

Disability Data: Survey and Methods Issues in Latin America and the Caribbean

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This working paper is being published with the sole objective of contributing to the debate on a topic of importance to the region, and to elicit comments and suggestions from interested parties. This paper has not gone through the Department's peer review process or undergone consideration by the SDS Management Team. As such, it does not reflect the official position of the Inter-American Development Bank.

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Summary

Collecting reliable data on disabilities is difficult throughout most of Latin America and the Caribbean (LAC). In many countries, collection is sporadic, and fluid definitions between surveys and countries make comparisons difficult. Surveys that include disability questions frequently fail to cover the entire sample population, resulting in small sample sizes that make statistical analysis unreliable. Without reliable, comprehensive data on disabilities, an opportunity is missed to gather data on the changing dynamics among people with disabilities. This, in turn, limits the development of effective programs of inclusion and restricts efforts to develop and monitor appropriate public policies.

Based on disability data derived from more than 70 national household surveys, this study aimed to 1) analyze disability prevalence and participation of persons with disabilities in the labor-force and educational system and 2) identify key methodology issues that future surveys should address in order to improve the quality of the data collected. Analysis was based primarily on data taken from household surveys conducted in Brazil, Costa Rica, and Nicaragua because—unlike many countries in the region—these three included disability questions in their household surveys. While disability data from eight other countries (Argentina, Bolivia, Chile, Honduras, Mexico, Panama, Peru, Uruguay) was presented, it was either too limited or the sample sizes were too small to permit in-depth analysis.

In Brazil and Costa Rica, disability questions were included in labor and health modules. Labor-module questions focused on reasons for not working (having a disability was one of several response categories), while health-module questions asked respondents to identify the type of disability they had and, in some cases, how it affected their ability to perform daily activities. In the case of Nicaragua, a separate module on disabilities was included. Of all the household surveys reviewed for this

study, Nicaragua's 1993 household survey was the only one that contained a separate disabilities module. Responses generated from that module's questions, which were asked of the entire sample population, well illustrate many of the methodology issues that arise in conducting disability surveys—poorly worded questions and definitions, shrinking sample sizes, loss of respondents between questions, and a high percentage of missing values.¹

This study underscores the poor quality and paucity of disability questions reflected in most LAC household surveys to date, as well as the need to move toward region-wide consensus on the types of disability data that should be collected as a basic minimum.

¹ The Social Information System (SIS) of the Inter-American Development Bank's Research Department, using various household surveys, was the information source for all tables presented in this study. For all tables, the percentages reported were based on weighted cases, while raw numbers represented number of cases.

Analysis of Disability Prevalence

Prevalence of disabilities was examined, using disability-related questions taken from household survey modules on labor and health.

Labor-module Questions

The typical labor-module questions highlighted in Box 1 were usually asked only to respondents who were not currently employed. *Question A* was specific in its attempt to identify reasons

why the respondent was not employed. *Question B*, on the other hand, focused more on the respondent's perception of his or her social function, and disability status competed with a variety of roles that the respondent may have considered more important. For example, a woman with a disability might consider her social and economic role as a housewife, rather than her physical condition, more relevant to her identity.

Box 1. Typical Labor-module Questions

A. You did not work during the last week (month, 3 months, 12 months) because of...?

Choice of response: vacation, waiting to hear back on a job opening, work at home, studies, pension, waiting to start job search, doubt of getting a job, family problems, illness, disability, other

B. Do you consider yourself pensioned, student, housewife, less than six years of age, or disabled?

Table 1 summarizes the data obtained from *Question A* in four countries (Chile, Mexico, Panama, and Peru) where “disability” was included in a response category. The analysis was restricted to individuals between the ages of 25 and 55 to exclude students and the elderly. This data could be interpreted to suggest that, for

people between the ages of 25 and 55, an average of 11.3% of currently non-employed men and 1.8% of non-employed women have a disability. However, this conclusion would be incorrect because the countries used different response categories upon which to base their statistics.

