Meeting the Health Care Needs of Persons with Disabilities

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THE MISSION OF THE AGENCY FOR HEALTHCARE Research and Quality (AHRQ) is to conduct and fund research to support improvement in health outcomes; strengthen quality measurement and improvement; and identify strategies to improve access to, encourage the appropriate use of, and reduce unnecessary expenditures in health care. The AHRQ's reauthorization (1999) directed the agency to address health care issues for such priority populations as low-income groups, minorities, women, children, the elderly, the disabled, and other individuals with special health care needs.

One of the AHRQ's responses was to establish the Office of Priority Populations Research to provide leadership for research on the improvement of health care for these populations. To achieve this goal, we are developing an agenda that addresses these populations' needs and also collaborates with other research funders. Identifying opportunities for health care research that improves health care for persons with disabilities (PWDs) will inevitably lead to debates about the relevance of current and prior research, whether the experiences of any of these populations are unique or shared with other groups, and how these research needs can best be met.

The articles in this issue of the *Milbank Quarterly* are an important first step (DeJong, Palsbo, Beatty, et al. 2002; Iezzoni 2002; Jette and Keyser 2002; Perrin 2002). In this article, we describe the background of the AHRQ's disability agenda and the opportunities for health care and health services research, and consider an agenda for disability-related health services research.

Challenges

The enactment of the Americans with Disabilities Act (ADA) in 1991 focused attention on the experiences and needs of PWDs in various areas of daily life, although health care delivery has been slower to come to the fore than other areas. In a health care system focused on diseases and procedures rather than populations, one challenge is defining the affected population. Relevant data come from many sources (e.g., National Health Interview Survey [NHIS], Survey of Income and Program Participation [SIPP], Behavioral Risk Factor Surveillance System [BRFSS]) and provide information on the prevalence of certain aspects of disability. Longitudinal data on incidence are restricted to special samples and studies (e.g., mature and older adults of the Health and Retirement Survey [HRS] and the Established Populations for Epidemiologic Studies of the Elderly [EPESE]). The heterogeneity of these populations—and the broad range of classifications and definitions—adds to the challenge of defining the group(s) that AHRQ should include in a research agenda. Whatever definition is used, the number of Americans with potentially special health care needs is substantial according to the following examples compiled from surveillance reports (Kraus, Stoddard, and Gilmartin 1996).

Estimates of the population with disabilities range from liberal (15% have some activity limitation) to restrictive (4.6% are unable to carry out their major activities, such as work for adults to age 64). The number of disabilities increases with age and in rural areas compared with urban areas and is disproportionately common for some ethnic minorities, for example, African Americans and Native Americans. In the 1990s the prevalence of disabilities rose among younger age groups but fell among older adults (LaPlante and Kaye 1998).

DeJong and his colleagues (DeJong, Palsbo, Beatty, et al. 2002) offer more details about the number of adults with disabilities and also

analyze the reasons for the changes. Since most of their information is from cross-sectional surveys, our current understanding of changes and transitions over time is strikingly limited. Beyond the definitions, however, demographic changes indicate continued growth in the number of PWDs and in the challenges confronting the health care system to provide high-quality care.

The expectations of people with disabilities and their perception of health care researchers should be included in a research agenda to improve health care for PWDs. Because of the apparent alienation of the disability movement from public health and medicine, PWDs believe that the subjects of investigations should also participate in the research (e.g., Charlton 1998; Seekins, Smith, and McCleary 1992; Stone and Priestly 1996). Accordingly, some funders require such participation (NIDRR 1998), and ethical guidelines often recommend involving the groups and communities affected by the results of research (e.g., ACE Ethics Guidelines 2000). Involving the intended beneficiaries of research is not a new idea to health services research. For example, "patient-centered" outcomes have become important to research questions (e.g., Curtis 1998; Fowler, MacRae, Stern, et al. 1999). Even though advocates and researchers may continue to discuss the boundaries of "participation," effective interactions between researchers and PWDs should contribute to understanding and improving health care. The consumers will benefit from participating; the researchers will have to resolve their concerns about losing control of their scientific questions.

Development of the Science

The priorities for health care research are based on work by a broad spectrum of federal, health care, and consumer agencies. One of these, the Institute of Medicine, supported two national committees on disability topics in the 1990s to address the health needs of PWDs and make recommendations.

The first committee's report, *Disability in America*, was supported by the Centers for Disease Control and Prevention (CDC) and the National Council on Disability (NCD) and was intended as a national agenda for prevention (IOM 1991). The report recommended moving away from a "medical model" that considers disabilities according to diagnoses and

impairments to a model that does not consider disability synonymous with impairment. Instead, disability is seen as a social construct, that is, an impairment in regard to all aspects of society, and is a change that has made it easier for disability consumers, advocates, and the research community to communicate with one another. The report also recommended that the CDC take the lead in drawing up a disability prevention program and agenda. Notably absent was a plan for health services research topics, although future assessments of some components of health care, such as assistive technology, were suggested.

