

# Introduction

DANIEL M. FOX and DAVID P. WILLIS

THE ARTICLES IN THIS SUPPLEMENT, TAKEN together, propose an ambitious goal for health and social policy in the United States: restoring social and economic independence to people who have impairments that result from illness, injury, or inheritance. In this formulation, no condition of life need be without both individual benefit and social purpose.

We use the phrase "disability policy" as a convenient and recognizable, though still inadequate, way to characterize interventions that seek to enable people with impairments to live in ways that are personally satisfying and socially useful. From a disability perspective, as we use the term, policies address results: that is, what people aspire, or could aspire, to do. In conventional perspective, in contrast, policies usually address methods and processes: that is, what interventions, usually treatments including rehabilitation and training, are available or desirable.

Disability policy is the result of complicated and continuous social negotiations. These negotiations involve elusive and continually changing definitions of impairment and handicap, of the rights and obligations of individuals, of collective responsibility, of the economic need for and the value of work, and even of national interest.

Disability, for many years a vague category, has become more precisely and usefully defined as a result of work commissioned in the 1970s by the World Health Organization (WHO 1980). The

contributors to this supplement generally follow the nomenclature proposed by the WHO. This nomenclature uses three terms: impairment, disability and handicap. The definitions of these terms, though blurred at the boundaries between each of them, have proved to be useful for understanding the social negotiations that we call disability policy. In this nomenclature, *impairments* are disturbances in the processes of, or the structures of, the body as a result of inheritance (or birth), illness (or disease) or injury. *Disabilities* are particular limitations in activity as a result of impairment. *Handicaps*, in this formulation, are the social disadvantages that result from impairment and disability. According to a recent gloss on these definitions,

Concepts of impairment, disability, and handicap refer to related though radically different areas of human experience. Accordingly, impairment is defined as any disturbance in body structures or processes which are present at birth or arise from disease or injury. Disabilities were originally defined as limitations in the functions customarily expected of the body or its parts *or* restrictions in activity consequent upon impairment. More recently, this definition has been modified so that functional limitations are classified as impairments in order to make the boundary between impairment and disability more clear cut. Handicap is the social disadvantage originating in impairment and disability because the individual does not or cannot conform to the expectations and taken-for-granted assumptions of the society or social groups to which he or she belongs (Locker 1983).

The WHO has also provided a useful scheme to characterize the causes of disability. In this scheme, disability has three causes: developmental, acute and chronic. Developmental disabilities are those that are congenital or the result of malnutrition. Acute disabilities are consequences of injuries or communicable diseases. The causes of chronic disability are mental illness, alcohol or drugs, or noncommunicable diseases (Wood 1983).

No other area of policy is precisely analogous to disability. An inexact analogy might be the mobilization of a country for modern warfare. Only in wartime have the people who make policy explicitly negotiated about who will be expected to work or to fight and then organized health and social services on the basis of these negotiations.

It may appear grandiose, and perhaps dangerous, to use the analogue

of war to describe policy for restoring social and economic independence to people with impairments that result from illness, injury, or inheritance. We use it to emphasize the connection, too often ignored, between collective goals and what a society requires of, makes possible for, and even grants as a matter of right to its individual members. The goals of health policy, for example, are usually described as increasing rates of survival after illness or injury, promoting longer life, and relieving pain. From the perspective of disability, however, health policy should also be about enabling people to function in and contribute to society. We believe that health and social policy should address more explicitly what individuals should be enabled to do for themselves and for others.

The articles in this supplement acknowledge and build upon a growing interest in disability policy in the United States and abroad. In the United States beginning in the 1970s, the ideals and achievements of the civil rights movement inspired advocates of what became the disability rights and independent living movements. The people who participated in these movements provided constituencies for new laws and public programs and brought suits that led to landmark court decisions. In the late 1970s and early 1980s, our largest disability program, Social Security Disability Insurance, became the focus on controversy about eligibility standards and the relation between the rate of disability claims and the behavior of labor markets. Since the 1960s, moreover, there has also been considerable change in federal and state policy for people with mental illness and developmental disabilities generally associated with the controversial practice of "deinstitutionalization."

