

**Working Paper 32: The Use of Administrative
Data in Disability Inclusive Policies**

Daniel Mont





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Center for Inclusive Policy and UCL International Disability Research Centre

Abstract. This article reviews the purposes of data collection and the strengths and weaknesses of administrative data. It makes recommendations as to how administrative data can best be used to further the goals of the CRPD and make societies more inclusive.

Introduction. The widespread ratification of the Convention on the Rights of Persons with Disabilities (CRPD) has been followed globally by a concerted effort to promote policies that break down the barriers that exclude people with disabilities from participating in society. Developing such policies requires timely, accurate data. Moreover, it is important to match the uses of data to the appropriate method of data collection. For over a decade, a great deal of international effort has been directed towards improving the quality of disability data derived from censuses and surveys. As a result, both the quantity and quality of available data on disability has been increasing. At the same time, many countries have also been using administrative data as another source of information. In fact, some countries have considered administrative data on disability to be a potential substitute for census and survey data.

This article reviews the purposes of data collection and the strengths and weaknesses of administrative data. It makes recommendations as to how administrative data can best be used to further the goals of the CRPD and make societies more inclusive.

The Purposes for Data Collection. Data can be used for four main purposes when it comes to public policy: justification, development, monitoring, and evaluation.

1. *Justification.* Data can demonstrate the nature and scope of problems that should be addressed by public policy. When it comes to policies related to the CRPD, this means measuring prevalence of disability and patterns within that prevalence (e.g., by age, gender, region of residence, etc.). Beyond prevalence, it also includes demonstrating gaps in outcome indicators by disability. These gaps (e.g. in education, health, employment, and poverty) provide evidence that barriers exist that create exclusion.
2. *Policy Development.* Data to justify policies tells us something needs to be done, but not what actions should be taken. For policy development, data on the nature and extent of barriers to inclusion are needed, for example the factors associated with a disability gap in employment. Is it mostly due to a lack of accessible transportation and workplace accommodations, or is it more rooted in discrimination, or exclusion from education, or the unavailability of assistive devices? Are there differences for sub-populations of people with disabilities?
3. *Monitoring.* After a policy is developed, it must be implemented. Monitoring systems can collect data on whether the required inputs are being allocated (e.g., financial and human resources), whether the intended outputs are being created (e.g., structures, training manuals, etc.), and whether transfer payments and/or services are being delivered.
4. *Evaluation.* The final use for data is to determine whether policies are having their desired effect. Primarily, in the case of the CRPD, whether the disability gaps in outcome indicators are being lessened, and the extent to which this is being done in a cost-effective manner.

Administrative versus Survey Data on Disability

Administrative data are data routinely collected on an ongoing basis as part of operating and managing a government program. As such, they contain 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 (EMIS) or Health Management Information Systems (HMIS).

There are several advantages to administrative data, namely:

1. *Sustainable.* Budgeting for administrative data is generally part of program delivery. As long as a program exists, data will be available. In addition, administrative data is usually cheaper to collect than surveys because it is included in program administration.
2. *Timely.* Administrative data is usually collected on an ongoing basis, so unlike surveys (and especially censuses) there are generally no time gaps in data collection. However, it should be noted that because data often needs to be processed there can be lags as to when that data is available.
3. *Universal for program recipients.* There are no issues related to sampling or sample sizes because all people being served by a program are necessarily included in the data.

4. *Less response error on programmatic data.* For example, administrative data on service delivery is probably more likely to record exactly the amount and nature of benefits received – and when they were received – than a person responding to a questionnaire.
5. *Ministry owned.* Agencies are sometimes more willing to accept and act upon data that they are collecting themselves and that they are familiar with, as opposed to a survey conducted elsewhere, especially if it is not conducted by the government but by independent researchers.

