

Originally Processed With FOIA(s):

S

FOIA Number:

S

FOIA MARKER

**This is not a textual record. This is used as an
administrative marker by the George Bush Presidential
Library Staff.**

Record Group/Collection:	Donated Historical Materials
Collection/Office of Origin:	Frieden, Lex, Collection
Series:	Related Materials
Subseries:	Conferences

OA/ID Number:	52080
Folder ID Number:	52080-003

Folder Title:

"Developing a Comprehensive Health Services Research Capacity in Physical Disability and Rehabilitation, August 1991"

Stack:

Row:

Section:

Shelf:

Position:

**DEVELOPING A COMPREHENSIVE
HEALTH SERVICES RESEARCH CAPACITY IN
PHYSICAL DISABILITY AND REHABILITATION**

**Proceedings of the NRH
National Invitational Conference
to Develop a Research Agenda**

Conducted by:

National Rehabilitation Hospital Research Center
Medlantic Research Foundation
Washington, D.C.

Sponsored by:

The National Institute on Disability and
Rehabilitation Research
U.S. Department of Education
Washington, D.C.

August 1991

DEVELOPING A COMPREHENSIVE HEALTH SERVICES RESEARCH CAPACITY IN PHYSICAL DISABILITY AND REHABILITATION

Proceedings of the NRH National Invitational Conference to Develop a Research Agenda

Conducted by:

National Rehabilitation Hospital Research Center
Medlantic Research Foundation
Washington, D.C.

Sponsored by:

The National Institute on Disability and
Rehabilitation Research
U.S. Department of Education
Washington, D.C.

August 1991

By:

Andrew I. Batavia, J.D., M.S.*

Gerben DeJong, Ph.D.

Jessica Scheer, Ph.D.

Ruth Brannon, M.S.P.H.

Marsha G. Meehan

Deborah Wilkerson, M.A.

Naomi Naierman, M.P.A.

* Mr. Batavia is currently on leave of absence from the NRH Research Center while serving as a White House Fellow as Special Assistant to the Attorney General in the Department of Justice. The views expressed in this report are not intended to be construed as those of any federal agency with which Mr. Batavia has been or is currently associated.

Supplemental funding for this conference was made possible with a gift from the American Reinsurance Company of Princeton, New Jersey.

August 23, 1991

William H. Graves, Ed.D., Director
National Institute on Disability
and Rehabilitation Research
U.S. Department of Education
Room 3060
400 Maryland Avenue, S.W.
Washington, D.C. 20202-2572

Dear Dr. Graves:

The NRH Research Center is pleased to forward our conference report entitled, *Developing a Comprehensive Health Services Research Agenda in Physical Disability and Rehabilitation*. This report is the proceedings of the National Invitational Conference held last fall under the direction of the NRH Research Center and the sponsorship of the NIDRR. Supplemental support was provided by the American Reinsurance Company.

The report makes a number of far-reaching recommendations for the development of a health services research agenda in the areas of trauma care, medical rehabilitation organization and financing, personal assistance services, and long-term care. Issues related to the primary health care needs of persons with disabilities were addressed at an earlier conference also conducted by the NRH Research Center and sponsored by NIDRR. The recommendations of this earlier conference are summarized in a 1989 report entitled, *Meeting the Primary Health Care Needs of Persons with Physical Disabilities: Setting the Agenda*.

We believe that this conference report will assist NIDRR and other research funding organizations in identifying the issues most urgently in need of research support. We are pleased to know that, as indicated in your speech at the conference, the recommendations of the conference will be considered in the development of NIDRR's long-range plan currently underway.

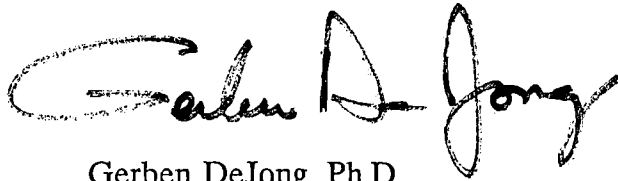
Because the delivery of health services to persons with disabilities is affected by a number of public agencies and private organizations, we believe that it is important that NIDRR share the report's recommendations with other key federal agencies concerned with health care delivery issues. One of our abiding concerns is that many federal agencies do not understand adequately the health care

William H. Graves, Ed.D.
August 23, 1991

needs of persons with disabilities. NIDRR's leadership on this matter within the federal establishment and elsewhere is essential.

We appreciate knowing of your concern for the health care needs of persons with disabilities and how these services are vital to an individual's ability to live independently and productively in keeping with the vision of the recently enacted Americans with Disabilities Act. We believe that this conference report will provide NIDRR and other federal agencies the road map they need to chart a course for the development of a health service research agenda in physical disability and rehabilitation.

Sincerely,

A handwritten signature in black ink, appearing to read "Gerben DeJong". The signature is fluid and cursive, with a large initial "G" and "D".

Gerben DeJong, Ph.D.
Director

GDJ:bmd

TABLE OF CONTENTS

I. Introduction	1
Background	1
Conference Agenda	2
Conference Participants	3
Conference Structure	3
 II. The Speeches	 5
Opening Remarks	6
Gerben DeJong, Ph.D., Director National Rehabilitation Hospital Research Center	
Greetings from NRH	8
Edward A. Eckenhoff, M.H.A., President National Rehabilitation Hospital	
Welcome From NIDRR	9
William Graves, Ph.D., Director National Institute on Disability and Rehabilitation Research U.S. Department of Education	
Prevention and Access to Health Care: Priorities for Health Services Research in Physical Disability	11
Keynote Address James O. Mason, M.D., Assistant Secretary for Health U.S. Department of Health and Human Services	
The Cost of Disability and Implications for Health Services Research	17
Ellen J. MacKenzie, Ph.D., Assistant Director Health Services Research and Development Center Professor, Department of Health Policy and Management Johns Hopkins University School of Hygiene and Public Health	
Toward a Health Services Research Capability in Medical Rehabilitation	24
Richard Materson, M.D., Medical Director and Vice President National Rehabilitation Hospital	
An Independent Living Perspective on Health Services Research	28
Judith Heumann, M.P.H., Director World Institute on Disability	