Table 1. Respondents Who Selected “Disability” as Reason for Not Working

Country	Year	Respondents Who Selected “Disability”		Missing Values (%)	Total No. of Respondents (ages 25-55)
		(%)	No.		
Men					
Chile	1998	14.61	806	53.68	4,763
Mexico	1996	15.06	127	--	858
Panama	1999	12.17	94	--	672
Peru	1997	3.54	7	42.44	210
Women					
Chile	1998	3.52	849	8.37	22,605
Mexico	1996	1.06	59	--	6,478
Panama	1999	1.22	50	--	4,186
Peru	1997	1.46	18	5.69	1,195

Several factors complicated response comparisons. First, countries used different proxies for “disability” in the response categories. While Mexico and Panama based their statistics on the “disability” response category, Peru used “disabled and elderly” as a single-response category (controlling for the effect of age by restricting results to those 55 years of age or younger), and Chile used “illness or elderly” as a single-response category. Second, the questions covered different time periods, which also affected the validity of the data (e.g., “Why didn’t you look for a job in the last couple of months?” versus “Why didn’t you look for a job in the last week?”). Third, variation in the number of responses further complicated comparisons because of the likelihood of violating the assumption of independence of irrelevant alternatives, which is critical in analyzing multiple responses. In Chile’s household survey, “disability” represented one out of 10 possible responses, while in Mexico’s survey, it represented one out of 17. The assumption of independence of irrelevant alternatives would require that the number of possible reasons for not working remain constant.²

Overall, the proportion of men who reported a disability was much higher than the proportion of women. This difference could result from the questionnaire’s wording. In many cases, non-employed female respondents reported that they were not working because of household responsibilities. A certain percentage may be women with disabilities who perceive that their household commitments, not their disabilities, are the primary reason for not participating in the formal labor market.

Responses to *Question B* (which required self-characterization) revealed a similar gender trend—that is, more men than women classified themselves as disabled (Table 2). While responses to *Questions A and B* might appear to provide the same type of information, they may also reproduce the same biases that could account for women’s low disability-prevalence levels. Having “housewife” and “disabled” as categories of response to the same question was particularly problematic. Another major constraint in these modules was the high percentage of missing values (more than 42% in Peru and nearly 54% in Chile).

² While it is beyond the scope of this study to extensively analyze the statistical implications of the assumption of independence of irrelevant alternatives on the data, the authors recognize that Tables 1 and 2 contain data based on questions with varying response categories and numbers of choices.

Table 2. Respondents Who Selected “Disabled” To Classify Themselves

Country	Year	Respondents Who Selected “Disabled”		Missing Values (%)	Total No. of Respondents (Non-employed, Ages 25-55)
		(%)	No.		
Men					
Argentina	1996	4.59	180	69.25	3,122
Bolivia	1999	7.54	13	52.53	157
Costa Rica	1998	16.79	109	37.21	563
Honduras	1999	16.83	39	--	239
Uruguay	1998	17.27	146	--	844
Women					
Argentina	1996	0.94	102	15.78	11,138
Bolivia	1999	1.64	13	20.87	839
Costa Rica	1998	2.25	208	4.35	4,818
Honduras	1999	1.38	29	--	2,338
Uruguay	1998	3.17	125	--	4,077

Health-module Questions

Unlike the questions asked in the labor module, health-module questions were not limited to

non-employed respondents, but were asked of the entire sample population. Health-module data was available from three countries: Costa Rica, Brazil, and Nicaragua (see Box 2).

Box 2. Typical Health-module Questions

**Brazil,
1981**

Qual a deficiência ou incapacidade que tem?

What is the deficiency or disability that you have?

**Costa Rica,
1998**

Alguna de las personas de este hogar presenta una o varias deficiencias que le impidan o dificulten permanentemente, realizar sus actividades cotidianas?

Does anyone in this household have one or more disabilities that permanently prevent or challenge him or her from performing daily activities?

**Nicaragua,
1993**

Tiene algun problema sensorial, actor, mental, tales como:

Do you have any sensory, movement, mental, or other problem, such as:

Differences in the characteristics of the countries selected and questions used made it difficult to assess the merits of the health module as a disability data source. From the data available, it is unclear whether the gender differential in disability prevalence changed according to the module used (labor or health). In Nicaragua, more women (20.3%) reported having a

disability than did men (17.1%), while in Brazil and Costa Rica, gender differences were not as marked (Table 3). Further analysis is needed to determine whether the high prevalence reported in Nicaragua reflects differences in the sampling frame, wording of the question, or the long-term effects of civil war.

