Crafting Questions About Disabilities: Learning More About How the Question Determines the Answer

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Abstract

It is well recognized that survey measures used to identify people with disabilities have limitations. To address these limitations empirical tests are needed to identify the strengths and weaknesses of the various measures used to assess disabilities. We used data from two surveys conducted for the National Science Foundation to review differences in question wording. The Survey of Earned Doctorates (SED) is an annual census of all recipients of research doctoral degrees. The information from an annual survey of about 40,000 SED responses is used as the sample frame for the Survey of Doctorate Recipients (SDR) which is usually conducted every two years to track the employment, educational, and demographic characteristics of scientists and engineers in the United States. The questionnaire items used to measure disabilities in each of these studies are very different: the SED has a screening question followed by five disability categories; the SDR requires a "level of difficulty" response for each of the four activities assessed in this survey. We expect that the SED measure is more likely to be "exclusive" because only those who are screened in from the prior question can report a specific disability compared to the SDR item which we expect to be more "inclusive" because all respondents are required to respond to the activity classifications. In comparing respondents' answers to the SED and the SDR disability items, we identified four analytic groups: (1) disability reported on both questionnaires, (2)disability reported on SED but not on the SDR, (3) disability reported on the SED but not on the SDR , and (4) no disability reported on either questionnaire.

1. Introduction

The data used for this paper is courtesy of the National Science Foundation. The use of NSF Data does not imply NSF endorsement of the research methods or conclusions contained in this report.

To improve our understanding of how to develop questions to identify people with disabilities and the on-going effort to expand our knowledge of questionnaire design, we used an existing data base, the National Science Foundation's Doctorate Records File (DRF), which includes data from the Survey of Earned Doctorates (SED) (an annual census of all recipients of research doctoral degrees) and the Survey of Doctorate Recipients (SDR) (a bi-annual survey used to track the employment, educational, and demographic characteristics of scientists and engineers in the United States). By cross tabulating the responses to the disability questions from the 29,915 people who participated in both surveys, we were able to analyze the performance of the different questions. Generally, research about disability methods is limited because of the small proportion who respond positively. Thus, beginning with a large number of survey participants in the data file increases the analytic opportunities by having a sufficient number of cases in the disability categories. While this paper presents a descriptive discussion of the results from these cross tabulations, it also identified additional questions to be answered by further analysis of these data.

The call for understanding more about sound questionnaire development is ongoing. One of the earlier and most explicit outlines of the challenges of questionnaire development came in 1951 from Stanley Payne in *The Art of Asking Questions.* In this seminal work, Payne challenged all of us in the profession to work at making progress to better understand question wording. Among the many contributions Payne makes in his book are the list of 1,000 words to consider in designing questions (Payne 1951, pp.151-157) plus 100 steps to take to develop a "passable question" (Payne 1951, pp. 228-237).

Disability researchers have the multiple challenges of both basic question design the complexity of the nature and perceptions of "disability". A further complication is the changing situational context of the physical, social, and policy definition of disability along with the change in the language that is used to talk about people with disabilities. A 2005 paper (Stern and Brault 2005) reviewed the disability questions asked in Census 2000 and the Census 2000 Supplementary Survey, important public policy statistical resources, concluded with a research agenda related to questions about disability: "Future research should follow three main paths: analysis of data available now, analysis of data we are collecting now, and administration methods". (Stern and Brault 2005, p.7)

The National Science Foundation (NSF) publication *Women, Minorities, and Persons with Disabilities in Science and Engineering* suggests three reasons why data on people with disabilities are "seriously limited:" (1) the operational definitions of disability vary; (2) data

on disabilities are generally not included or is kept confidential in comprehensive institutional records; and (3) survey information is self-reported. The report concludes: "In the final analysis, although considerable information is available about individuals with disabilities in the education system and in the S&E [science and engineering] workforce, it is often impossible to compare statistics from these different sources". (p.2)

2. Methodology

Secondary analysis of existing data was used to contribute to the body of knowledge about questionnaire design and specifically questions used to obtain information about people with disabilities. The following provides an overview of NSF's two surveys and the data base used for this analysis of 2003 respondents.