III. Panel Presentations	33
The Role of NIDRR	34
J. Paul Thomas, Ph.D., National Institute on Disability and Rehabilitation Research	
The Role of the Health Services Research Community	38
Stephen C. Crane, Ph.D., Association for Health Services Research	
The Role of the Agency for Health Care Policy and Research	41
J. Michael Fitzmaurice, Ph.D., Agency for Health Care Policy and Research	
The Role of the Rehabilitation Research Community	45
Marcus J. Fuhrer, Ph.D., Baylor College of Medicine The Institute for Rehabilitation and Research	
The Role of NIH	48
Lynn Gerber, M.D., National Institutes of Health	
The Role of Disability Organizations	51
Mary Jane Owen, M.S.W., Disability Focus, Inc.	
The Role of the Foundation Community	55
Randy Davis, The Dole Foundation	
IV. Workshop Sessions— Guidelines and Recommendations	57
Trauma Care	58
Medical Rehabilitation – Financing	63
Medical Rehabilitation – Organization	69
Personal Assistance Services	75
Institutional Long-term Care	83
V. Closing Remarks	87
Gerben DeJong, Ph.D., Director National Rehabilitation Hospital Research Center	
References	91
Appendices	93
A. Conference Participants	95
B. Conference Planning Committee	105
C. "Developing a Comprehensive Health Services Capacity in Physical Disability and Rehabilitation," Andrew I. Batavia and Gerben DeJong, <i>Journal of Disability Policy Studies</i>	107

ACKNOWLEDGEMENTS

The National Rehabilitation Hospital Research Center (NRH-RC) wishes to thank the National Institute on Disability and Rehabilitation Research (NIDRR) of the U.S. Department of Education for sponsoring this conference through Innovation Grant #H133C9001. The following individuals deserve particular credit for their strong support of the conference and its objectives: William Graves, Ph.D., Director of NIDRR; David Gray, Ph.D., former Director of NIDRR; James Reswick, Sc.D., Research Director of NIDRR; J. Paul Thomas, Ph.D., Director of the NIDRR Medical Sciences Program; and Toby Lawrence, the NIDRR project officer for the conference. We are similarly grateful to Joseph Adamczyk of the American Reinsurance Corporation for helping to secure supplemental support for the conference.

We thank James Mason, M.D., Assistant Secretary for Health of the U.S. Department of Health and Human Services, who served as the keynote speaker for the conference. We also thank the other excellent speakers who are listed in Chapters II and III, and whose speeches and panel presentations are summarized in those chapters. The conference moderators, recorders, and participants deserve substantial recognition for providing their expertise, as reflected in the recommendations presented in these proceedings. The names of moderators and recorders are listed in Chapter IV, and the names and affiliations of all conference participants are listed in Appendix A.

Finally, we want to thank Edward A. Eckenhoff, M.H.A., President of the National Rehabilitation Hospital (NRH), and our other colleagues at NRH who provided their support for this conference, including: Richard Materson, M.D., Medical Director; Robert Hartman, Director of Marketing and Public Affairs; and Patricia Van Sickle, Director of Patient Relations and Volunteer Services.

The Authors

CHAPTER I

INTRODUCTION

On September 26 and 27, 1990, the National Rehabilitation Hospital Research Center (NRH-RC) in Washington, D.C., conducted the first national invitational conference on health services research (HSR) in the areas of physical disability and rehabilitation. The conference, held at the Ramada Renaissance Techworld Hotel in Washington, D.C., assembled many of the most prominent experts in a variety of fields associated with HSR and disability research. Participants included representatives of national and local disability organizations, physiatrists and other health care practitioners, health services researchers, representatives of insurers and other payor organizations, and public sector policy makers.¹

The conference addressed research issues on the organization, provision, and financing of (a) trauma care, (b) medical rehabilitation services, (c) personal assistance services, and (d) institutional long-term care. The general goals of the conference were to:

- 1) identify and prioritize the leading HSR issues in physical disability and rehabilitation;
- 2) determine the adequacy of the current HSR capacity in physical disability and rehabilitation;
- 3) identify innovative approaches to the development of a comprehensive HSR capacity in physical disability and rehabilitation; and
- 4) recommend essential components of an HSR agenda in physical disability and rehabilitation.

Background

Health services research is the field of research that systematically examines the organization, provision, and financing of health care services. HSR draws on the skills of many disciplines, including bioethics, biostatistics, health care economics, epidemiology, health care financing, health law, political science, medicine, allied health, and medical sociology. Health services researchers commonly consider issues

¹ A list of conference participants and their affiliations is provided as Appendix A.

concerning access, cost, efficiency, effectiveness, and quality of health care services (Batavia & DeJong, 1990).

In addressing HSR in the area of physical disability and rehabilitation, the conference focused primarily on the needs of persons with neurological and mobility impairments such as head injury, spinal cord injury, cerebral palsy and post-polio syndrome. People with such disabilities face certain common problems. Among these are high susceptibility to pressure sores (decubitus ulcers), urinary tract infections, respiratory infections, and scoliosis; high rates of health care utilization, including emergency room visits, hospitalization, and other forms of institutionalization; and poor access to health care providers (DeJong, Batavia & Griss, 1989).

While the conference focused primarily on the needs of persons with neurological and mobility impairments, it also recognized the need for HSR to address the concerns of persons with other physical, cognitive, and sensory disabilities such as those caused by hearing, speech, or visual impairments.

