

Corinne Kirchner

Recipient of NYAAPOR's

Harry W. O'Neill Outstanding Achievement Award

Dr. Kirchner's Acceptance Speech

June 16, 2001

Surveying People with Disabilities-- A Rant in 2 Parts:

Part I. The Case for Beating a Dead Horse

Part II. Looking for Impact in All the Wrong Places

First, of course, I want to thank NY-AAPOR's Council for giving me this extraordinary honor; and other NY-AAPOR members for being in attendance tonight; and my family and friends who are here, many of whom have had only a dim idea of what I've been doing in this long career but took on faith that it must have been worth something to someone - and who no doubt are as astounded as I am that it was *award*-worthy. The generosity of all of you would make me speechless -- if it weren't for the greater opposing urge to speechify!

I dedicate this occasion in memory of my late sister, Phyllis Endreny. Her twin, our brother Raymond, came from Rhode Island to be here. Most of you don't remember Phyllis, though some may recognize her name as junior author with Eleanor Singer of the book *Reporting on Risk*¹. But those who do remember her from AAPOR conferences prior to 2001, know that she ran the Book Exhibit there for many years. Thank you, Phyllis.

As Marjorie and several others know, I had a hard time believing this really was happening to me. In fact, it strained my sense of "reality" for a couple

¹ Singer, E. with Endreny, P. (1993), *Reporting on Risk: How the mass media report accidents, diseases, disasters and other hazards*, New York: Russell Sage Foundation.

of weeks -- until I decided to deal with it by *not* focusing on the indecipherable *causes* of the Council's decision, and instead focusing on its *consequences*.

Regarding the first consequence: I am NOT going to accept the unstated message in this type of achievement award, which -- unless it is going to a youngster -- is some version of "*Enough Already!*" Instead, I'll use the occasion as a stimulus to add points toward retroactively earning such an award with my career going *forward*.

The 2nd consequence is the chance to be a sort of "role model" - that is, giving hope to an often-negatively-stereotyped group that I belong to. I'll gladly serve as evidence that, at least in this profession and at least in New York, survey researchers are not captives of that particular public stereotyping; to the contrary, these colleagues appreciate the efforts of this stigmatized group. The group I'm referring to are "little old ladies."

And the 3rd consequence is that I get to give a little talk on a subject that has been a driver for much of my social research career -- the topic is survey techniques that create barriers to including people with disabilities, thus losing data on their characteristics, actions and opinions. The talk has two main parts: "1. The Case for Beating a Dead Horse," and "2. Looking for Impact in All the Wrong Places."

Compared to what I've had to say on that topic of disability access in surveys for many years, this will be a rant of a slightly different color (that's my sneaky introduction of the horse metaphor, which I will start beating in a moment). For a long time, I and a few others used the rare opportunities we could find to urge that survey researchers apply their ingenuity and commitment to inclusiveness - you could call it commitment to "good coverage of populations" - to figuring out ways to avoid barriers to survey participation by people with disabilities. Few researchers realize that their usual methods inadvertently exclude people from studies because of some type of impairment which need not *inherently* exclude them. Of course, those excluded cannot contribute data to inform policy or practice decisions based on those studies.

National AAPOR conferences have provided an important venue for our longstanding though marginalized efforts. By now, a substantial roster of AAPORites -- individuals and firms -- have taken up the challenges. They have unearthed and dealt with some of the non-obvious barriers, such as question-wording that can bias results because of incorrect assumptions about disability built into them.

Let me give you just one prime example: a long-standard question, "*Are you limited in or unable to work, due to a physical or health condition that has lasted 6 months or more?*" What's wrong with that question? The problem is that there are many disabling conditions for which it is the barriers *in the workplace*, NOT the impairment, that prevent doing the work. For example, if blind people have a speech program on their computer, they can work at many jobs where they could not if only visual print were available.