Table 3. Summary of Responses to Health-module Question in Three Countries

<i>Country</i>	<i>Survey Year</i>	<i>Those Who Responded "Yes" When Asked If They Had a Disability</i>		<i>Total No. of Respondents (Ages 25-55)</i>
		<i>%</i>	<i>No.</i>	
Men				
Brazil	1981	2.36	1,757	76,583
Costa Rica	1998	6.09	517	8,049
Nicaragua	1993	17.12	592	3,312
Women				
Brazil	1981	1.46	1,189	82,841
Costa Rica	1998	5.76	484	8,314
Nicaragua	1993	20.30	727	3,657

Labor-force Participation

Given the relative completeness of survey data from Brazil, Costa Rica, and Nicaragua, these three countries were used to analyze labor-force participation. As Table 4 shows, in Brazil, 25-55-year-old men with disabilities have

dramatically lower employment levels than do their counterparts without disabilities. This differential is not as pronounced in Costa Rica, and, in Nicaragua, there is almost no difference in employment level by disability status (73.7% with versus 78.5% without).

Table 4. Comparison of Male Employment (with and without Disabilities) in Three Countries (Ages 25-55)

<i>Country</i>	<i>Year</i>	<i>% Employed</i>	<i>No. Employed</i>	<i>Total Sample Population</i>
With Disabilities				
Brazil	1981	42.68	728	1,757
Costa Rica	1998	70.54	368	517
Nicaragua	1993	73.67	451	592
Without Disabilities				
Brazil	1981	93.33	69,471	74,826
Costa Rica	1998	94.42	7,118	7,532
Nicaragua	1993	78.53	2,190	2,720

Table 5 shows that the pattern of labor-force participation varied more among women. Brazil had the largest differential in employment rates between women with and without disabilities. In Nicaragua, the percentage of employed women with disabilities was slightly higher than the percentage of employed women without

disabilities (46.9% versus 42.6%). In Costa Rica, 37% of women with disabilities reported that they worked, compared to 45% of their counterparts without disabilities. However, one should note the enormous differences between samples.

Table 5. Comparison of Female Employment (with and without Disabilities) in Three Countries (Ages 25-55)

<i>Country</i>	<i>Year</i>	<i>% Employed</i>	<i>No. Employed</i>	<i>Total Sample Population</i>
With Disabilities				
Brazil	1981	15.60	186	1,189
Costa Rica	1998	36.81	168	484
Nicaragua	1993	46.91	319	727
Without Disabilities				
Brazil	1981	39.00	33,032	81,652
Costa Rica	1998	44.90	3,328	7,830
Nicaragua	1993	42.65	1,219	2,930

Analysis of Educational Achievement

Survey data from Brazil, Costa Rica, and Nicaragua was also used to analyze levels of educational attainment. In these three countries, men with disabilities were less likely than their counterparts without disabilities to have received an education. This differential was particularly

pronounced among those with no education. In Brazil, for example, nearly 44% of men with disabilities reported having received no schooling, compared to about 22% of men without disabilities. As Table 6 shows, this differential was largest in Costa Rica (13% versus 3.4%).

Table 6. Comparison of Educational Levels among Men (with and without Disabilities) (Ages 25-55)

Country	Year	Level of Schooling Attained								Total Population	
		None		Primary		Secondary		Post-secondary			
		No.	%	No.	%	No.	%	No.	%	No.	%
With Disabilities											
Brazil	1981	739	43.60	765	43.29	209	11.00	39	1.97	1,757	100
Costa Rica	1998	69	12.95	302	56.67	92	18.72	53	11.54	517	100
Nicaragua	1993	213	33.01	234	40.61	93	16.36	52	10.02	592	100
Without Disabilities											
Brazil	1981	14,815	21.88	35,421	49.11	17,752	21.16	6,495	7.54	74,826	100
Costa Rica	1998	318	3.44	4,014	48.75	2,092	29.83	1,053	17.98	7,532	100
Nicaragua	1993	785	26.73	1,049	40.17	690	25.96	196	7.15	2,720	100

As Table 7 illustrates, educational attainment levels for women with and without disabilities were similar to those of men. At all schooling levels, women with disabilities demonstrated less achievement than their counterparts without disabilities. However, in Nicaragua and Costa Rica, the differential by disability status at the

primary-school level was small or non-existent. Levels of educational attainment appear relatively similar to the data on men, except in the case of Brazil, where the proportion of women with disabilities who had no schooling was markedly higher than the corresponding percentage for men (56% versus 44%).