Conference Agenda

The conference focused on identifying HSR issues in four general areas of care that affect persons with physical disabilities:

- trauma care
- medical rehabilitation services
- attendant care and personal assistance
- institutional long-term care

Because of the large number of participants from the medical rehabilitation field, the area of medical rehabilitation was divided into two sub-areas: rehabilitation organization and rehabilitation financing.

During the conference, national experts on health care and disability research made presentations on issues important to the conference objectives. These presentations helped to inform the deliberations of working groups, to which each conference participant was assigned. The working groups met several times over the two-day conference to develop guidelines and recommendations for research in each area. These recommendations were presented to all conference participants in a plenary session at the end of the conference.

Conference Participants

Because this was the first national conference of its kind, and because it involved a newly emerging field of inquiry, invitations were limited to 65 participants with recognized expertise in the area of disability-related health care. The experts invited to the conference included persons who:

- have made substantial research contributions to the field of HSR for persons with disabilities or disability research in the health care field;
- are recognized authorities on the financing, organization, or provision of health care for disabled persons;
- have first-hand clinical experience either as a provider or as a consumer of health care services for disabled persons; and/or
- are in policy-making positions that bear significantly upon issues of health care or HSR for persons with physical disabilities.

A number of professions and academic disciplines were represented at the conference, including rehabilitation medicine, family and community medicine, health care administration, health policy, medical sociology, medical economics, health law, and health insurance. Among the participants were representatives of public- and private-sector agencies, including representatives of national and local disability organizations. A substantial number of participants were health care professionals with physical disabilities. They offered both a consumer and professional perspective on HSR and disability.

Conference Structure

To provide a point of departure for conference discussions, researchers of the National Rehabilitation Hospital Research Center developed and disseminated three papers addressing the health care needs of persons with physical disabilities (DeJong, Batavia & Griss, 1989; Batavia & DeJong, 1990;² DeJong & Batavia, 1991). They also conducted a pre-conference survey of the invited experts on the most important issues concerning HSR and disability.

² This article, "Developing a Comprehensive Health Services Research Capacity in Physical Disability and Rehabilitation," which was published in Volume 1 of the *Journal of Disability Policy Studies*, is included as Appendix C.

Through a series of speeches and workshops, the conference examined approaches currently being tested or contemplated to address issues in each of the four areas of health care delineated above. It focused specifically on the adequacy of the current knowledge base in each area, unresolved issues and major challenges, the capacity of HSR and disability research communities to address these issues, and recommendations for research priorities and capacity building.

The speeches provided background information on these areas of inquiry. The group workshops provided an opportunity for in-depth discussion and development of conclusions and recommendations for each of the four areas of care addressed. These proceedings present the views and recommendations of the speakers and conference participants. They are designed to assist policy makers in setting the agenda for research and for the development of research capacity that will strengthen the nation's ability to respond to the health care needs of persons with disabilities.

CHAPTER II

THE SPEECHES

The conference featured seven speakers who addressed topics of importance to HSR and persons with physical disabilities. The speakers were:

Gerben DeJong, Ph.D., Director of the National Rehabilitation Hospital Research Center, and Professor at the Department of Family and Community Medicine of Georgetown University School of Medicine, who presented opening and closing remarks;

Edward A. Eckenhoff, M.H.A., President of the National Rehabilitation Hospital, who discussed the importance of HSR to persons with disabilities and the health care professionals who assist them;

William Graves, Ph.D., Director of the National Institute on Disability and Rehabilitation Research, the primary sponsor of this conference, who provided welcoming remarks from NIDRR;

James Mason, M.D., Assistant Secretary for Health of the U.S. Department of Health and Human Services, who presented the keynote address in which he discussed the federal government's capacity for HSR in the area of physical disability and rehabilitation;

Ellen J. MacKenzie, Ph.D., Assistant Director of the Health Services Research and Development Center, and Professor in the Department of Health Policy and Management of the Johns Hopkins University School of Hygiene and Public Health, who discussed the costs of physical disability and issues associated with assessing such costs;

Richard Materson, M.D., Medical Director and Vice President of the National Rehabilitation Hospital, who spoke on developing an HSR capacity in medical rehabilitation;

Judith Heumann, M.P.H., Director of the World Institute on Disability, who presented an independent living perspective on HSR, including perceptions of the health care system by persons with disabilities.

The following sections present key excerpts from their speeches and presentations.

Opening Remarks

**Gerben DeJong, Ph.D., Director
National Rehabilitation Hospital Research Center**

- This conference was motivated by the current lack of a comprehensive health services research capacity in physical disability and medical rehabilitation – a lack of what I would call an HSR infrastructure. Such an infrastructure does exist in bits and pieces scattered around the country, but it is not very organized at this time.
- If you look at the HSR literature, you will see an almost total absence of any mention of physical disability or medical rehabilitation. I don't know if that is an indictment of the HSR community or of the disability and rehabilitation research community for having failed to penetrate that literature effectively.
- The medical rehabilitation industry is one of the fastest growing sectors of the health care economy today. It is something of a travesty that this industry has been largely overlooked by the HSR community until very recently.
- The working-age disabled population is growing at a far faster rate than is the elderly disabled population. Many people simply are not aware of this, but any review of the national survey data demonstrates it clearly. Yet, the working-age disabled population is one of the least studied populations in health care (DeJong, Batavia & Griss, 1989).
- In addition, the post-rehabilitation health care needs of persons with disabilities are not well understood. In fact, there is really no medical specialty that advocates on behalf of disabled people once they have finished their medical rehabilitation. Yet, we know that people with disabilities are high users of health care services after rehabilitation.
- Some important statistics highlight the need for this conference. For example, people who are unable to carry on their major activity are six times more likely to be hospitalized and incur six times the amount of hospital costs than do persons who are not disabled or have no activity limitations. We also know that 18 percent of those who have a work disability (persons who are unable to work or limited in their work) have no access to either private or public health insurance (DeJong, Batavia & Griss, 1989).