Some AAPORites have been leaders in identifying ways that survey research conventions can exclude or distort the experience and views of people with disabilities. Because of limited time I will name just a couple. Gerry Hendershot, formerly at the National Center for Health Statistics and now an independent consultant in the D.C. area, is a stand-out. Gerry realized that AAPOR's standards for reporting "final disposition" of cases needed to be reviewed from the perspective of possible disability bias. (I might add they still could use such review.)

Gerry also understood that interviewer training was urgent from that perspective and developed appropriate training protocols. For example, he found that some well-meaning interviewers for the national "Health Interview Survey" didn't ask wheelchair users the questions on physical exercise. But exercise is possible and at least as important for "assistive device" users as it is for others.

Janice Ballou and others at Mathematica Policy Research have looked at improvements such as in rules for proxy interviews. Other researchers have considered how issues of sampling that apply to *group quarters* and to

homeless populations are especially germane in trying to avoid under-representing people with disabilities.

An important point is that such investigations go beyond simply identifying that disability-related bias may exist. The good studies get to a nitty-gritty level about barrier-free survey design, which might be quite technical, certainly beyond the routine knowledge of the average well-meaning researcher.

The point here is parallel to distinguishing between cultural *sensitivity* and cultural *competence*. Disability *competence* requires time and effort learning about specific barriers and specific technologies, not just an attitude of "disability sensitivity," however commendable and necessary that attitude is.

For example, after my 30 years in social research involving people with varied types and degrees of visual impairment, during which amazing new technologies for accessibility were being developed, I think I gained some competence in that narrow range. But I don't have real competence in techniques for access to interview studies with people who are deaf or hearing impaired, or people who have cognitive or orthopedic impairments; I know only that there are many possibilities.

By now, there have been so many relevant conference presentations – AAPOR's and others' -- and journal articles, that in recent years at least two solid books concerned with survey access have been published, one in 2007² and the other in 2009³. So that's why this talk can be a rant of a different color; you might say that drumming on the old theme that disability access is important and do-able is like beating a dead horse. Which brings me to the aim of Part I – Making the Case for Beating a Dead Horse.

I can think of two reasons for doing that: the first is that the horse may just be *playing* dead. And the second is that since you can't ride him anymore,

² Kroll, T., Keer, D., Placek, P., Cyril, J., and Hendershot, G., (2007) *Toward Best Practices for Surveying People with Disabilities*, Happaage, NY: Nova Science Publishers.

³ Houtenville, A., Stapleton, D., Weathers, R., Burkhauser, R., (2009) *Working-age Persons with Disabilities: What Current Data Tell Us and Options for Improvement*, Kalamazoo, MI: W.E. Upjohn Institute for Employment Research.

it's another way to get exercise. We can ignore that second reason because it's just plain silly, but the first has to be taken seriously. For example, in spite of all the attention that has gone to this issue, I've been disappointed that it seems still to be overlooked in some rather important AAPOR resources. I'll give just one example, but could name others.

The most germane example right now is the upcoming "2012 Conference on Methods for Surveying and Enumerating Hard-to-Reach Populations." I looked closely at the 10 categories of hard-to-reach groups listed in the "Call for Papers," and although people with disabilities are without doubt included in all of them, they are not explicitly on the list. That omission pretty well ensures that specific issues that need to be addressed in reaching that group will *not* be addressed.

There *is* a category called "stigmatized persons" - which might be code for people with disabilities, but even if it is, getting around the problems posed by stigma amounts to the cultural sensitivity part of what needs to be done - it does not address technical issues of access to (a) being recruited into specific studies in the first place, nor (b) data collection instruments and processes.

So I conclude that the horse (which here signifies problems of disability-related access to participating in research) is *not* dead. The situation reminds me of several years ago when AAPOR's national conference theme was about being inclusive in research. Some colleagues at AFB and I were excited about being able to feature disability access issues in that context, but when I broached it to the Conference chair, he or she (I don't remember) said that their aim was to be more general for the plenary session on the theme, and the disability access issues could be discussed in a session on health-related research. I protested to no avail.

That situation can be the segue to Part 2 of my rant: i.e., "Looking for impact in all the wrong places." Or more precisely, "*Not* looking for impact in all the *right* places."

