questions:[21]

> *"Assume that a panellist, on ethical grounds, responds that extending the life of 1000 sighted people and 1000 blind people is equivalent. The resulting disability weighting for blindness is zero. Assume that in the second question the panellist answers that relieving 5000 people of blindness is as valuable as prolonging the lives of 1000 people. This gives a disability*

weighting of 0.2. The valuation so far has yielded two different disability weightings for the same health state."[21]

The final weight is an average of these two weights. To then simulate the burden of a certain condition in a population, or estimate the value of a proposed public health intervention, the weight is multiplied by the number of years lived with that condition in the population, and added to the number of years lost due to that condition. By design, DALYs define disabled lives as less valuable than non-disabled lives, that disabled people have less claim over resources than non-disabled people, and that evaluating interventions by DALYs avoided would deprioritise supporting those with disabilities that would not be alleviated by the intervention. Though ethical and methodological issues have been thoroughly discussed,[21,23,24] these measures are still widely used in global public health, often through the Global Burden of Disease study[25–27] and cost-effectiveness evaluations.[28]

Healthy life expectancies (HLEs) are summary measures used to characterise a population's health, calculated as the years lived with disabling conditions subtracted from the total years lived.[29] This measure can be used to calculate when a certain condition normally hits in the lifespan of individuals in a population, and how many years are lived with it. However, when this measure is adapted to disability to calculate disability-free life expectancy, it relies on a rigid premise:[30]

> *"Disability-free life expectancy is a type of HLE that reflects the presence or absence of a disability. The weight of the level of dysfunction is classified as 0 (absence of disability) or 1 (presence of disability), wherein a disability is handled in the same manner as death."*[30]

As the disability-free life expectancy assesses health on a binary scale of disability, it is not sensitive to differences in the health levels of a population group.[30] The disability-adjusted life expectancy (DALE) is a further HLE index that reflects disability measurements in terms of DALY weights, which allows more nuance than disabled or not disabled. However, it relies on DALY weighting assumptions.

Digital assistive technology for disability (also called mobile health or mobile rehabilitation) can be used to collect data on the prevalence of disability and develop personalised interventions for disabled people. Though disabled people are already using wearables to track many aspects of their health, they use them less than their non-disabled peers).[31] Many applications are based on the idea of data classification – "the act or process of dividing things into groups according to their type" for personalisation – "the process of making something suitable for the needs of a particular person."[32] The idea of wearables being able to classify different impairment types has been demonstrated in fields as diverse as the classification of dementia phenotypes,[33] identification of pain,[34] and classification of wheelchair pushes.[35–37] Sensors are now routinely embedded into lower limb high-end prosthetic devices to share data on use (and possible component failure) with the manufacturers and multinational information and communications technologies (ICT) companies have developed whole proprietary health platforms (e.g. Apple

HealthKit, Google Fit, Samsung Health) to securely collect, visualise and automate reports on health metrics and health-related activity.[32] Despite claims that such embedded sensor technology is at the forefront of a technology healthcare revolution,[38] there are ethical concerns on how data is collected and used. This is of particular concern to those who might not consider themselves disabled and for whom technologies often look to normalise their behaviours rather than build on their abilities. For example, a recent review of ICT-based research for the autistic community found little overlap with the research priorities of the community the technology purported to serve, instead, technologies were being developed to normalise autistic people's behaviour.[39]

III. Self-reported measures

Self-reported data on disability often take the form of functional assessments, wherein individuals are asked about difficulty experienced when during specific activities. In self-reported functional assessments, the participant tells the investigator how disabling a condition is in the context of their daily life. These assessments reflect an important component the social model of disability, in that individual's physical and social environments and barriers affect functioning.[40] Functional assessments are often used in population surveys, as clinical assessments at the same scale would be costly, time-consuming, and require clinicians, who are often scarce in low resourced settings. Functional assessments do not require an individual to identify as being disabled, which is especially salient among older age groups in terms of personal identity,[41] or in stigmatising contexts in terms of disclosing. Further, these assessments can more easily take into account the use of assistive technologies (AT).[42] Functional assessments don't directly mention disability or clinical diagnoses, and so seek to create an international standard that circumvents a degree of misreporting that would come from stigma, variations in perception of disability, and ascertainment bias. Several types of functional assessments are widely used.