- If we are going to live up to the promise of the Americans with Disabilities Act, then we also must address the health care issues that have precipitated this gathering. People with disabilities must be assisted in maintaining their health so that they will be able to take advantage of the employment, transportation, communication, and public accommodations opportunities that will be brought about through the ADA.

Greetings from NRH

**Edward A. Eckenhoff, M.H.A., President
National Rehabilitation Hospital**

- I bring you greetings from NRH and its nearly 1,000 staff members. Our hospital has five very important missions: (1) to be an excellent care-giving facility, (2) to be a center for meaningful research, (3) to be a center for training and education, (4) to be a center for rehabilitation engineering, and (5) to be a strong institutional advocate for disabled people. Research is absolutely essential to the medical and social progress of the disabled population. We have to do a great deal more to support research, and particularly health services research, than we ever have before.
- As a person with a disability myself, I am a direct consumer of the research that this conference advocates. My body, while it is not crumbling, is beginning to show the effects of having walked on crutches for nearly 30 years. Other persons with disabilities have other disability-related health problems, and many of these problems are aggravated by the aging process. Additional research is needed to enhance the ability of the health care system to meet the specific needs of disabled persons as they get older.
- I am also concerned about issues of health insurance for disabled persons and about the financing of care provided in rehabilitation hospitals and other health care facilities that address the needs of disabled persons. I am particularly concerned about the payment policies of HMOs and PPOs. Everybody is tightening their belts. That means that there are likely to be, in many respects, fewer services available to disabled persons. Research is needed on expanding the availability of adequate, affordable health insurance for disabled persons to ensure the adequate financing of their care.
- Therefore, I am personally very supportive of this conference. I would like very much to thank NIDRR and its director, Dr. William Graves, for serving as the conference's primary sponsor. I also would like to thank the American Reinsurance Corporation, which also provided essential funding. Finally, I want all of the participants to know that our hospital very much supports your efforts over the next two days and the important research that will emerge from this conference in the years to come.

Introductory Remarks

**William Graves, Ph.D., Director
National Institute on Disability and Rehabilitation Research
U.S. Department of Education**

- I am very pleased to see all of you here this morning to address issues surrounding comprehensive health services research for people with disabilities. Let me say, first of all, welcome to Washington. NIDRR is delighted that you are here in the nation's capital to discuss research issues on the organization, provision, and financing of trauma care, medical rehabilitation services, attendant care and other personal assistance services, and long-term institutional care.
- Each of these topics is vitally important. Each strongly affects the amount of independence experienced by women, men, and children having disabilities, as well as their families. This conference will help shape our nation's vision of the HSR needs in physical disability and rehabilitation. With the results of research in this area, our nation will move closer to providing a comprehensive array of health services that includes prevention, acute care, rehabilitation, and primary care. These services are essential in fostering community integration for persons with disabilities.
- Individuals with physical disabilities have different health care needs than people with acute illnesses. This tenet is only beginning to be understood in the development of public policy. Increased research is needed to identify these differences and to develop health services that are responsive to them.
- Recent studies show that some diagnostic groups use greater amounts of health services than others. The reasons for these different utilization patterns are unknown. Does the system meet the needs of one group better than the other? Or, is the system so unresponsive that some groups use fewer services because members know the system does not work for them? We do not know the answers to these kinds of questions, but we know that additional research is needed to answer them.
- NIDRR is pleased to co-sponsor this important conference. As I look around this room, I see some of the country's most qualified and influential researchers ready and willing to contribute their abilities and wisdom in meeting the objectives of this conference. I am especially interested in the priorities that you identify as leading HSR issues, particularly those that are germane to the mission of NIDRR.

- I can assure you these recommendations will be considered in the development of NIDRR's long-range plan. As you know, NIDRR has a limited budget. This limitation does not, however, negate the Institute's role in serving as a catalyst within the federal government and the foundation community. Through this conference, we hope to foster a greater awareness of the need for an enhanced research capacity that responds to, and anticipates, the health care needs of people with disabilities.
- Among the first items I will place on the agenda of the newly-revitalized Interagency Committee on Disability Research will be issues this conference identifies as important in meeting the comprehensive health care needs of persons with disabilities. It is unfortunate that, over the past decade or so, the disability and rehabilitation research community has overlooked questions surrounding the need for a comprehensive HSR capacity in this nation. However, those of us in the disability and rehabilitation research community must not take all the blame for this neglect; the HSR community also has overlooked these issues.
- I am very pleased that Dr. James Mason, the Assistant Secretary for Health at the Department of Health and Human Services, will deliver the keynote address following these brief remarks. His presence as keynote speaker is a clear signal that the issues to be addressed in this conference will no longer be neglected. All of us in the federal government will place issues affecting the health and well-being of people with disabilities high on the public policy agenda.
- We appreciate the commitment you are making to these important issues. It is through the work of groups of distinguished scholars and individuals with disabilities that true progress will be made in empowering people with disabilities to enjoy the freedoms and responsibilities of this great nation.

Prevention and Access to Health Care: Priorities for Health Services Research In Physical Disability

James O. Mason, M.D.
Assistant Secretary for Health
U.S. Department of Health and Human Services

Keynote Address
September 26, 1990

First, let me commend the National Institute on Disability and Rehabilitation Research and the National Rehabilitation Hospital Research Center for organizing this most important conference. A generation ago – even as little as a decade ago – there couldn't, or wouldn't, have been such a far-reaching conference as this. Issues involving physical disability and rehabilitation research weren't then as high as they are today on the agenda of the public or private health care sector.