Table 7. Comparison of Female Educational Levels (with and without Disabilities) in Three Countries (Ages 25-55)

Country	Year	Level of Schooling Attained								Total Population	
		None		Primary		Secondary		Post-secondary			
		No.	%	No.	%	No.	%	No.	%	No.	%
With Disabilities											
Brazil	1981	648	56.05	410	33.67	115	8.93	16	1.35	1,189	100
Costa Rica	1998	79	15.67	260	51.38	91	20.55	50	11.65	484	100
Nicaragua	1993	269	34.58	302	42.96	129	18.56	27	3.89	727	100
Without Disabilities											
Brazil	1981	18,748	25.34	37,976	48.21	19,256	20.72	5,295	5.73	81,652	100
Costa Rica	1998	298	3.04	4,099	48.85	2,322	31.12	1,083	16.98	7,830	100
Nicaragua	1993	856	25.98	1,170	42.94	737	25.28	167	5.80	2,930	100

Nicaragua's Disabilities Module: 1993

Of the household surveys reviewed for this study, Nicaragua's 1993 household survey is the only one that contained a separate module on disabilities. Questions in that module were asked of the entire sample population. The responses generated from that module's questions on the types and causes of disability illustrate the problems involved in collecting data on disabilities.

Concerns with General Questions

The data presented in Table 8 are based on responses to the question: "*Do you have any sensory, movement, or mental problem, such as...?*". The responses would suggest that the

percentage of people reporting some type of disability increases with age. Using the data based on responses to that question, nearly 12.4% of the population would be classified as having a disability. However, by not defining what constitutes a "sensory," "movement," or "mental" problem, the question's wording permits an overly wide range of responses. For example, a respondent with a slight hearing problem or one who uses a hearing aid could be classified as having a disability, along with a respondent who is deaf.

Table 8. Percentage of Respondents with Disability, by Age, Nicaragua 1993

<i>Age</i>	<i>% "Yes"</i>	<i>Total Sample Population</i>
Under 15	4.16	1,609,303
15-25	7.17	619,033
26-35	10.02	440,770
36-45	21.35	291,416
46-55	40.04	177,626
56-65	48.44	118,673
66-75	58.14	71,873
76-85	67.39	35,005
86-95	75.20	8,113
Over 95	71.81	1,611
Total	12.42	3,373,423

To obtain more specific information on their disabilities, respondents were asked two questions: The first required them to identify their type of disability (e.g., blindness or deafness), and the second asked them to describe the extent of that disability (e.g., blindness in one or both eyes) (Table 9). The added clarity provided by the response to the second question

illustrates the need for a series of questions that allows individuals to specify the type and extent of their disability. In addition, broad, descriptive questions on disability should be linked to the individual's ability to function in a variety of spheres, including home and work; otherwise, the disability's effects cannot be determined.

Table 9. Specific Type of Physical Disability Reported, Nicaragua 1993

<i>Disability Type</i>	<i>Cases Reported (No.)</i>	<i>Respondents with Disability (%)</i>
Hearing	277	9.61
Speech	100	3.79
Sight	1,896	63.08
Movement	153	5.13
Deformity	93	3.38
Mental	131	4.04
Attacks or Convulsions	124	4.67
Hearing and Speech	14	0.71
Various	185	5.58
Total Population	2,973	100.00

Table 10 shows that more than 58% of those who reported having a sight disability had problems seeing when they did not wear glasses. From this statistic, it cannot be assumed that these individuals had a disability. Conversely, only 1% reported complete blindness and 3% blindness in one eye. Similar trends were found among those with hearing and speech problems. For example, while 9.6% of the sample reported having a hearing disability, only 5.8% of this group reported complete deafness. Data on speech problems was the least disaggregated; that is, of the 3.8% who reported having a speech disability, 90.8% reported having some

difficulty, without giving further details (Tables 9 and 10).

The issue is thus one of definition; that is, were there people with slight visual problems who did not have a disability, or were there people with serious visual difficulties who could not obtain glasses? Given the range of potential visual problems, a sharper definition of *visual disability* is needed. Moreover, in employment surveys, the more refined definition should be linked to functional capacity.

Table 10. Extent of Specific Types of Disabilities Reported, Nicaragua 1993

<i>Type and Extent of Disability</i>	<i>Cases Reported (No.)</i>	<i>Respondents with Disability (%)</i>
Hearing		
Deafness	26	5.85
Serious hearing loss	180	42.02
Mild hearing loss	242	52.13
Speech		
Muteness	18	9.20
Speech difficulty	134	90.80
Sight		
Total blindness	19	.94
Blindness in one eye	57	2.95
Difficulty with glasses	740	37.76
Difficulty without glasses	1,202	58.35
Movement		
Cannot walk/move on own	45	22.03
Limited/no use of arm(s)	27	15.77
Limited/no use of leg(s)	96	54.26
Cannot move one side of body	9	3.42
Involuntary movements	12	4.52
Deformity		
Loss of both legs/arms	2	0.45
Loss of one or both arms	7	6.46
Loss of one or both legs	16	16.22
Loss of one leg and arm	5	9.01
Deformed head/face	5	4.08
Deformed arms	15	11.98
Deformed legs	38	38.61
Deformed torso	10	13.19
Mental		
Retardation	88	59.21
Psychological Trauma	47	36.18
Insanity	7	4.61