In addition, the committee recommended that more attention be paid to such health services research questions as how to measure disability, the effectiveness of and access to rehabilitation services, and the need for longitudinal data to analyze various aspects of disabilities and outcomes. One result of the report has been the establishment of “secondary conditions”—conditions that are more common among persons with certain primary impairments (e.g., skin problems for people with lower limb immobility). Accordingly, research priorities include demonstrating a connection between adequate health services and a lower incidence of secondary conditions, similar to the questions addressed in outcomes research for specific conditions.

The IOM followed its 1991 report with another that looked at rehabilitation science, a core disability health care service (IOM 1997). This report also described the limits of the research on rehabilitation science, with recommendations for future directions and increased funding. The report recognized the central role of the National Institute on Disability and Rehabilitation Research (NIDRR), including the committee’s finding that about 48 percent of the federal funds targeted to rehabilitation research were from the NIDRR. Both the current and future research agendas included research by and funding of agencies such as the AHRQ (formerly AHCPR), the U.S. Department of Veterans Affairs, and the CDC. The report also summarizes health services research, example studies and methods, and priorities in rehabilitation science and service, and it describes the need for health services research to offer multidisciplinary training at the doctoral and postdoctoral levels.

The IOM reports helped make the transition from a medical model to a social/contextual model. This transition also is apparent in the recently revised companion to the *International Classification of Diseases*, which is the World Health Organization’s most recent version of the *International Classification of Functioning, Health and Disability* (ICF,

formerly *ICIDH*) (World Health Organization 2001). The *International Classification*'s coding scheme enables very detailed coding of individuals based on their body functions and structures, activities and participation, and environmental factors. The previous classification system was not widely used in American health care settings. But the current system has been endorsed by the National Committee on Vital and Health Statistics as a "promising approach to coding functional status information in computerized patients records and standardized data sets" (U.S. Department of Health and Human Services 2001). At present, however, there is not a clear consensus in the United States regarding its utility in the agenda of disability and health service research.

Reasons for the Present Emphasis on Health Care

The ADA provides general and broad protection of civil rights of people with disabilities, and to protect these rights, we must investigate issues such as access to quality health care and even access to health care researchers (Meyers and Andresen 2000). Here, our use of "access to care" refers to physical accommodations in the built environment of medical care facilities (e.g., Fowler, MacRae, Stern, et al. 1999). Beyond the recommendations for a "universal design" for medical care offices (e.g., Jones and Tamari 1997), there are only sporadic confirmations that such accommodations exist at any level (e.g., Kramer 1990).

A recent analysis of data from the 1994 and 1995 National Health Interview Surveys found that few women with major mobility impairments, compared with other women, were given Pap smears and mammogram screening and speculated that this might be partly due to inaccessible equipment (Iezzoni, McCarthy, Davi, et al. 2000). The differences in health care access for persons with disabilities is only one example of the need for more health services research.

Changes in the organization and financing of the health care industry also account for this new emphasis on both health services research and people with disabilities. Managed care, including Medicare, Medicaid, and disability programs, has grown rapidly over the past decade (e.g., DeJong, Palsbo, Beatty, et al. 2002). The increase in managed care, patients' rights, and quality indicators (including

consumer satisfaction and experiences of care) and the enrollment of more Americans in some kind of managed care program, plus the growing demands for accountability, offer several opportunities for research on which services are most effective and how much they cost for individuals with multiple needs. The results of such inquiries are needed for new benefit designs and efforts to improve the quality of care for PWDs.

Health services research that improves health care for PWDs is similar to health outcomes research, which is defined as “research that studies the end results of the structure and process of health care on the health and well-being of patients & populations” (Foundation for Health Services Research 1994). In an expanded definition, Clancy and Eisenberg described this research as follows:

The dimensions of health and well-being that encompass consequences for the daily lives of individual patients are referred to as health-related quality of life (HRQL). Broad aspects of HRQL include health perceptions, symptoms, functioning, and patients’ preferences and values. The sum of these constitutes a continuum of effects of health care services in health and well-being ranging from mortality to patient satisfaction. (1998, 245)

A broad evaluation of the return on investments in health care for PWDs is a logical, albeit underdeveloped, component of health outcomes research.

Another important motivation for a research agenda that includes disability outcomes is *Healthy People 2010*, which, for the first time, addresses health goals for people with disabilities as a subgroup similar to other populations requiring special attention (U.S. Department of Health and Human Services 2000). Chapter 6 of *Healthy People 2010* lists 13 objectives covering a range of health goals. The first goal is data and surveillance and asks for standard questions to define disability among federal data sets. Here, disability is viewed as another demographic variable that provides a method and rationale for examining differences in health and health care. Disability is also included as a component of many more of *Healthy People 2010*’s goals. More discussions about the best way to define or classify people with disabilities are likely, and the next decade should bring a much larger menu of data resources for health services researchers.