Remember, it wasn't until the late 1950s that the federal government first acknowledged the fact of disability to the point where it established the Social Security Disability Insurance program and the Aid to the Totally and Permanently Disabled program, the precursor of today's Supplemental Security Income program. Before then, there was little or nothing other than state aid to some disabled workers. Today, these federal programs alone pay more than \$32 *billion* annually to more than 3 million former workers classified as permanently and totally disabled, 1.2 million of their dependents, and two million more disabled men, women, and children who don't qualify for Social Security Disability benefits.

And remember, it was only *this* year that our national consciousness of the special needs of those with disabilities led the Congress to pass, and President Bush to sign, the Americans with Disabilities Act. This serves to highlight the growing need for primary and extended health care for this population *and* the need for new avenues of research.

Your agenda highlights the issues of prevention of secondary disabilities, access to quality care for the disabled, and research to improve prevention, treatment and rehabilitation. Just two weeks ago, the Public Health Service – in consort with nearly 300 state, local, private, and voluntary health organizations – spelled out an ambitious agenda of health promotion and disease prevention objectives for the nation for the decade to come. In that blueprint for action, which we call *Healthy People 2000*, people with disabilities are highlighted as a special population group with accentuated needs for health promotion and access to quality care.

There is much to be done to improve the health status of America's people with disabilities and the health care services delivered to them. And there is much to learn about how to best organize and finance those services. You can be sure that this will be prominent on the agenda of Under Secretary Constance Horner's working group on health care financing – and will be discussed at a cabinet level review of the group's recommendations later this year. President Bush, in his State of the Union message last January, asked Secretary Louis W. Sullivan to bring recommendations to the Domestic Policy Council. This conference, with its focus on health services research, is an excellent opportunity to more clearly define the issues and begin to address the "next steps."

Over 43 million Americans have a measurable disability of one kind or another. And who are these people? About 33 million have physical or mental impairments that limit their activity. That means they may not be able to participate in the workplace. Or if they do, they may not be able to function in the same manner as their non-disabled co-workers. That does not mean they do any less work. Many do even more than their co-workers. More than nine million of these Americans have functional limitations so severe that they cannot work at all, attend school, or even maintain a household. Two million are in institutions because of their functional limitations.

For many of these Americans, injury is the cause of their disabilities. For others, the underlying problem may be (1) arthritis, (2) heart disease, (3) spinal curvature, (4) back ailments or impairments of lower extremities, or (5) intervertebral disk disorders. These are the top five chronic conditions causing activity limitations. For our children, the most prevalent types of disability are mental retardation, birth defects, asthma, mental illness, hearing impairments, and speech impairments. Including the institutionalized population, we estimate that 3.6 million people under age 65, and 5.7 million over age 65, need assistance with personal care and/or with other everyday activities necessary to manage their own lives.

Above and beyond the tragic human cost that these numbers represent, look at the cost to our economy. We'll spend more than \$200 *billion* dollars this year in disability benefits, workers' compensation, insurance, health care services, and loss of productivity due to the disabilities of this population. Thus, we face both a human and economic imperative to make our preventive services and rehabilitation care systems work better.

What are we doing now to develop an adequate research capacity to address the special needs of people with disabilities? Why hasn't this field yet engendered the kind of exhaustive research that we see in virtually every other category of illness

or condition? The Public Health Service has growing activity targeted at medical rehabilitation research and disability prevention. Many of our injury and disease prevention and health promotion programs are aimed at the primary prevention of disabilities. Medical rehabilitation research in the National Institutes of Health, and research in the prevention of disability in the Centers for Disease Control, have highlighted our efforts.

The Agency for Health Care Policy and Research (AHCPR) will augment these traditional Public Health Service research activities with a new emphasis on issues involving the effectiveness and quality of health care services. Created by Congress in December 1989, AHCPR is the newest agency in the Public Health Service. It is our focal point for health services research. Among its priorities is determining the effectiveness of health care treatment to evaluate outcomes and determine what works best and disseminating information on model treatments through practice guidelines. The new agency also maintains the National Medical Expenditure Survey which provides information on persons with disabilities in households, who provides care to them, and the effect of these services on family income.

You will hear more about many of these activities during this conference. Suffice it for me to say here that we are enthusiastic about what the new agency can do to further our understanding of the human and economic dynamics of rehabilitation medicine.

Before outlining what I think our future research agenda should be, I'll comment briefly on some specific areas of medical research and prevention that are essential components of the Public Health Service's approach to disability issues.

The National Institutes of Health will devote more than \$120 million this year to research into physical and behavioral processes as they relate to rehabilitation. The NIH Clinical Center's Department of Rehabilitation Medicine provides comprehensive services to patients who need rehabilitative intervention and/or evaluation. In addition, the Department provides support to investigators who conduct intramural research within the scope of the clinical program. Extramural projects have been funded by several of the NIH institutes addressing basic mechanisms of impairment, response to interventions, and education's effects on function.

Here are some of the areas in which significant NIH resources have been dedicated: development of functional assessment instruments that adequately quantify disability and reflect rehabilitation potential over time; identification of the pathophysiology of impairments, particularly in the area of biomechanics; the

relationships between pain, structure, and function; the influence of growth factors on repair of the nervous system and the musculoskeletal system; and support for the development of prostheses, including neural and limb prostheses and cochlear implants and other assistive devices.

The Centers for Disease Control's Center for Environmental Health and Injury Control, emphasizes *prevention* of disabilities as well as prevention of secondary disabilities relating to an original condition. Today, the CDC is providing financial and technical assistance to nine states for disability and injury prevention programs. Its Division of Injury Control supports extramural research on disability prevention through injury prevention and the rehabilitation of persons with disabilities. CDC's Division of Birth Defects and Developmental Disabilities provides surveillance services to identify the special needs of over 100,000 children born each year with birth defects. The CDC Center for Chronic Disease Prevention and Health Promotion focuses in part on prevention of disability resulting from chronic conditions.