Overlapping Response Categories

Assessing the overall percentage of persons with physical disabilities was difficult, as the survey module permitted separate responses for those with a “deformity” and “movement” problems (Table 9). While 5.1% of respondents reported having a movement problem and 3.4% reported a deformity, both response categories address movement-related disabilities. More than 54% of those who reported a movement problem had

limited or no use of a leg (Table 10). However, 38.6% of those with a deformity reported having deformed legs, and 16.2% reported the loss of one or both legs. Overall, more than 4% of persons with a physical disability were classified as having a mental disability; of these, over 59% were defined as retarded; yet, more than 36% were classified as having psychological trauma, and nearly 5% as insane (Table 10).

As Table 11 shows, the principal cause of sight

problems, the most common disability reported, was “aging.” For hearing, speech, and sight problems, “illness” was the most frequently mentioned factor, followed by “aging” and “birth/genetic defects.” It is unclear whether the birth defects were related to illness during pregnancy. For physical and mental disabilities, “accident, trauma, or violence” and “illness”

were reported as the main causes. War was infrequently listed as a cause of disability, except for deformities. Within the Nicaraguan context, the relationship between the response categories “accident, trauma, or violence” and “war” warrants further research, particularly given the distribution of responses between categories.

Table 11. Disability Causes, Nicaragua 1993

Cause	Disability Type											
	Hearing		Speech		Sight		Movement		Deformity		Mental	
	No.	%	No.	%	No.	%	No.	%	No.	%	No.	%
Birth/ genetic defects	44	11.17	89	58.08	134	5.97	22	11.26	20	25.40	67	48.32
Illness	143	30.83	29	20.00	546	28.11	78	40.75	34	30.41	32	18.29
War	18	3.71	1	0.74	14	0.68	8	3.92	15	11.19	2	0.46
Accident, trauma, or violence	58	14.12	6	4.00	149	7.72	59	34.25	27	30.84	31	23.75
Aging	135	29.09	7	3.45	812	39.18	12	6.22	1	0.35	2	0.47
Unknown	44	11.07	19	13.74	362	18.35	8	3.60	2	1.81	11	8.71
Total	442	100	151	100	2,017	100	187	100	99	100	145	100

Changing Sample Sizes

Changes in sample size were a problem with this module. More than three million people were asked the original question: “Do you have any sensory, movement, mental, or other problem, such as...?”. In principle, the follow-up question on type of disability should have been asked to 12% of the sample who reported a

disability; however, responses were obtained from only 1% of the sample or 2,973 people. While little loss of sample size occurred between this question and the subsequent one on extent of the disability, the question on causes of disability was asked to only 629 persons, less than one-third of those who gave information on the type of disability.

Summing Up: Data-collection Deficiencies and Their Effects

Despite LAC's growing concern over disabilities and widespread support for inclusive policies, data is insufficient. Current data-collection methods are not sophisticated enough to capture information across the range of disabilities or their effects on functional abilities. Ad-hoc ways of collecting data and fluid definitions of disability exacerbate the problem, making comparisons over time difficult.

In this study, disability-prevalence ranged between 2% and 20%. While some of the data showed prevalence rates higher than the 10% estimate used by the United Nations, Dudzik, Elwan, and Metts (2002) have argued against using this fixed estimate, supporting a range of 1.2-13.1% for developing countries in LAC. Most of the data for LAC would fall within these parameters. In countries that have experienced civil war, estimates may be higher as a result of

injuries during and after war. It must be recalled that data were derived primarily from the health and labor modules of household expenditure surveys—instruments not designed to collect disability data.

In all of the surveys reviewed, the paucity of questions on disability and their narrow scope limits the reliability and validity of the data obtained. The absence of accurate, country-specific data limits the type of advocacy work that can be conducted by disability groups. Without better estimates of the number of persons with a disability, the effect of disability on their individual and household incomes, and the potential contribution of persons with a disability to economic development, policymakers are less likely to implement programs or policies that facilitate the greater inclusion of persons with disabilities.

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