However, relative to surveys they also have several disadvantages. These include:

1. *Definition of disability is often program based.* There is a difference between a person being eligible for disability benefits and being considered to have a disability when it comes to the CRPD. For example, eligibility for a disability benefits may be means-tested, targeted only to a working-age population, or only meant for people with severe disabilities.
2. *Less detail on non-programmatic data.* Because of the burden on administrative staff, administrative systems tend to only collect data that is of direct use in program administration. Therefore, less information is collected on personal and household characteristics and factors outside the program.
3. *No data on people not receiving services.* To enter an administrative data base, a person must be receiving services (or at least has applied for services). Thus, people's experiences that are not in a program are unavailable.
4. *Not representative.* A result of point (3) is that since people are systematically excluded from administrative data, the data are not representative of the entire population.

Sometimes there are ways to lessen the problem of the lack of data on people not in a program by linking administrative data sets. For example, in Armenia, children who are identified as having a disability for the purposes of disability benefits are automatically entered into the EMIS (Armenian Ministry of Education, 2019). Thus, the EMIS has records of children who are out of school, where they live, their type of disability and other information. However, this does not completely solve the problem because there are no data on children with disabilities who are neither in school nor in the disability benefit system. And of course, to take this approach requires a universal identifier in order to link records across administrative systems. Also, for the purposes of disability, if different systems have a different definition of what constitutes a disability, it may not be possible to link data on people with disabilities across systems.

Data quality on disability in administrative systems

Of course, when using any type of data, the quality must be assessed. Are the data concepts clearly defined? Are they directly relevant to the purpose for which they will be used? However, with administrative data two further issues arise. First, if particular data fields are not used routinely in the administration of a program there may be little incentive for that data to be collected accurately, even at all, and even if collected the data may not be processed or cleaned. Thus, while it might appear that such data exists when looking at administrative forms, in actuality it may not be usable.

Second, 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, and will probably not be re-collected it does not have direct relevance to program administration. Thus, collecting data on disability status in

an administrative data system for a program that does not directly deal with disability will probably yield out of date information. 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 which is able to include wider and more detailed indicators.

Data for Policy Justification

As mentioned earlier, measuring disability prevalence and the patterns of prevalence is a key aspect of justifying action on inclusion. Another key aspect is using that identification of people with disabilities to disaggregate outcome indicators by disability status to document outcome gaps that are indicative of exclusion. In the past, censuses and surveys have primarily been used for these purposes. The problem with censuses is that they are often conducted every 10 years and because they are expensive to implement, tend to collect a limited amount of information. Thus, recently there has been more emphasis on survey data. Because of the cost of collecting survey data and its intermittent nature, however, administrative data have been suggested as a means to estimate the prevalence of disability as well as for disaggregating outcomes by disability, such as employment or poverty. This raises a series of questions that must be addressed if administrative data is to be used for issues of disability prevalence and patterns of prevalence.

The first question is, can administrative data be used to obtain the prevalence of disability, and thus for examining the patterns of prevalence by other personal or family characteristics? 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) will not reflect the breakdown of the full population of people with disabilities.

The following issues are relevant for administrative systems generated by program that require the individual to apply:

- 1) **Knowledge of program.** For administrative data to have records 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 persons with a disability in cases where it is necessary to apply for the program

Lack of knowledge can be a major barrier. Data from two states in India, for instance, show that over 90 percent of people with disabilities in 2007 were unaware of the national disability rights law and almost half of people with disabilities were unaware that education stipends were available (O'Keefe 2007).

- 2) **Decision to apply.** People with disabilities have to decide if they want to apply for a particular program to obtain disability related benefits or other types of benefits. For disability targeted 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. 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 than disability benefits and a person cannot receive both types of benefits simultaneously. 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.

In Vietnam, for example, survey and census data show that most people with disabilities have a moderate level of functional limitations, but data from the disability registry shows a much higher percentage of people with a disability certificate have more severe functional limitations (UNICEF and Vietnam General Statistical Office, 2018). Qualitative data has shown this is because the benefit levels for people qualifying at the lowest level of Vietnam's three-tiered benefit structure, receive very little, making it not worthwhile for them to apply (Vietnam Ministry of Labor, Invalids, and Social Affairs (2017).