We have been steadily building our store of knowledge and science that will help us better answer questions about the most effective means of treating disability: what works, what does not work, and *why*. We may not yet be satisfied fully with the rehabilitation medicine data base we have, but it is precisely a conference like this that can move us forward rapidly on a strong collaborative research agenda. The research challenge we face is compound because rehabilitation is a process whose scope is broad, spans all ages, and is not disease specific. We need to write new chapters in our research agenda – and by "we," I mean those of us in the public sector and those of you in the voluntary and private sectors. I see three primary areas where we need to focus:

1. We need to develop a scientific basis for the measurement of functional capacity. In many instances, we do not yet have the right measures to assess limitations in activities involving jobs or plain daily living. For example, what about the factory worker who has had two myocardial infarcts? Is he or she automatically "disabled"? Or can he or she benefit from modern-day medical techniques to the point where a return to the workplace is not just possible, but probable? How do we measure that worker's capacity?

What about the elderly widow with advanced osteoporosis who fractures a hip? Is she a candidate for a nursing home? Or is she, like the 87-year-old mother of a member of my staff, a promising candidate for a rehabilitation hospital like the National Rehabilitation Hospital, which can send her home to live her own life? That woman benefited from

rehabilitation at a hospital which employed techniques that didn't exist a decade ago. She's at home today because they took the time – and cared enough – to make what would have been an unlikely prognosis 10 years ago.

How can the patient's capacity in a case like this be measured adequately? Since any individual's capacity to function is determined by the interaction of anatomic, physiologic, psychosocial, and environmental variables, measurement of functional capacity *must* include input from a wide variety of disciplines and professions. We need research to develop appropriate functional status measures akin to those developed by health services researchers (e.g., activities of daily living, quality of well-being, and sickness impact profile), which can be used to determine residual functional capacity. Whenever possible, we need to ensure that this research incorporates as many disciplines as possible that may have something to contribute.

2. We need to develop more meaningful outcome measures to gauge treatment effectiveness. Our new Agency for Health Care Policy and Research has set out to make more sense in this difficult area. There are several conditions causing disability for which there is substantial professional uncertainty about the appropriate form of treatment. The Patient Outcome Research Teams (PORTs), funded by AHCPR, are examining the variations in treatment for certain conditions. Ultimately, we expect these studies will contribute to the development of clinical practice guidelines that will be disseminated throughout the health care professions. The areas we are examining currently include low back pain, knee replacement, treatment for acute myocardial infarction, cataract management, ischemic heart disease, and hip replacement.

While not all these studies will be specific to the effectiveness of rehabilitation services, the methodological approach of examining the effectiveness of treatment and the resulting outcomes should be applicable to rehabilitation services. All of these activities are intended to expand our knowledge base. Indeed, that's what this conference is all about. And that's what the Public Health Service research agenda is all about. We in the Public Health Service look forward to seeing the ideas that will flow from this conference.

3. We need to use new technologies developed through chemistry, engineering, and physics. Many of the new materials utilized in aerospace,

defense, and athletics could be used to enhance the capabilities of people with disabilities.

Finally, the three broad areas of organization, financing, and delivery of health care services deserve our special attention: (a) the need for better understanding of the full range of barriers to the delivery of comprehensive health care services to people with disabilities; (b) the need for new models of health services for people with disabilities that integrate a comprehensive range of needed services, such as primary care, resolution of financial barriers, and linkages with the social services delivery system (such as attendant care); and, (c) the need to devise effective preventive interventions based on what we learn about the causes of disability.

Speaking for government, we feel our activities in rehabilitation medicine and research are a vital part of our responsibility. We will listen carefully to your deliberations at this national invitational conference. President Bush has proclaimed the '90s "The Decade of the Brain." We can also make the '90s a decade of progress in health services research in physical disability and rehabilitation.

The Costs of Disability and Implications for Health Services Research

Ellen J. MacKenzie, Ph.D.

**Assistant Director, Health Services Research and Development Center
Professor, Department of Health Policy and Management
Johns Hopkins University School of Hygiene and Public Health**

**Luncheon Address
September 26, 1990**

Measures of the societal burden or costs of illness and injury are increasingly being used by policy makers in their decisions to allocate limited funds among competing programs of primary, secondary, and tertiary prevention. The continuing rise in health care expenditures and growing pressures for cost containment no doubt will constrain the resources available for providing state-of-the-art health care to all who need it.

The question then arises: where should health care priorities be placed? One solution is to place priorities in those areas with the greatest burdens and where there is likely to be the greatest improvement in welfare or well-being. If one accepts this, the next question is: how does one consistently enumerate and value the burden associated with a broad array of conditions that may result in very different consequences? The most convenient approach has been to value the burden of illness and injury in monetary terms.

Measuring the Cost of Injury

Methods have been developed to estimate both the direct and indirect economic costs to society. Direct costs include the costs of goods and services purchased as a result of the injury. They represent costs for which payments are actually made. Indirect costs represent the dollar value of reduced activity and personal losses.

The most widely used method of estimating indirect costs is the human capital approach, in which a dollar value is attached to the lost output due to reduced productivity caused by an illness, including the value of lost work days and lost housekeeping days (Rice, 1967; Cooper & Rice, 1976). According to this approach, an individual is seen as producing a stream of output over time that is valued at (1) market earnings and/or (2) the imputed value of housekeeping services.

When using the human capital approach, however, it is important to understand some of its limitations. First, because value of life is based on market earnings, this method yields relatively low values for children and the retired elderly. Second, the human capital approach undervalues life if labor market imperfections exist and wages do not reflect true abilities. Finally, and perhaps most importantly, it does not attempt to quantify pain and suffering.