Activities of Daily Living (ADLs) aim to measure functional independence, focusing on tasks related to self-care and safely maintaining quality of life.[43] ADLs are examined in clinical assessments and are often integrated into older-age population cohort studies, allowing the study of changes in functioning that accompany aging.[44] Basic/physical ADLs include ambulating, feeding, dressing, personal hygiene, continence, and toileting. Instrumental ADLs (IADLs) further assess more complex thinking skills, including transportation and shopping, managing finances, preparing meals, housecleaning, managing communication, and managing medications. I/ADL assessments are intended to determine whether an individual may require further rehabilitation, assistance at home, or situation within a long-term care facility.[43] Ultimately, it is a task-based functioning assessment, which directly ties an activity with a need for support, and does not necessarily rely on a threshold of disability definition.

The UN's Washington Group on Disability Statistics developed question sets for functional assessments as a quick and low-cost way to collect functional assessment data, designed for integration in existing national data collection.[45] The question sets comprise (among others) a short set (WG-SS), an extended set (WG-ES) and a child functioning module (WG-CFM) for children under five,[46] for whom a specialised functioning module is more appropriate. The short set is the most commonly implemented tool and includes six questions on difficulties in seeing, hearing, mobility, communication, cognition, and self-care, asking individuals to report levels of difficulty for each category from 'none', 'some', 'a lot', to 'cannot do at all.' The Disability Data Initiative reports on which countries have integrated WG sets into routine national data collection, including censuses and demographic health surveillance surveys, and report as of 2023, 70 countries have used the WG-SS set in at least one wave of national data collection, while 77 countries have used other functioning questions.[47] These sets have also been integrated in international surveys, such as the UN Multiple Indicator Cluster Survey (MICS)[48] and the WHO Rapid Assistive Technology Assessment Survey (rATA).[49]

The International Classification of Functioning (ICF) developed by the WHO is a "standard language and framework for the description of health and health-related states,"[50] which is can be used in clinical practice, support services, education, policy, advocacy, and population statistics.[51] The ICF characterises disability as something a person with a health condition or impairment experiences, depending on the barriers they face in their daily life, and emphasises that disability is dynamic, situational, and can change should the environment become more enabling.[52] For its multifaceted conception of disability, the ICF constitutes the biopsychosocial model.[5] The Model Disability Survey (MDS), a stand-alone general population survey informing on many aspects of functioning,[45] maps to the ICF.[52,53]

Functional assessments are not without limitations, as they are subject to self-report bias, and can be difficult to communicate without any language around disability. Mactaggart et al (2016) identify that functional assessments can estimate a higher prevalence of needs than clinical thresholds, noting that "tools to assess reported functional limitation alone are insufficient to identify all persons with participation restrictions and moderate or severe clinical impairments," and finding that a self-reported functional assessment tool, followed by a clinical assessment, was most effective in identifying disability in a population.[54] Yet with respect to scaling support needs in a population, functional assessments can relate more directly to specific supports, compared to an assumption that the same needs apply across all individuals with a specific disabling condition.

Reported difficulties can be more directly linked to need for a supportive measure, like a mobility assistive product for climbing steps, or personal assistance for showering. However, individuals' social and physical needs and environments still challenge this assumption.

IV. Disability identity

It must be noted that self-identifying as disabled is not present in any data type mentioned so far. Identifying as disabled is motivated by uncountable individual factors, and is not by itself sufficient to plan resource allocation. However, it is useful to study the correlation between other thresholds defining disability with self-identification. This is particularly relevant at older ages, where individuals don't renegotiate their identity to include disability, but who more often experience changes in functioning which would constitute disability.[41] The England Country Capacity Assessment for Assistive Technology (CCA) surveyed disabled individuals specifically, and so provided several measures by which a participant could indicate their eligibility to participate to accommodate varying perceptions of disability.[55]

V. Disability misrepresentation

The persistent use of uncontextualized measures of disability in population data limits the representation of disability in society and subsequently our capacity to appropriately resource support among populations with diverse, dynamic needs. Disabled people may be over/underrepresented in certain cases, for example mild-moderate vision impairment in registry data;[20] ineligibility of disabled people to enrol in population cohort studies;[42] or individuals with intellectual and communication disabilities may have difficulties providing self-reported data in the absence of adapted survey modules[56,57] (resulting in the common use of proxy responders, which can be more problematic when used with subjective measures).[58] It can also be challenging for an investigator to reach disabled people in population-based data collection and achieve a representative dataset. For example, in the context of general population household surveys, sign language interpreters may be needed if deaf individuals have low literacy rates due to school exclusion, or stigma can prompt the hiding of disabled children from surveyors. Institutionalised individuals are often not accommodated for in the design of the survey data collection.

