

## Introduction

### **Disability, Economic Value and Cultural Values: Rarely-Examined Linkage**

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Special Editor

Economics, the discipline, studies value in monetary terms, but too rarely questions underlying socially and culturally generated values that define its analytic approach. So, for example, economists pursue questions like: What processes determine the cost/value of items that people want? How do people's productive activities (labor) affect the value (cost) of those items? Stepping back a short pace from that question, labor economists examine factors that promote or limit people's productive activities.

In the traditional economics framework, disability by definition limits a person's productive activity. Given that definition/assumption, a rich lode of research questions about the "cost of disability" can be tapped. Hahn's seminal classification of perspectives on disability (1985) presumably referred to that research gold mine (so to speak) by recognizing economics as the source of one of three significant perspectives - the two other being medical and sociopolitical.

But before focusing on value in the cost/benefit and market sense, one must step back several paces. We need to question the underlying values that make some products or services desirable on the market, while others are not, and more fundamentally, the values that make some people's wants and activities (consumption and production) more valued than those of other people. Economic sociology is a long-established arena where that type of prior question is asked. However, judging by the index, and a selective reading, of the recent massive *Handbook of Economic Sociology* (Smelser and Swedberg, 1994), I find no evidence that those scholars have applied their prism to economic assumptions about people with disabilities. By contrast, the *Handbook's* chapter on "Gender and the Economy" (Milkman & Townsley) offers a possible template for exploring ways of factoring disability into economic studies.

Delving into the *Handbook* came late in my still-tentative foray into the somewhat daunting terrain of economic sociology. (Since sociology is my discipline, I find economics "proper" even more daunting.) My sense of urgency to locate sociological work, or any nontraditional perspective on

economic aspects of disability, grew from deep discomfort sparked in 1993 at a conference on "Economic Consequence of Disability," sponsored by the Paralyzed Veterans of America (PVA).

The one-day conference began with a keynote speech and comments by high federal appointees (one with a disability, another the mother of a severely disabled young adult), who dynamically outlined and exemplified the personal and the political sides of the disability rights perspective. These and a few other presentations clearly reflected the "paradigm shift" that locates the cause of many disability-related problems in the social environment instead of in an individual's impairments. But, virtually all the presentations from economists that filled the rest of the meeting pursued the traditional angle of "costs of disability due to impairment." (PVA, 1994).

For that meeting, my prepared remarks raised questions about the social construction of disability costs: Who defines what are "costs"? Whose activities are counted as "productive," while the same or similar activities by others with socially-devalued characteristics are not counted as productive? I drew the obvious analogy between people with disabilities and women who are full-time homemakers, whose contributions to familial and national economies through housework, until recently, were simply omitted by economists calculating productive effort.

Continuing in that vein: Why has economic research concerning people with disabilities not measured their contributions in the household and in volunteer activities? Why are "reasonable accommodations" for people with disabilities counted as special costs, whereas accommodations for people without disabilities are factored in as ordinary costs of doing business? I gave a hypothetical example to illustrate the last point, highlighting that our society's implicit perspective on disability conceals the fact that individual accommodations in the work setting are regularly made for people without disabilities, especially in higher-status positions. Why is the creativity that most people with disabilities necessarily use to function with alternative techniques not accorded the value that creativity elicits in many economic pursuits?

I asked, further, why the syndrome of nondisability factors that are labor market disadvantages, notably low socioeconomic status prior to disability, typically are not factored out when reporting the disability disadvantage in employment rates? (A major exception is the growing body of work by Yelin and associates, e.g., Yelin & Katz, 1994) And why is discrimination as a powerful factor in unemployment and underemployment

of people with disabilities typically not measured? Here, the important exception is the body of work being painstakingly constructed by William Johnson and Marjorie Baldwin (Johnson & Baldwin, 1993).