- 3) **Ability to apply.** Often there are barriers to applying for benefits. For people with disabilities these can be related to transportation, communication or cognitive difficulties. More generally, they can also be related to how the program is structured and how well it is run, all of which may differ by geographic area or various personal characteristics (Kidd, 2017).
- 4) **Disability determination criteria.** Information on disability status included in administrative records for disability-targeted programs is a function of how disability is defined for that program with disability certification closely related to program objectives. As a result, disability certification criteria and the information used to determine disability status often varies 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 or even in other administrative data systems. For programs that are not targeted to disability, there can be program related features that influence how disability is identified.

At each of these four stages, people with disabilities may be excluded from administrative data in a non-random way. This seriously undermines the usefulness of administrative data for prevalence estimates. Some people have suggested including the Washington Group questions on the intake forms of all administrative data systems whether targeted to disability or not. The Washington Group, formed by the UN Statistical Commission, has developed and tested a set of survey questions that have been widely recommended by the UN Statistical Division for use in censuses and many other international agencies for use in surveys for the purposes of identifying people with disabilities (Groce and Mont, 2017). Including these questions on administrative forms would address the issues surrounding program specific eligibility criteria but prevalence rates would still not represent the total population with disabilities if not all those who would be considered to have a disability using the Washington Group questions would apply to the program on which the administrative system is based.

Using administrative data for disaggregation indicators such as the Sustainable Development Goals (SDG) 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. Making those comparisons is not possible for disability-specific programs that do not have data on non-disabled people, even if the outcome indicators are included.

For programs that are not targeted to disability, collecting data on disability would be useful to know 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 EMIS's. The outcome characteristics of interest (e.g. attendance and grade progression,) are included in these systems making it possible to disaggregate these outcomes by disability status. As noted above, the limitation, however, is that there are data only on people in the programs. 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 disability on marriage or land ownership, it would be intrusive to have to answer 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.

Overall, administrative data is generally not well suited for estimating the prevalence of disability in the population, or in disaggregating SDG or other indicators to identify disability development gaps.

Data for Policy Development

Administrative data can be useful for policy development in that it can be used to correlate disability gaps to program characteristics. For example, a survey can demonstrate at a national or regional level that there are gaps in educational attendance between children with and without disabilities. But if an EMIS uses the same definition of disability as the survey used to estimate the percentage of children with disabilities in the entire population, policy analysts can correlate the gap between the expected and actual number of students with disabilities with detailed information on the school – the training of teachers, the accessibility of structures, the availability of services, etc.

For example, the Fiji EMIS (FEMIS) collects detailed data on the disability status of its students and school characteristics (Mont and Sprunt, 2019). During parent-teacher conferences, teachers note what services or accommodation the child needs. When there are accessibility or service gaps, those are noted in the EMIS with an estimate of the cost of providing them. The EMIS can then report how many children have disabilities, what their needs are, what needs are not being met, and what the cost of meeting all those needs would be. This type of information is very valuable for identifying gaps in policies and programs that may be undermining the education of children with disabilities (Mont and Sprunt, 2019).

The FEMIS example could be extended to other administrative data systems. For example, if a country is considering expanding its services to people with disabilities, questions about the types of assistance they need – including those that are currently not part of the program or even related to eligibility for the program – can be included. These data can then be used to plan for the expansion of services, or maybe a change in the type of services provided. Currently, a number of countries are considering using

the International Classification of Functioning as the basis for disability determination¹. These data, that include information on the types of difficulties people have in daily activities and the environment they live in, can be used in this manner.

Administrative data can also reveal how well services are being delivered in a variety of ways. For example, if records show that a much higher rate of applications for disability benefits by men are approved than for women with the same type of disabilities, this may indicate some form of systemic discrimination against women's applications. A study by Sightsavers using the Washington Group questions in their administrative data found gender differences in how Sightsavers's service delivery was working. Sightsavers delivers services in two types of locations – in the community and at a nearby hospital. From their administrative data they learned that while women with disabilities were equally likely to receive services as men at the community location, they were less likely to get them at the hospital². They concluded there were gender-related barriers to service delivery at the latter type of location.