Decisions based on unethical, misconstrued data will yield unethical, misconstrued results, if the data origin and context are not considered in the decision-making process. For example, using DALYs in cost-effectiveness decision-making models assigns higher priority to interventions that reduce the most DALYs, though disabled individuals cannot have their DALYs fully reduced. The DALY approach effectively lowers the value of life-extending programmes for disabled people compared to corresponding programmes for nondisabled people.[21,23,24]

Misrepresentation and inconsiderate decision-making patterns will be amplified by machine learning algorithms, which are increasingly used in resource allocation decision-making at the population-level. Trewin et al (2019) describe how their use has implications for disabled people, especially with respect to employment, education, public safety, and healthcare, and that in many existing situations, non-AI solutions are already discriminatory.[59] Informing models with misrepresentative data and introducing AI risks exacerbating these flaws. Trewin *et al.* thus emphasise the need to gather inclusive data with confidentiality and privacy, advocate for increased awareness of biased patterns to avoid replication in future decision-making and test the final model with diverse users (particularly those deemed as outliers).[59]

With respect to creating a dataset based on wearables or digital AT, the adoption of such technology by the disabled community is more complicated than applications designed for non-disabled people. This is due in part to the heterogeneity of disabled people and disability classification. Further, 80% of the disabled population live in low-resource settings,[60] which introduces issues such as insufficient language and image data sets within many of these communities. The Technology Amplification Theory states technology alone does not create resources, it simply amplifies effects already present in society,[61] and has been used to explore the differential motivations of technology adoption within the disabled community, especially in low-resource settings. Estimates derived from digital AT data collection in these settings must take account of, for example, differential access to technology (e.g. ownership of a suitable smartphone, internet connectivity, and language spoken); differential capacity to use technology (e.g. literacy, availability of support, understanding of how technology works); and differential motivation to use technology (e.g. life experiences, willingness to risk, perceived benefit),[62] when assuming representation for decision-making. For example, a recent analysis of the Google Relate application adoption in Ghana found that challenges in language (i.e. speaking English, and in a pattern of diction which represents American or British English), data consumption, functioning speed, contextual understanding, and ease of use prevented full adoption.[62]

In a 2020 report analysing lawsuits arising from the use of algorithm-driven systems to assess people's eligibility for, or the distribution of, public benefits, Brown et al explore how these tools "have used faulty and unreliable data, added eligibility criteria not required by law, and produced results based solely on disability diagnoses (i.e. expected needs typically associated with a diagnosis) rather than a person's actual needs," further highlighting that systems relying on algorithm-driven needs assessments inhibit beneficiaries to challenge those decisions.[63]

Harmful decisions in resource allocation will be made where assumptions are not explicit and definitions are overinterpreted. Some data types described require fewer assumptions to generate evidence to scale supportive measures. Interpreting needs from a functional assessment is more straightforward than from a prevalence of a clinical diagnosis. Evidence for supportive measures that touch the social realm needs to map to the social model, to ensure the data are being used to answer questions that do not require overinterpretation of what evidence the data are able to provide.

VI. Assistive technology & access to it

To fulfil the need to scale and distribute resources for aging populations, measures of access to assistive technology (AT) provide a practical alternative to disability prevalence estimates. AT includes the assistive products help maintain or improve an individual's functioning related to five domains (cognition, communication, hearing, mobility, self-care and vision), as well as the related systems and services for these products.[64] AT is a critical support for independence, participation, and longevity.[2,14] An individual is considered to have access to AT if they report their AT needs are met. Gaps in AT access can be indicated in part by having and using AT, in lieu of self-reported data on met or unmet needs, which are typically used to indicate an individual has AT access.[14,65]

Though increasingly present in population-based datasets,[42] the AT dataspace has many gaps and challenges. Private providers and manufacturers of AT often occlude the dataspace. Problems affecting the generalisability of disability prevalence estimates can further affect AT indicator estimates if they are only collected among people subset by a perceived measure of disability. However, AT modules are also often incorporated alongside functional assessments in population-based surveys, which can allow for an understanding of AT need in a population that is independent from perceived disability measure pitfalls. Their alignment with functional assessments like the Washington Group Questions facilitates their integration with routine data collection that already use functional assessments.[47] User-centred design in accessibility and AT spaces are also based on the principle that individuals are reliably the best judge of their own needs,[66] and so further draw from the social model to deliver more value at an individual level.

The need for AT correspondingly increases with population drivers like aging, highlighting the importance of forecasting to anticipate and meet dynamic AT needs. AT indicators in population datasets are a useful entry point to target support for aging populations as they avoid many assumptions that come with data and evidence based on the medical model of disability. Generating forecasts with AT indicator data, to anticipate and meet supportive needs of dynamic populations, is an urgent public health priority. Doing this well requires considerate use of data representing people with disabilities in population health, with attention to the ethical and methodological limitations when collating evidence for decision-making.

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