These events affecting traditional categories of people with disabilities coincided with growing awareness of the disabilities of children and working-age adults. This awareness was expressed most frequently as dismay about the growing costs of private health insurance and Medicaid. At the same time, an increasing number of people were living longer and were translating into political pressure their eagerness to maintain their independence while managing the disabling consequences of chronic disease.

These familiar events stimulated an impressive body of research and writing. Some of the notable contributions to this literature, notably books by Deborah Stone and Edward Berkowitz, and the 1987 report on pain and disability by a committee of the National Academy of

Sciences, helped us to formulate the questions that we put to the contributors to this supplement in meetings held early in 1988.

The most important reason for advocating this new approach is that disability, in its contemporary definition, has become a universal social experience in industrial countries. The universality of disability is a consequence of the socioeconomic, scientific, and technological advances of the past century. More people survive birth, injury, and illness and live longer as a result of better nutrition, housing, birthing technology, surgery, patient management, and specific interventions against microorganisms. The steadily rising prevalence of chronic disease since the 1920s is an index for health policy of the consequences of increasing survival and longevity. The survival of progressively higher percentages of newborns, children, injured workers, and war casualties throughout the century attests to the effectiveness of twentieth-century standards of living and medical science.

Most people in industrial countries can now anticipate prolonged periods of disability during their lives. Their disabilities will, of course, vary in type, intensity, duration, and, most important for policy, in their psychological, social, and economic effects. It is no longer rational for societies that value civility and productivity to conceive of disability as a residual category; or of the disabled, a conventional reification of this category, as a minority of people who suffered particular misfortunes. Disability is both temporary and permanent. It is a concomitant of work, of retirement from work, and of participation in every conceivable social activity.

A second reason for advocating the usefulness of a disability framework for health and social policy is that it addresses the full complexity of many health and social problems. From a disability perspective, there is no arbitrary boundary between the biological, the social, and the economic aspects of disease. Similarly, a disability framework places loss of function as a result of inheritance or of injury in its social context. It is an oversimplification to view either congenital disabilities or injuries as results of chance, on the one hand, or individual behavior, on the other. Effective policy would regard disabilities as the results, and often the ameliorable results, of complicated processes in which there are many opportunities for intervention. Moreover, effective policy involves the legislative, executive, and judicial branches of government. Such policy is based on concepts of collective welfare, of the uniquely American emphasis on the rights

of individuals, and on competition (and at times collaboration) among interest groups.

A third reason for advocating a new framework is that the universality of disability highlights the problematic boundaries of many conventional social policies. There are good reasons why health, social services, income, housing, and transportation policies, for example, each have separate—though sometimes overlapping—constituencies and networks of providers. But it now makes little logical sense, except in the politics of interest groups, and in particular of provider interests, to persist in many established premises of these policies. Two of the many examples of illogical policies are the separation in policy for financing health services of acute and long-term care, and the construction of houses and transportation systems on the assumption that their “normal” users will have no, or hardly any, limitations of functions.

A disability framework would, moreover, require more intense and precise public discussion about the goals of health and social policy and how to achieve them than occurs at present in the United States. Such discussion would require more awareness than we have at present about a number of issues. These issues include:

- the extent and distribution of disability in the population;
- the relation between disability and work;
- policy responses to disability in different countries at different times;
- how health and social policy in the United States has responded to the need and demand of people with disabilities;
- how research and social values could, together, create a new context for political debate about policy responsive to disability.

The articles in this supplement address some of these issues. We chose to emphasize the *restoration* of socioeconomic independence to adults whose impairments result in disabilities and handicaps. Only two of the articles, by Herr and Zola, address the provision of independence to people who have never had it; and they argue that the lessons of rights-based policy for traditional categories of disabled people should be extended to the problems of restoration. We believe that our emphasis on restoring socioeconomic independence permits the authors to demonstrate most clearly the benefits of a disability

perspective on policy. Most of the articles address the potential effects of a minimal investment or reinvestment of resources on behalf of individuals who have acquired disabilities as adults. Thus, we chose not to address such important matters as the "handicapping" of race, class, and inheritance, or the prevention of impairments, the management of developmental disabilities, mental illness, and the education of children with disabilities. The role of rehabilitation as a medical discipline is addressed only in passing, as one of the methods that contribute to the goals of disability policy.