Because of its universal coverage of program participants, the size of administrative data sets may enable questions to be answered that are difficult using survey data. For example, what is the relative impact of a general vocational training program on people with and without disabilities? In a household survey the number of people with disabilities having participated in a particular vocational training program would most likely be small – especially if there was interest in differences in outcome by type of disability. However, if a general vocational training program identified their participants' disability

¹ <https://www.who.int/classifications/icf/en/>

² <http://www.washingtongroup-disability.com/washington-group-blog/everybody-counts-2/>

statuses, they could see if program outcomes differed for people with and without disabilities. It should be noted that comparing outcomes of people in a program versus not in a program requires a different approach, as will be explained in the evaluation section below.

The use of administrative data for policy development is made more powerful if information on people's functional limitations is collected in the same manner as in the surveys, namely based on a functional approach consistent with the bio-psychosocial model of disability that informs the Washington Group Questions (Altman 2016). That is not to say that the programmatic definition of who is eligible for programs needs to change, only that the data being collected includes such information. Being able to link information in the two forms of data allows for insights into how those in the administrative data sets differ from the general population.

Data for Monitoring and Evaluation

Clearly, administrative data is the appropriate data source for monitoring the implementation of a policy. It records what resources are used and what outputs are produced. To be consistent with the CRPD and the goal of inclusion, those data sets should contain information on whether those inputs involve people with disabilities – as employees or contractors – as well as whether the outputs are fully accessible, both in terms of physical accessibility but also informational accessibility for people with hearing, vision, or cognitive difficulties.

The main goal of public policies, though, is outcomes. Does a policy actually lessen exclusion by closing the gaps in social and economic outcomes between people with and without disabilities? Monitoring is

the first step. Before a program can be evaluated to see if it worked, it first needs to be determined if the program did what it said. To see if a policy of building accessible schools increases the enrolment of students with disabilities, it should first be determined if those schools were actually built and built properly. But to determine if the outcomes that were hoped to arise from those outputs occurred several conditions must be met. Without proper attention to the administrative data in the project management system, we do not know if we are actually evaluating a completed policy. One doesn't want to discard a teacher training program that doesn't improve student outcomes, because very few teachers were actually trained. Maybe if they were trained, the program would have been effective.

For a true evaluation one also needs a baseline from which to make a before/after comparison. Also needed, is a proper control or comparison group. To isolate the impact of a program, a comparison must be made between those with access to a program and those without such access. For example, vocational training program graduates might do better than people not in the program not because the program was effective, but because the most motivated, capable people decided to apply and were able to participate in the program. Therefore, the outcomes of people in places with and without access to the program must be compared. For this reason, administrative data would not be useful for evaluating outcomes if it does not contain data on people not covered by a program or a policy. It can only be used to evaluate the impact on outcomes, if a program is rolled out to a portion of the population, with the construction of an appropriate comparison group. Administrative data can always be used, though, to evaluate the process of implementation – but that is more of a monitoring function.

Conclusion

Interest in administrative systems as a less expensive source of statistical information is growing.

Administrative data is very valuable for a number of purposes, but not all. Care should be taken in choosing the appropriate source of data for the desired purpose. In particular, administrative systems can usually not be used for estimating the prevalence of disability or to disaggregate on disability status. In order for it to do so it needs to define disability in a way appropriate for the way prevalence estimates and disaggregated data are used. In addition, knowledge of the program, its accessibility, and its value to people with disabilities should be such that it is nearly universal in coverage. Administrative data can be used for other purposes related to policy development, implementation and evaluation. To maximize the effectiveness of those data, using a consistent approach to identifying disability consistent with the CRPD can allow for linkages across administrative data systems and with survey and census data in a way that can increase the power of all the data collected.

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