2.1 Survey of Earned Doctorates (SED)

The SED is a yearly census to collect information about first-time research doctorate graduates from academic institutions in the United States in July1 of one year to June 30 of the following year. Data collection is administered by institutional coordinators who distribute and collect the questionnaires from eligible graduates. Data are available beginning in 1957-1958, but limited information is also available for graduates from 1920 to 1956. In 2003, the universe was over 400 institutions and 40,710 graduates with a 91 percent response rate. The National Opinion Research Center (NORC) at the University of Chicago is the NSF contractor who administers the SED.

The following is the SED disability question (Type A)[1]:

C10. **Are you a person with a disability?**

1. Yes ☐ ⟶ **GO TO C11**
2. No ☐ ⟶ **SKIP TO C12**

C11. (IF YES) **Which of the following categories describes your disability(ies)?**

Mark (X) one or more

a. ☐ Blind/Visually Impaired
b. ☐ Deaf/Hard of Hearing
c. ☐ Physical/Orthopedic Disability
d. ☐ Learning/Cognitive Disability
e. ☐ Vocal/Speech Disability
f. ☐ Other – Specify

Figure 1: June 2002 Survey of Earned Doctorates

Additional information about the SED methodology is available at http://www.norc.uchicago.edu/issues/docdatat/htm and http://www.nsf.gov/statistics/showsrvy.cfm?srvy_CatID=2&srvy_Seri=1.

2.2 Survey of Doctorate Recipients (SDR)

The SDR is a bi-annual longitudinal survey of people with doctorate degrees in the science, engineering, or health fields, and tracks sample members until age 76.[2] Every two years a sample of new graduates is added to the SDR from the SED survey data file. NORC administers the SDR. The survey administration is mixed-mode and includes self-administered mail, telephone, and web. The 2003 survey had a sample of 40,000 and an 80 percent response rate.

The following is the 2003 SDR disability question (Type B):

E18. What is the USUAL degree of difficulty you have with . . .

Mark (X) one answer for each item.	None	Slight	Moderate	Severe	Unable to Do
1. SEEING words or letters in ordinary newsprint (with glasses/contact lenses if you usually wear them).	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
2. HEARING what is normally said in conversation with another person (with hearing aid, if you usually wear one)	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
3. WALKING without human or mechanical assistance or using stairs	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
4. LIFTING or carrying something as heavy as 10 pounds, such as a bag of groceries	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐

E19.⟵ 0 **Mark (X) this box if you answered "None" to all the activities in question E18, and go to question E21.**

E20. What is the earliest age at which you first began experiencing any difficulties in any of these areas?

AGE |__|__| OR 0 ☐ ⟵ SINCE BIRTH

Figure 2: 2003 Survey of Doctorate Recipients

[1] This wording was used in the 2002 questionnaire; however, the SED disability question has changed over time. Therefore, some of the respondents may have responded to an SED question as long ago as 50 years or as recently as in the past two years that had somewhat different wording.

[2] The SDR was conducted bi-annually until 2003. Post-2003 the next administration was in 2006.

Additional information about the SDR methodology is available at http://www.norc.uchicago.edu/issues/docdatat/htm and http://www.nsf.gov/statistics/showsrvy.cfm?srvy_CatID=3&srvy_Seri=5.

2.3 Doctorate Records File (DRF)

Although the data for this analysis was originally collected from the two surveys described above, the 2003 SDR/DRF File is the database that combines the information from both of these surveys.[3] This file consists of SED records and data from completed SDR questionnaires to make up the Doctorate Records File (DRF) variables, with the exception of name, address, and social security number. A total of 29,915 people eligible for this analysis are included in this file. DRF variables were taken from the historic DRF, 1920-2003, compiled from the annual SED. The DRF is the frame from which the SDR is sampled. Information from the SED provides demographic data to facilitate sampling.

3. Analysis

As described above, the same group of respondents was asked two different questions about disabilities. Type A uses a screening question where SED respondents determine their own eligibility to answer a series of items about specific disabilities by answering yes or no to the question, "Are you a person with a disability?" Those who report that they have a disability mark all the five listed categories that describe their disability. Type B has SDR respondents describe their level of difficulty with four disabilities—seeing, hearing, walking, and lifting. In addition to this difference in basic question structure, there are other question components that differ: the words that describe specific disabilities and the context that frames the question that offer additional future analytic opportunities[4]. Table 1 compares of the types of disabilities included on the 2003 SDR and the SED question from 2001 and 2003.