Public discussion about disability policy must be based on considerable knowledge about the extent and the consequences of impairment in the population. Just how many children, youth, working-age adults, and older people suffer what limitations on their ability to function (in families, communities, and the economy) as a result of which impairments and at what social cost? This is a different question than asking about the incidence and prevalence of morbidity in particular age cohorts. It is a different, and more difficult, question because limitations of function are influenced by social class, race, cultural values, economic status, and individual psychology as well as by diagnosis. Disability is socially constructed. Yet, it is a question that can be answered, if only partially, using existing tools of epidemiology, demography, and economics.

The articles by Manton (on disability among the elderly and its origins at earlier ages) and by Chirikos (on aggregate economic losses from disability) describe the problems of disability for the largest populations in our society. Manton is critical of the pervasive *laissez-faire* assumption that disability is the "natural" correlate of increasing age. He demonstrates how the priorities of policy could be rearranged if disability, rather than impairment, became its organizing framework: "The most efficient interventions involve prevention of disability by intervening in the early stages of the chronic disease processes producing the greatest proportion of disability in middle, and even early adult, years." If this action is taken, Manton observes, the prevalence of disability in later stages of adults' working lives will be reduced. Extending work ability may also allay some of the pressures for early retirement.

Chirikos suggests some of the economic consequences of our current policies. He calculates conservatively that aggregate national losses from functional disability in 1980 equalled 6.5 percent of the gross

national product. Had functional disability among working-age men and women been avoided or delayed, a potential per capita bonus of \$6,880 would have been added to the economy that year. Continuing gaps in national data sets pose difficulties for effective monitoring of disability and the impact of policy changes.

The relation between disability and work is central to policy for a variety of reasons, some of which are obvious, others less so. Work, broadly defined to include education and participation in families and other social groups, is probably the central activity by which individuals assert their worth and dignity and others assess it. There is also a strong societal interest in having a work force that is optimally productive in order to create resources to support and care for those who are, temporarily or permanently, less able than others. Yet too often, consideration of disability and work is focused almost exclusively on withdrawal from work—on the effects of levels of retirement benefits and wage rates on disability claims at different stages in business cycles.

The articles on work and disability in this supplement emphasize very different themes. Edward Yelin regards exclusive attention to the economic effects of disability claims as displacement from the central issue: rising disability among people in the work force, its effects on their lives, and their preferences among policies to address it. He deplores “blaming the disabled for their own plight in an economy gone sour.” Instead, Yelin advocates “more systematic and directed efforts to keep individuals with activity limitations in the labor force.”

James Robinson and Glenn Shor urge a new approach to some of the economic consequences of disability in a case study of the impact of the business cycle on work-related injuries in California. They demonstrate that the incidence of five types of disabling occupational injuries, occupational fatalities, and acute occupational illnesses is strongly influenced by cyclical economic fluctuations. Policy to reduce injury rates should address, they conclude, macroeconomic stabilization, health and safety training, and worker participation in shop-floor decision making.

Three articles offer comparative perspectives on important issues in disability policy. Richard Burkhauser and Petri Hirvonen examine policies for disabled workers in West Germany, Sweden, and the United States. They emphasize the significant differences in each

country's policies for temporary or partial disability as a result of how that country's values work. At one extreme is Sweden, where employment is regarded as a social obligation and where individuals who can return to or remain at work are required, and supported, to do so. The United States is the other extreme, with no public income-support policies for the partially disabled, except welfare and veterans' benefits, and generally weak policies to encourage people who leave the work force as a result of disability to return to it. West Germany is in between, mandating employers to hire persons with disabilities in the context of a flexible income-support policy and universal health insurance.