An important advantage of the human capital approach, however, is that it can be applied using data that are readily available. There are now several studies that have used this approach or variants of it to quantify the costs of disability either in the aggregate or for specific conditions and impairments. My intent today is not to compare and contrast these studies. Rather, I would like to share with you some of our own estimates of the lifetime cost of traumatic injury and use our findings as a paradigm for discussing the implications for the direction of health services research in this area.

This work was a joint effort between the University of California, San Francisco, and the Johns Hopkins School of Hygiene and Public Health, with funding from the Centers for Disease Control and the National Highway Traffic Safety Administration. It resulted in a report that was submitted to Congress one year ago (Rice, MacKenzie et al., 1989).

Costs of Injury

Injury is well recognized as the fourth leading cause of death over all ages and the leading cause of death for persons under the age of 45. Each year injuries account for more than 142,000 deaths. What is less well appreciated is that fatalities represent only the tip of the injury iceberg. Each year an estimated 57 million people, or one out of every four U.S. residents, are injured. Included in this figure are 2.3 million Americans who are hospitalized as a result of injuries and an additional 54 million who sustain injuries requiring outpatient medical attention or which result in one or more days of restricted activity without medical attention.

This means that for every injury death there are 16 hospitalizations and 381 less severe episodes. Comparatively little is known about these nonfatal injuries, yet their consequences for the individual, the family, and society are profound. Using the human capital approach, we have estimated that the total lifetime costs associated with all injuries occurring in 1985 totaled \$158 billion (or \$180 billion in 1988 dollars).

Nonfatal injuries and indirect costs

Over two thirds of this cost, or \$108 billion, represents the direct and indirect or morbidity costs associated with nonfatal injuries. It is particularly important to point out that fully one half of the total societal cost of injury is associated with nonfatal injuries serious enough to result in hospitalization. Let us take a minute to look at these costs in more detail. Morbidity costs totaling \$65 billion represent the value of five million years of productivity lost due to temporary and, in many cases, permanent disability. For every 100 injured persons, nine years are lost due to reduced productivity.

Yet these are conservative estimates of the indirect costs. Not accounted for in these calculations are the secondary morbidity losses or the value of lost productivity accrued among other members of the households who may have to reduce their work to take care of a disabled person in the home. Chirikos (1989) found, for instance, that these secondary productivity losses accounted for 10 percent of the aggregate economic losses from disability in 1980. Also not adequately addressed in these figures are what are referred to as debility costs or costs associated with reduced wage rates among persons with disabilities who remain at work.

Direct costs

Direct expenditures for health care and other goods and services total \$43 billion or 40 percent of the costs associated with nonfatal injuries. They include the initial treatment of the injury as well as ongoing lifetime treatment received on an outpatient or inpatient basis. Lifetime medical expenses include treatment and therapy aimed at reducing functional limitations, long-term care and attendant services, and primary health care.

Persons with disabilities are more vulnerable to medical problems, and thus use a disproportionate amount of medical care. DeJong, Batavia and Griss (1989), for instance, found that working-age persons with disabilities, on the average, visit a physician two to three times more frequently than their nondisabled counterparts, are almost six times more likely to be hospitalized in the previous year, and spend five times more for prescribed medicines and durable medical equipment.

Direct costs also include other nonmedical costs such as those related to vocational rehabilitation, home modification, and insurance administration, which can in many cases add substantially to the overall cost. We estimate that approximately 55 percent of the direct expenditures for injuries are for hospital care (including

rehabilitation). An additional 15 percent are for physician visits and 5 percent for nursing home care.

Age distribution

If we look at the distribution of costs by age, we find that the highest costs are among persons who are in their most productive years. They have a large number of years of lost productivity, high labor force participation rates, and high lifetime earnings. Working-age adults, in particular, account for over two thirds of the morbidity costs and nearly one half of the direct costs.

The high direct costs among the elderly, however, should not be overlooked. These high direct costs reflect long hospital stays and need for nursing home care. The morbidity costs, however, are low for the elderly, due to shorter life expectancy and low labor force participation rates and earnings.

Implications for Disability and Health Services Research

So what do these numbers tell us about where we should place our priorities? A number of important conclusions can be drawn from this analysis – many of which are generalizable beyond injuries to other disabling conditions.

Public health importance of injuries as a major contributor to disability. Our results underscore the public health importance of injuries, not only as a leading cause of death but also as a major contributor to disability in the United States. Although substantial progress has been made recently in establishing injury as a major public health concern, considerably more could be done to reduce the burden of injury with adequate support for research and development into the causes and treatment of injuries. Expenditures for research on injury causation, prevention, and control continue to be dwarfed by research expenditures for other health problems.

For example, injury research expenditures by all federal agencies amounted to \$160 million in 1987, about one tenth of the National Cancer Institute expenditures and one sixth of the National Heart, Lung and Blood Institute expenditures. Life years per injury death (36 years), however, are more than twice the number for cancer (16 years) and three times the number lost to cardiovascular diseases (12 years). Moreover, the mortality cost per injury death (\$335,000) is almost four times the cost for cancer (\$88,000) and more than 6.5 times the cost for cardiovascular diseases (\$51,000) (Rice, MacKenzie et al., 1989). In light of these comparisons, there is a clear case for allocating significantly increased funds to prevention, treatment, and research on injury in proportion to the burden placed on society.