	Survey	
Disability	SDR 2003	SED 2003
Blind	Seeing	Blind/Visually Impaired
Deaf	Hearing	Deaf/Hard of Hearing
Physical	Walking	Physical/Orthopedic Disability
Cognitive	NA	Learning/Cognitive Disability
Vocal	NA	Vocal/Speech Disability
Lifting	Lifting	NA
Other	NA	Other-Specify

NA = Not Asked

Table 1: Comparison of Disabilities on Each Survey

Although all 29,915 respondents in this analysis were asked the same set of questions on the 2003 SDR, the SED questions were asked at one point across a series of years beginning as far back as 1952 or as recently as 2001. A caveat to this analysis, therefore, is that the cohort of respondents who first answered the disability questions when they exited from the school where they received their doctorate, may have developed a disability over time that did not exist when they completed the SED. This means that the differences between the two surveys in self-reported disabilities could result from changes in the respondents condition or from question differences. All data used in this description are unweighted to compare actual responses.

A general overview of the data are given in the frequency distributions in Table 2-A for the SED and Table 2-B for the SDR information.

Blind/Visually Impaired		
	%	0.1
	(n)	(49)
Deaf/Hard of Hearing		
	%	0.1
	(n)	(49)
Physical/Orthopedic Disability		
	%	0.31
	(n)	(95)

Table 2-A: 2003 Sed Unweighted Frequency Distributions

[3] The DRF variable descriptions and appendices are from the *Documentation of the Doctorate Records File, 1920-2003* (Chicago: National Opinion Research Center, 2004). Access to the SED or DRF data is available only under special licensee from NSF. Access to the full SDR also requires a special license from NSF, although a public version of the 2003 SDR that has been subjected to some confidentiality masking is expected to be available this summer.

[4] For example, the SDR introduces the series of disability questions using the following framing information: "The next series of questions are designed to help us better understand the career paths of individuals with different physical abilities."

	No Difficulty	Slight Difficulty	Moderate Difficulty	Severe Difficulty	Unable to Do	Total	Have Disability
Seeing							
%	83.3	13.1	3.1	0.3	0.1	100	16.7
(n)	(24,928)	(3,927)	(942)	(96)	(22)	(29,915)	(4,987)
Hearing							
%	84.3	12.1	3.4	0.2	0.0	100	15.7
(n)	(25,209)	(3,648)	(1,003)	(50)	(5)	(29,915)	(4,706)
Walking							
%	95.1	3.2	1.3	0.0	0.0	100	4.9
(n)	(28,437)	(952)	(374)	(10)	(10)	(29,915)	(1,478)
Lifting							
%	94.9	3.1	1.4	0.4	0.2	100	5.1
(n)	(28,392)	(927)	(414)	(127)	(55)	(29,915)	(1,523)

Table 2-B: 2003 SDR Unweighted Frequency Distributions

The right-most column in Table 2-B has the percentage of respondents who reported any type of difficulty for the four activities included in the SDR questionnaire. This overview shows that the proportion of respondents with reported disabilities was higher in the SDR than in the SED.

The DRF is a robust data file that can be used to address multiple research questions. The focus of this initial analysis was a preliminary evaluation of the potential for under or over-reporting a disability as a result of question wording. While the response choices are not an exact match, this discussion here will be based on three disabilities included in both questionnaires: visual(SED)/seeing(SDR), orthopedic(mobility)(SED)/ walking (SDR), and auditory(hearing)(SED)/hearing (SDR).

For each type, the SDR categories were first combined to compare to include all those who give a positive response to having some level of difficulty with an activity. However, since the SDR asks for an self-assessment of the perceived level of difficulty in performing an activity, the more detailed responses provide an opportunity to see how the perceived level of difficulties might affect how a respondent would answer the type of screening question that the SED uses and that we assumed would result in fewer respondents reporting a disability. In the comparisons for each of the three types of disabilities, the response given in the SED was used as the independent variable. The assumption was that because respondents answered the SED first, and this was the first opportunity for self-identification, the SED description should be it should be designated as primary. The caveat here is the extent to which an individuals may recall the answer they gave in the SED and attempt to make their SDR response consistent. It is important to remember that for the SED results all the respondents who described a specific disability had to have said yes to the screening question that preceded the list of specific disabilities, wheras each disability in the SDR was presented as a question.