My point is that channeling concerns about improving inclusion of people with disabilities in survey research only into the health policy and practice arena

- as important as that has been and will continue to be - is missing a large span of the issues in public opinion that survey research typically addresses.

I'll explain that indirectly. I mentioned that there is a 2009 book⁴ on surveying people with disabilities. I've only read part of it, but I'm impressed. AAPOR's Janice Ballou and her colleague at Mathematica, Jason Markesich, have a chapter on "Survey Data collection methods," and there's a chapter by Dave Stapleton on "Options for improving disability data collection." So with the complaint I'm about to make, I'm not panning anything about what's in the book - rather, my critique is about what *isn't* in it.

Using word search in "Google Books," I ran several searches that turned up nothing, using a series of terms like "vote", "voter", "voting", "politics", "political" and another series, "marketing", "customer", "purchasing", "advertising". (The term "consumer" did appear but in the disabilities field that term has specialized meaning as consumer of welfare or rehabilitative services, not as consumers in the usual business sense.)

So, granting that public policy, especially health policy, is an important rationale for public opinion research - that's not *all* there is, for people with disabilities any more than anyone else. After all, what are the two other significant areas of research -- arguably more appealing for many who go into this line of work? They are *political polling research* and *marketing research*. If we're looking for areas of impact that could come out of dealing with disability-related access issues, why not look in those areas? I'll take them separately.

The first - political polling - may be the more problematic one, though maybe not. The issue came up many years ago, when I tried to make the case to Murray Edelman that disability should be added to "exit polling" as a demographic category, like age, sex, race, for better understanding of the political process. I expected the typical response, i.e., that disability is harder to measure, for which I have a practical answer. (I'm not going into it here.)

Of course, I should have realized not to expect a typical response on anything from Murray. In any case, his response was harder for me to address:

⁴ Houtenville et al. [full reference above]

"Do you have good evidence that people with disabilities vote as a bloc?" Good point. Back then (the 1980s), the "Disability Rights movement" was just developing, and I couldn't produce such evidence. Since then, there may be a stronger case; research that can shed light on that. It's an area to watch but I'll grant that, given the severe constraints of exit polling, it still may be premature to make such changes.

Turning now – and in closing – to market research:

With little searching, I found several relevant articles in the marketing journal, *International Review of Retail, Distribution and Consumer Research*⁵ (*IR-RDCR*); also, a 2009 article on "Expanding opportunities for online shoppers with disabilities" in the *Journal of Business Research*⁶, and in 2010, "Flight experiences of Persons with Disabilities" in the *Journal of Travel Research*.⁷

So the areas for application of research results exist and are waiting for data that adequately reflect the wide agenda of interests among what I'll call "disability cultural minorities." Benefits will accrue to understanding specialized disability-related perspectives operating in the arenas of consumer and voting behavior and attitudes. Finally, we can also expect benefits even when there is no specific disability perspective, due to enhanced coverage of other analytic groups differentially associated with disability status -- e.g., age, education, employment status -- when the day arrives that disability-related barriers to participating in public opinion research will be removed.

Thanks for your attention – and again, for this meaningful award.

####

⁵ Williams, P. and Hubbard, P., (2001), "Who is disadvantaged? Retail change and social exclusion," *IR-RDCR*, v. 11, 267-286; Woodliffe, L., (2007) "An empirical re-evaluation of consumer disadvantage," *IR-RDCR*, v. 17, 1 -21; Bromley, R., and Matthews, D. (2007) "Reducing consumer disadvantage: Reassessing Access in the retail environment," *IR-RDCR*, v. 17, 483-501.

⁶ Childers, T. and Kaufman-Scarborough, C. (2009), "Expanding opportunities for online shoppers with disabilities", *J. of Business Research*, v 62, 572-578.

⁷ Poria, Y., Reichel, A., Brandt, Y., (2010), "The flight experiences of people with disabilities: An exploratory study," *J. of Travel Research*, v. 49, 216-227.