The United States, alone among industrial countries, predicates its national income and health program for impaired persons of working age—Social Security Disability Insurance—on permanent retirement from employment. Such an approach almost inevitably maximizes the likelihood that impairments will lead an individual to disability and even to a handicap. Edward Berkowitz explores the history of disability policy in Europe (and especially Britain) and the United States in order to explain the unique American emphasis on requirement from work. He describes how American values, and the political institutions that express them, have made it difficult to expand the scope and flexibility of Social Security as a true social-insurance program.

Gerald Markowitz and David Rosner compare responses to silicosis in the United States at different times in the twentieth century. Their article is a case study of how powerful groups in a society have negotiated about the causes and consequences of a disabling work-related condition, even when it is labelled as a disease with observable pathology. The occasions for these negotiations have usually been debates in the states and nationally about what policies are appropriate for treating and compensating people with particular disabling conditions.

Four articles address health policy in the United States for people with chronic illness and disability. Daniel M. Fox argues that the history of public and private policy for financing health services has been shaped by illness and disability—that is, by what he calls the epidemiological situation—as well as by ideas and by interest groups. He describes negotiations that have influenced the gradual accommodation of public and private health insurance to the increasing pressure of chronic illness and disability since the 1930s. Like Berk-



owitz and Markowitz and Rosner, Fox regards the history of our political and social institutions as the source of explanations for the policies we have chosen and how they have changed. In contrast to most other accounts of health policy, he finds that these institutions have adapted to the rising incidence and prevalence of disabling conditions, even if they have not been as responsive as many of their critics would have preferred.

Sandra Tanenbaum uses historical methods to explain how Medicaid has become a significant source of health care and related services for persons with disabilities. Medicaid now serves nearly one-half of all Americans too disabled to work. She explains this unanticipated priority of Medicaid policy in two ways. First, Medicaid has grown in the absence of alternatives. Second, and more important, Medicaid has been adaptable to the needs of people with disabilities who meet its income qualifications because of its origins as a welfare rather than a social insurance program. Welfare benefits are, historically, "plastic." Unlike insurance coverage, welfare benefits have traditionally blurred the boundaries between health and social services. Thus, Medicaid has proved to be uncommonly sensitive to the needs of disabled people for personal care in their homes, for drugs, and for assistive devices.

Gerben de Jong and his colleagues assess the adequacy of the medical care that is currently provided to adults with disabilities by public and private payers in the United States. As more people live longer with more chronic disease and disability, the inadequacies of our medical services will have greater social impact. Yet, the authors also argue that people with particular disabling conditions have special needs for health services. They caution that universalizing the concept of disability could have the negative effect of reducing attention to the needs of people who have severe disabilities.

Stanley Herr evaluates some of the problems of making policy through litigation about the rights of the disabled. Rights-based policy has, in the United States alone, become a significant alternative to policies made by executive and legislative branches of government. During the past several decades the federal courts have become significant sources of social policy for people with developmental disabilities. Services that "were once dispensed as charity have now been established as legal rights." Herr relates the ways lawyers have represented clients who are often unable to articulate their needs.

Most people with disabilities are, however, quite capable of speak-

ing for themselves and participating in the political institutions of our society. Richard Scotch describes how significant numbers of people with disabilities have mobilized to define the rights and social policies to which they believe they are entitled. To Scotch, disability rights activists became a social movement, as sociologists define that phrase, during the past two decades. He assesses the history and present situation of this movement. It remains unclear what will happen to the disability rights movement if disability becomes a significant organizing principle of social policy for everyone.

Irving K. Zola insists that this is precisely what should happen and that it is essential to adjust society to take account of the universality of disability. "What is done in the name of disability today will have meaning for all of society's tomorrows," he claims. Zola arrays recent evidence from research that persuades him that policies that enhance the ability of people with disabilities to live as independently as possible benefit society as a whole. Moreover, these measures need to be generalized for both the existing and potential population of people with disabilities. He chooses his examples from housing and transportation policy in order to complement the emphases of other articles in the supplement on policies for health, employment, and social services. Zola synthesizes advocacy for independent living in least-restrictive settings with arguments for universalizing health and social policy.