The PVA paper was my somewhat risky plunge into the turbid waters of economic analysis. Next, a panel session on economics of disability at the 1994 meeting of the Society for Disability Studies confirmed that these questions are important but rarely studied from the perspective of socio-cultural construction of disability costs/values. Again, there is an important exception: Gary Albrecht's award-winning book, *The Disability Business: Rehabilitation in America* (1992), which he appropriately characterizes as a study in political economy. Albrecht portrays the organizational structures that have grown up in our capitalist economic system around the rehabilitation and maintenance of people marginalized because of their disabilities, using monetary data illustratively. Albrecht's panoramic lens should stimulate researchers from several disciplines, economists among them, to delve deeper into empirical features of the changing landscape of disability issues.

In November 1995, my PVA paper, re-worked, was published in the *Journal of Visual Impairment and Blindness* (JVIB) (Kirchner, 1995). And now, this theme issue of DSQ is piecing together more planks in a raft (to retain the metaphor of entering "turbid waters") that is still small and rickety, but will begin to support the innovative work so urgently needed.

Briefly, some comments to link the few pieces that follow: The Call for Papers had asked for "think pieces" which I hoped would extend, dispute, or otherwise take off from ideas in the JVIB article. Three of the four submissions (those by Scotch, by Fortini & Litvak, and by Hershey) clearly extend the ideas. They broaden the formulation of economics issues from the sociopolitical perspective on disability, and add an action-orientation. The fourth piece, by Eames & Eames, does not relate to the JVIB article though it remains consistent with its perspective. All four fulfill the aim of "think pieces" in two senses - they treat us to glimpses of the developing thoughts of authors whose varied and intense commitments to disability studies make their thoughts of interest. Secondly, they provoke us to think. Maybe that is an advantage of the severe constraints on length that we have imposed - you, the reader, must do some work of filling in details and examples and extending the authors' ideas into their implications.

Scotch brings the broadest view: by referring to "economic discourse" he invokes the social construction of disability costs. He goes on to advance

the framework for needed research by locating that discourse within the concrete politics of this period in the U.S. and by linking his ideas to the concepts and language that economists use.

Fortini & Litvak bring a more focused interest in "cost effectiveness" studies of disability programs. They alert us to the central issue of who defines not only "costs," but "effectiveness," arguing that the consumer perspective is often short-changed. They refer to their own work - putting their money where their mouth is, so to speak - in developing a measure from the consumer perspective on personal assistance services.

Hershey takes the matter of "consumer perspective" even further, both in the role it should play in economics and in how to make that goal a reality. She argues that there are many questions related to economics, going well beyond cost-based evaluation of programs, that people with disabilities whose lives are affected could fruitfully formulate. And she suggests exciting possibilities to remove the mystique of expertise that has been a massive barrier to such participation so far.

Shifting gears, the Eames' paper raises serious questions about a particular "cost effectiveness" analysis that has been published in a leading medical journal. The underlying question, in my view, is whether mainstream medical economics research tolerated weak evidence in relation to disability issues that would not have been otherwise tolerated because of their lack of real understanding of disability and of nontraditional approaches to achieve independent living. The Eames' paper is followed by a rejoinder.

In closing: a few words are needed about important questions in a "new economics of disability" that are not explicitly represented here although they are certainly implied. Most significant among the "missing" areas is the increasing, and increasingly dangerous, use of economic equations to determine whose lives are "worth living." Urgent life and death issues are involved, focusing on newborn infants and on elderly persons with disabilities. Positive exceptions can be cited here too, e.g., Elkins & Brown, 1993, who argue in a medical journal against "attaching a price tag to persons with Down syndrome."

Also missing is a review of data resources and data needs to explore the important questions. Worth noting is the 1994-95 "Disability Supplement" to the Health Interview Survey of the National Center for Health Statistics; data are just becoming available for analysis. While the Supplement does not contain a great deal of economic data, what little there is can be combined with measures that take into account environmental

barriers, rehabilitation and adaptive technology, and other societal influences on the lives of people with disabilities. A refreshing item is information on the extent of unpaid volunteer work by people with disabilities.

To steal from Scotch's powerful closing paragraph in the first of the think pieces: "Disability economics is too important to leave to economists and policy analysts who do not know much about disability." By the same token, we need to welcome not only social scientists who can provide the socio-political and cultural context for questions of economics, but also "real" economists who do understand the multidimensional influences on the experience of disability, positive as well as negative.

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