3.1 Seeing

Among 49 respondents who described their disability as visual in the Type-A SED question, 61 percent also identified themselves as having at least some difficulty seeing in the Type-B SDR format, while 39 percent did not identify themselves as having a seeing problem (Table 3-A).

SED: Blind/Visually Impaired		SDR: Seeing Yes	SDR: Seeing No	Total
Yes				
	%	61.2	38.8	100
	(n)	(30)	(19)	(49)
No				
	%	16.6	83.4	100
	(n)	(4,957)	(24,909)	(29,866)

Table 3-A: Seeing: Summary Comparison

This suggests an underreporting of a visual problem in the SDR. However, among the 29,820 respondents who did not report a visual disability in the SED, 17 percent did say they had at least some level of difficulty seeing in the SDR compared to 83 percent who reported not having a visual disability to both questions. Thus the SED question format may have excluded 4,957 people who did report in the SDR that they had some level of difficulty seeing. A closer look at the level of difficulty reported by those who did not report a disability in the SED suggests why these people may have excluded themselves as having a disability. About 8-in-10 of this group described their visual difficulty as "slight" (Table 3-B).

SED: Blind/Visually Impaired		SDR Seeing: No Difficulty	Slight Difficulty	Moderate Difficulty	Severe Difficulty	Unable to Do	Total
Yes							
	%	38.8	24.5	24.5	6.1	6.1	100
	(n)	(19)	(12)	(12)	(3)	(3)	(49)
No							
	%	83.4	13.1	3.1	0.3	0.1	100
	n)	(24,909)	(3,915)	(930)	(93)	(19)	(29,866)

Table 3-B: Seeing: Comparison by Level of Difficulty

We can also learn more about the extent of the visual disability among the small group that had positive responses to both the SED and the SDR. Since this group originally screened themselves in the SED by reporting that they had a disability, they were expected to report higher levels of difficulty than those who did not self-screen as having a disability. However, about 8-in-10 of the self-screened respondents reported slight or moderate difficulty seeing.

3.2 Hearing

There were also 49 respondents who described their disability as auditory in the Type-A SED question (Table 4-A).

SED: Deaf/Hard of Hearing		SDR: Hearing		Total
		Yes	No	
Yes				
	%	89.8	10.2	100
	(n)	(44)	(5)	(49)
No				
	%	15.6	84.3	100
	(n)	(4,166)	(25,204)	(29,866)

Table 4-A: Hearing: Summary Comparison

Ninety percent of this group reported in the Type-B SDR disability format that they had at least some difficulty with hearing while 10 percent did not identify themselves as having a hearing problem. This difference suggests a slight underreporting of hearing problem in the SDR. Among the 29,866 respondents who did not report an auditory disability in the SED, 16 percent did say in the SDR that they had at least some level of difficulty hearing compared to 84 percent who reported not having hearing problems to both questions. This suggests that the Type-A SED question format may have excluded 4,662 persons who did report in the SDR some level of difficulty hearing. A closer look at the level of difficulty reported in the SDR by those who did not report an auditory disability in the SED finds that about three-quarters of this group describe their hearing difficulty as "slight" (Table 4-B).

SED: Deaf/Hard of Hearing		SDR: Hearing					
		No Difficulty	Slight Difficulty	Moderate Difficulty	Severe Difficulty	Unable to Do	Tota
Yes							
	%	10.2	38.8	44.9	6.1	0.0	100
	(n)	(5)	(19)	(22)	(3)	0.0	(49)
No							
	%	84.4	12.1	3.3	0.2	0.0	100
	(n)	(25,204)	(3,629)	(981)	(47)	(5)	(29,86

Table 4-B: Hearing: Comparison by level of difficulty

The SDR gradations of hearing difficulty among the 49 people who had positive responses to both the SED and the SDR help to shed light on the SED response. Since this group originally reported in the SED that they had a disability, we expected them to report higher levels of difficulty than those who did not self-screen as having a disability. However, about 4-in-10 reported slight difficulty hearing.

Walking

Among 95 respondents who described their disability as orthopedic (mobility) in the Type-A SED question, 64 percent also identified themselves as having at least some difficulty with walking in the Type-B SDR format, compared to 36 percent who did not identify themselves as having a mobility problem (Table 5-A).