A number of important issues are not addressed in sufficient detail in this supplement because the authors who initially accepted commissions were unable to complete their essays. We regret three omissions which were very much part of our design. The first is an article, grounded in moral philosophy, on social obligations to people with disabilities. The article we envisioned would have examined the concept of the rights of the disabled and their claims on the collectivity.

The second regrettable omission is an article on how changes in technology have influenced the definition of disability and the array of policies to address it. The causal connections between technology and disability are familiar; for instance, the influence of neonatal intensive care on the prevalence of developmental disabilities or of a variety of technical innovations on enhancing mobility for people with paraplegia. Any projections of the numbers of people with disabilities and the nature of their problems must be based on estimates of the impact of new and existing technologies. Moreover, many technologies

are available or reimbursable by medical prescription only (for instance, wheelchairs and carts as well as prostheses), which raise important questions about the relation between medical care and disability policies.

A third regrettable omission is an article reciprocal to that by Richard Scotch focusing directly on conflicts and contradictions *within* the disability rights movement. Advocates for particular groups of people with disabilities have not always been comfortable with efforts to universalize disability policy. Some of them have formed alliances with special interest groups—abortion rights, for example—whose members do not generally advocate expanded entitlement to health care and social services. Others are claiming that people who acquire disabilities at birth or in childhood have different perceptions and problems than people whose disabilities are the result of injury or illness later in life. We invite other contributors to the *Milbank Quarterly* to remedy these omissions, as well as to write articles that challenge and augment those we have assembled.

This supplement makes a strong case that it is timely to reexamine some of the fundamental premises of health and social policy in the United States. Although each of the authors approaches this reexamination differently, all agree that the most useful purpose for health and social policy is to restore social and economic independence. Disability is a measure of what people can and cannot do for themselves and for others.

We have only begun to explore the implications of such a reorientation of policy. It is easy to imagine both positive and negative consequences of policies that reverse traditional priorities. Would, for instance, an emphasis on restoring independence expose in useful ways some of the contradictions and hypocrisy of much current policy? Would, on the other hand, an emphasis on restoring independence reduce the value we place on the alleviation of suffering? We encourage discussion and debate about such questions as a preferable alternative to the anguish, anger, and resignation, or to the preoccupation with financing to the exclusion of most other issues, that seem to characterize most debate about health and social policy in the United States as we enter the last decade of the century.

## References

- Locker, D. 1983. *Disability and Disadvantage: The Consequences of Chronic Illness*, London: Tavistock.
- Wood, P.H.N. 1983. Prospects for Control. In *Disability Prevention: The Global Challenge*, ed. John Wilson, 92. Oxford: Oxford University Press.
- World Health Organization. 1980. *International Classification of Impairments, Disabilities and Handicaps: A Manual of Classification Relating to the Consequences of Disease*. Published for trial purposes in accordance with resolution WHA29.35 of the Twenty-Ninth World Health Assembly, May 1976. Geneva: World Health Organization.

---

*Acknowledgments:* The editors were helped in identifying the themes addressed in this supplement by Ernest M. Gruenberg (Bethesda, Md.), Cille Kennedy (Johns Hopkins University), and John B. McKinlay (New England Research Institute). Attending a round table at Arden House in September 1988 as critical discussants of early drafts of these papers were: Sheila Akabas (Columbia University School of Social Work), Adrienne Asch (New Jersey Bioethics Commission), Norman Daniels (Tufts University), Pamela J. Doty (ASPE/Department of Health and Human Services), Richard J. Greene (Veterans Administration), Frederic W. Hafferty (University of Minnesota, Duluth), Williams S. Hoffman (United Automobile Workers), Tom Joe (Center for the Study of Social Policy, Washington), Robert Master (Boston University School of Public Health), Donald L. Patrick (University of Washington), Ray C. Rist (U.S. General Accounting Office), David J. Rothman (Columbia University College of Physicians and Surgeons), Judge Joseph Schneider (Circuit Court of Cook County, Illinois), and Rosemary Stevens (University of Pennsylvania). Sidney S. Lee, Visting Professor of Health Policy, Harvard Medical School, was president of the Milbank Memorial Fund when work began on this supplement; his interest and support are gratefully acknowledged.