Strategies and Selected Priorities

Improving health care for PWDs is a logical evolution in health care research. Similar to other areas of health care research, a research agenda that takes into consideration the needs of PWDs should include questions relevant to PWDs, data and methods development and training, and studies evaluating the strategies for translating into practice the results of research. Additional challenges for the AHRQ and other funders are developing research investments and implementing strategies for conducting and supporting the research. Such strategies may include policies to ensure the participation of PWDs in current and future health care research studies and database development, as well as support for studies of and data on PWDs and for studies of the challenges common to all or most of the priority populations identified in the AHRQ's legislation. Next we briefly discuss these approaches.

Including People with Disabilities in Health Services Research

The aging of the population of the United States and all developed nations, combined with substantial increases in life expectancy, has made the improvement of care for persons with one or more chronic conditions even more important. For this population, because the expected outcome of health care is the improvement or maintenance of functional status rather than cure, the inclusion of disability-relevant outcomes such as independence is "logical." Moreover, the question of which patient-reported outcomes relevant to PWDs can be attributed to health care is closely related to current efforts in health outcomes research, which usually focuses on disease- or condition-specific measures of "outcome."

Although many of the AHRQ's current and past investments in outcomes research have been based on specific clinical conditions, many studies could be expanded to important areas of disability in addition to the metrics defined by clinical conditions. Research that shows which financial and organizational characteristics support the provision of patient-centered care, as emphasized in the IOM report *Crossing the Quality Chasm*, also is relevant to persons with disabilities (IOM 2001). For example, the concerns of people with disabilities about poorly coordinated services across settings and providers are not inherently different

from those of people with specific chronic conditions. In regard to policy, the distribution of health care expenditures has long been recognized as critical to health services research, and PWDs are likely to be disproportionately represented in the minority of the population that accounts for the majority of health spending. Other recommendations are disability supplements to the Medical Expenditure Panel Survey or other national surveys. Current health services research could specify persons with disabilities when soliciting funds to ensure their inclusion in priority areas such as medical errors and patient safety. The success of this strategy will depend on whether PWDs see that their needs are being seriously considered in such research.

Common Challenges of Priority Populations

Many of the health care needs of persons with disabilities are the same as those of the elderly, persons with chronic illness, children, low-income groups, and others. An issue for all these groups is determining medical necessity and insurance coverage. Criteria that rely exclusively on evidence linking health care to improved outcomes will exclude many groups—and even much health care—because of a lack of evidence. But a lack of evidence of effectiveness is not the same as evidence of ineffectiveness. What, then, should be the basis for coverage when evidence is limited, particularly for services that are acknowledged to be helpful (e.g., durable medical equipment, selected rehabilitative services, services that enhance independence at home or in the community) but are not always included in benefits packages? Other issues include support for caregivers, the intersection of health and supportive social services, and the effects of two or more characteristics associated with vulnerability, for example, race and disability or socioeconomic position, age, and disability.

The Special Needs of People with Disabilities

Enhancing health care for people with disabilities is clearly necessary. Not all disability researchers would agree that a health care or “medical” model can be successfully adapted to resolve all issues for PWDs. At this time there is no consensus on a framework for disability research that pays sufficient attention to the intersection of personal characteristics, environmental factors, and health care. In fact, there is little guidance for

defining and measuring environmental factors. Health services research studies typically analyze the individual, provider, or organization but rarely a population defined by functional limitations, a fact of which people with disabilities are painfully aware. More empirical work is needed to clarify the health care implications of different definitions of disability and the dynamics of the population defined as disabled as well as any overlaps between populations defined by functional limitations and those defined by specific diagnoses. Other issues specific to PWDs are access to health care and health care settings, the use of restorative technologies, evidence of the effectiveness of various rehabilitative services, and discrimination by health care providers.

Training

An agenda for improving health care for PWDs must be linked with training programs in health care research. The AHRQ currently provides several training aids for future health services researchers. The AHRQ's allocation of National Research Service Awards (NRSAs) was approximately \$7 million in fiscal year 2000. These aids include support for dissertations (RO3), fellowships (F32), postdoctoral mentored (K08) and independent scientist awards (K02), institutional training grants (T32), and opportunities to train on-site with AHRQ scientists (Kerr White Visiting Scholars Program). The AHRQ's interests in training researchers mirror the scientific agenda to work on priority health care issues and with priority populations. Attracting a diverse group of applicants to these programs, including researchers from the disability community, will enrich the AHRQ's disability research agenda.

Future Directions

The themes described briefly here and in more detail in this issue of the *Milbank Quarterly* touch on a variety of opportunities for health care research to improve care for people with disabilities in particular and to inform health system requirements for the current and future U.S. population in general. For no other population are the challenges and opportunities of supporting research informed by the expressed needs of the users or target population more clearly delineated. Strategies for the coordination and integration of research initiatives sponsored by public and private research funders are essential to ensure the greatest benefit.

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