SED: Physical/Orthopedic Disability		SDR: Walking		Total
		Yes	No	
Yes				
	%	64.2	35.8	100
	(n)	(61)	(34)	(95)
No				
	%	4.8	95.2	100
	(n)	(1,417)	(28,403)	(29,820)

Table 5-A: Walking: Summary Comparison

Similar to the prior items, this suggests an underreporting of a physical problem in the SDR. Among the 29,820 respondents who did not report a mobility disability in the SED, however, 5 percent indicated in the SDR that they had at least some difficulty walking compared to 95 percent who reported in both the SED and the SDR not having any problem walking. The SED question format, therefore, may have

excluded a smaller number of mobility disability responses than visual or hearing disabilities, yet 1,417 persons did report in the SDR having some difficulty walking. Further examination of difficulty levels reported in the SDR by those who did not report a disability in the SED suggests why these people may have excluded themselves as having a disability: about two-thirds of this group described only a "slight" level of walking difficulty. (Table 5-B).

SED: Physical/ Orthopedic Disability	SDR: Walking					
	No Difficulty	Slight Difficulty	Moderate Difficulty	Severe Difficulty	Unable to Do	Total
Yes						
%	35.8	18.9	23.2	11.6	10.5	100
(n)	(34)	(18)	(22)	(11)	(10)	(95)
No						
%	95.2	3.1	1.2	0.3	0.2	100
(n)	(28,403)	(934)	(352)	(87)	(44)	(29,820)

Table 5-B: Walking: Comparison by Level of Difficulty

We can also learn more about the extent of the mobility disability among the 61 respondents who reported disabilities on both the SED and the SDR. Since this group originally had to self-screen in the SED by reporting they were a person with a disability, we expected that they would report higher levels of difficulty than those who did not self-screen as having a disability; however, about two-thirds reported slight or moderate difficulty walking.

4. Summary and Observations

This preliminary descriptive analysis confirmed the expectation that the Type-B SDR format of the question consistently identified more people who had some level of difficulty seeing, hearing, or walking than the SED identified. Because of the various uses of statistics related to people with disabilities, this suggests that a more inclusive questionnaire item provides additional flexibility for potential analyses of survey data. The percentage of possible underreporting in the SED based on the SDR response varied by disability. The most underreported disabilities were related to seeing (17%) and hearing (16%) and the least was walking (5%). Some of this underreporting may be the result of the "aging" factor among SED respondents noted earlier.

Although we expected underreporting in the SDR relative to the SED, we did not anticipate the extent of underreporting. Reporting that you are a person with a disability is a notable self-description. It was expected that when these answers were given in the SED, there would be minimal or no change in the SDR. Also of interest is that among the three types of disabilities considered here, more respondents (90%) gave consistent on the SED and SDR to the questions about being deaf, compared to about 6-in-10 who consistently reported on both surveys that they had visual or mobility difficulties. The results of the more inclusive SDR are more consistent than the SED results with other general population surveys. Generally, about 10 to 15 percent of the general population reports some type of disability depending on the question and the population. However, the average for the disabilities reported in the SED are less than 1 percent.

5. Future Research

We can learn a great deal about questionnaire design and disability questions by conducting experiments. However, available data files, such as the DRF, can provide learning opportunities without having to conduct primary research. The comparison of responses on the SED with those on the SDR by the same group of survey participants underscores the usefulness of existing data files to address ongoing survey research issues. Future analyses could investigate how the aging of the population that first responded to the SED influenced the later SDR disability response compared to changes in response that were solely the result of the question wording.

Other studies of question format and context issues could include the effects of the multiple changes in the wording that have occurred over time in both the SED and the SDR. In particular, the SDR frames the item by describing "abilities". Some cognitive work conducted in 2003 suggested that survey respondents might be influenced by concerns of social desirability related to reporting on a "disability." In addition, looking at the extent of abilities or using an "other abled" approach for discussing disabilities reflects recent changes in the language used to describe disabilities.

In addition to reviewing changes in the wording of response choices, the SED coding directions for both the selection of multiple disabilities and for the "other-specify" selections could be reviewed to see if this is a reason for a possible under representation of people with disabilities. For example, if multiple disabilities are selected in the "mark all responses," but only one is recorded in the data file, those who selected multiple classifications might be undercounted. Additional information about the number who responded in the "other" classification and how they were included or excluded in the data file would be a contribution to improving disability research.

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