

Administrative data have been suggested as a means to analyze the prevalence of disability as well as for disaggregating outcomes, such as employment or poverty, by disability status. These are related but different issues that this blog addresses.

Administrative data contains information considered necessary for running and monitoring government programs, and thus reflect the requirements and characteristics of those programs. These programs may be disability specific, such as a disability pension system, but they can also be general programs not primarily related to disability but collecting information relevant to disability issues, such as education management information systems. Many of the issues we will discuss apply to both types of systems but not all.

Our first question is, can administrative data be used to track the prevalence of disability? In order for this to be the case a number of conditions must hold. If they don't, then the number of people identified as having a disability will not only be an undercount but will not be a representative group of people. That is, the breakdown of their characteristics (e.g., gender, income, urban/rural) may not reflect the breakdown of the full population of people with disabilities.

- 1) **Knowledge of program.** For administrative data to collect data on people with disabilities in a complete and unbiased way, the program must be universally known. This can sometimes be a challenge, especially for people with disabilities that impede their ability to communicate. This applies both to programs targeted and not targeted at disability where it is necessary to apply for the program. It is less of an issue for programs that are more universal, such as education management systems which cover all children in the school. However, it is possible that persons with disability may be less likely to be included in these programs such as not being enrolled in school.
- 2) **Decision to apply.** People with disabilities have to decide if they want to apply for a particular program whether it is to obtain disability related benefits or for other objectives. For disability programs, this means they have to perceive themselves as having a disability and also perceive the benefits from being certified as worth any costs – including possible stigma or work disincentives that are built into some disability programs. And sometimes the benefits are quite low and therefore may not be seen as worth the effort. Older people with disabilities may not want to apply because old age benefits are similar or better to disability benefits and a person cannot receive disability benefits on top of old age benefits. Decisions to apply are less of an issue for more universal programs but could still affect whether persons with disability are included in the program.
- 3) **Ability to apply.** Often there are barriers to applying for benefits. These can be related to transportation, communication or cognitive difficulties. It can also be related to how well the program is run, which may differ by geographic area.
- 4) **Disability determination criteria.** It is important to note that information on disability status included in administrative records are a function of how disability is defined for that program. Eligibility for disability certification is closely related to program

objectives and often varies across programs. The definitions used often vary across programs as they reflect the specific intents of the individual programs. For example, eligibility is often linked to ability to work, and so excludes people with disabilities who are employed. In some cases, eligibility may be related to age or income and thus leave out part of the population that would be considered to have disability. The definitions of disability in administrative data may thus not match the definitions used in non-administrative databases such as surveys. For programs that are not targeted to disability, there can be program related features that influence on how disability is identified.

At each of these four stages, people with disabilities can be excluded from administrative data, and in a non-random way. This seriously undermines the usefulness of administrative data for prevalence estimates. Some people have suggested putting the Washington Group questions on the intake forms of all administrative data systems whether targeted to disability or not. This would address the issues surrounding program specific eligibility criteria but prevalence rates would still not represent the total population with disability if not all those who would be considered to have a disability by standard criteria would apply to the program on which the administrative system is based.

Using administrative data for disaggregation by disability status would need to meet the same conditions as for prevalence but there are added requirements, as well. Disaggregation requires that information on the outcome of interest (e.g. poverty, educational level, employment) be included in the data system and that it be possible to compare those with and without disability on these characteristics.

For programs that are not targeted to disability, it would be useful to see how many program participants have a disability and how they are faring. For example, UNICEF and UNESCO have both been working to improve the collection of disability related statistics in Education Management Information Systems (EMIS). The outcome characteristics of interest, e.g. attendance and grade progression, are included in these systems making it is possible to disaggregate these outcomes by disability status. As noted above, the limitation, however, is that there is data only on people in the programs. For instance, an EMIS can tell you nothing about the children who are out of school. A survey is needed for that. Also, while disability status might be very important to a school system or health care system, and so included in their administrative data, it is less relevant for other purposes – for example, administrative data on marriage certificates or land ownership. While it would be useful to have a survey to study the impact of disabilities on marriage land ownership, it might seem intrusive to have to answer these disability questions for every interaction with the government, when the government's role in the program has little to do with a person's functioning. Unlike some characteristics, like birth date, it is necessary to update information on disability, as functioning is not a static state. This adds to the reporting burden. The administrative burden of asking these questions on a continual basis may not be worth the payoff relative to what can be obtained via an occasional disability survey.

Programs targeted to persons with disability do not include data on people without disabilities, so disaggregation is not possible. Many outcomes of interest may also not be included in these systems. While it possible to generate the percent of the population getting benefits from these systems, these systems would need to be linked to other systems for disaggregation purposed. As noted above, the definition of the population with disabilities will be tied to the requirements of the specific program and may not include all persons with disability based on more standard definitions.

Interest in administrative systems as a less expensive source of statistical information is growing. Before current systems are used for estimating the prevalence of disability or to disaggregate on disability status it is necessary to understand how a given system generates disability data and whether it meets the criteria outlined above. Moving forward, work is needed to develop administrative systems that will be appropriate sources of information on disability.