Injury and the working-age population. Another important conclusion is that over 66 percent of injury costs are accrued among working age adults – a conclusion that is generalizable across many other disabling conditions. It has been estimated that, in the aggregate, there are 19 million individuals of working age who have a disability. Working-age adults comprise nearly 60 percent of all persons with disabilities. Furthermore, the number of working-age adults is increasing faster than any other segment of the disabled population (Chirikos, 1989; DeJong, Batavia & Griss, 1989). Yet, to the extent that the field of health services research has included disability in its agenda, it has focused primarily on issues regarding the care of disabled children and the elderly (Batavia & DeJong, 1990). More attention must be given to the special needs of the working-age adult with a disability.

The direct costs of health and human services. Over 40 percent of the lifetime costs associated with nonfatal injury are for the direct purchase of health and human services. These costs total an estimated \$43 billion for injuries that occurred in 1985. The investment in these direct expenditures more than likely would be outweighed by the economic, social, and personal benefits accrued from getting people back to work or school and living independently. Unfortunately, very few studies have examined adequately the costs and benefits of avoiding injury, or determined what strategies work best.

Effectiveness of rehabilitation. Central to the current agenda in health services research is the development and dissemination of scientific information regarding the effects of presently used health care services on patients' survival, health status, functional capacity, and quality of life. Clearly, such a focus also should be central to the research agenda in medical rehabilitation. In today's climate of rising health care expenditures and emphasis on cost-containment, it is incumbent upon the rehabilitation community to demonstrate what works best and at what cost. Studies should focus on the appropriateness of specific treatments and therapies, as well as on the cost-effectiveness of alternative systems for delivering care.

Access to rehabilitation services. Few studies have addressed the factors that influence the access to, and use of, rehabilitation services. Clearly, one of the most important determinants of access to care is the availability and adequacy of health insurance. More research is needed to evaluate alternative systems of payment for both rehabilitation and post-rehabilitation services. Are current systems of payment fair and equitable to providers, consumers, and the public at large?

Post-rehabilitation health care needs. Of increasing concern is whether existing delivery systems address adequately the post-rehabilitation health care needs of persons with chronic disabilities. As indicated above, persons with disabilities use a disproportionate amount of health care resources, due in part to increased

vulnerability to medical conditions. More research is needed to identify the most effective and cost efficient ways to deliver these services (Batavia & DeJong, 1990).

Medicare/Medicaid, work disincentives, and uncompensated trauma care. A pressing issue remains the extent to which eligibility criteria for Medicare and Medicaid provide work disincentives for persons with chronic disabilities. Another issue that must be addressed is how to adequately pay trauma centers that care for a disproportionate share of uninsured and Medicaid patients. The viability of trauma care systems is being threatened severely by the amount of uncompensated and undercompensated trauma care (Champion & Mabee, 1990).

Adaptation to impairment and return to work. Studies of the costs of injury and illness emphasize the significant losses in productivity resulting from both temporary and permanent impairments. These losses often extend beyond the person with the limitation to family and friends who serve as informal care providers. More work is needed to understand better the nonmedical factors that contribute to productivity loss. Individuals vary greatly in their ability to adapt to an impairment or functional limitation. Variability in outcome depends on a host of personal, social, and environmental factors, many of which are not addressed adequately in traditional rehabilitation settings.

In some of our own work we found that only a little over half of individuals with a significant lower extremity injury were back to work within one year. A more significant finding, however, is the fact that over half of those *not* back to work reported minimal or no functional limitations (MacKenzie et al., 1988). It would appear that these individuals should be able to work; the largely unanswered question is what can be done to get them back to work? Are there financial incentives to remain out of work, is job retraining needed, or are other social and vocational services required?

Some might argue that such studies do not fall strictly under the purview of health services research since many of the services aimed at getting people back to work are focused on educational and training interventions and relate to broader social issues. Yet I would argue strongly that many of the failures we see in getting people back to work following a serious injury or illness are due to the fragmented nature of the services provided and the lack of communication between the providers of health services on the one hand and psychosocial and vocational services on the other. Better ways to integrate these services are needed. Outcome studies must take a broad perspective in looking at the multiple determinants of recovery so that appropriate interventions can be identified and effectively targeted.

Methodologic and Analytic Issues

Let me close by highlighting what I see as some of the methodologic and analytic issues which our study on the cost of injury has raised.

First, estimates are based on multiple sources of data and many simplifying assumptions. This is because, in fact, we know very little about the incidence of nonfatal injuries and their short- and long-term impacts. This is equally, if not more, true for many other disabling conditions. Available national data are inadequate for determining reliable estimates of the incidence and prevalence of disability. Priority should be given to improving surveys such as the National Health Interview Survey to include better information on the origin, severity, and duration of disabilities.

Second, in addition to developing better information on the size and characteristics of the disabled population, we need to invest in longitudinal research that will define better both the medical and nonmedical factors that contribute to disability. It is important that these studies measure impairment, functional limitation, and work disability so that appropriate interventions can be designed and targeted.

Finally, it is important to continue to look for better ways to quantify the societal burden of illness and injury. As noted previously, the human capital approach has its limitations. Alternative approaches such as willingness-to-pay attempt to overcome some of these limitations by valuing life according to the amount individuals are willing to pay for a change that reduces the probability of illness or disability (Acton, 1975; Landefeld & Seskin, 1982). This approach is difficult to apply in practice, however, and has therefore not been used as extensively as the human capital approach.

Still others would agree that *any* attempt to value life in monetary terms is fundamentally flawed (Lubeck & Yelin, 1988). Luchter (1987) and others, for instance, have introduced the concept of measuring the burden of injury in terms of the number of persons-years lived at reduced functional capacity.

It is unlikely that in the near future one of these approaches will emerge as the solution to our need to quantify the societal burden of illness and injury. But they can and should be used to complement each other so that we can better understand where our priorities should be placed. Although estimates of cost alone cannot guide choices, they provide a quantifiable measure of the public health impact of illness and injury that can be used in turn to evaluate costs and benefits of alternative strategies for preventing disability.

Toward a Health Services Research Capability in Medical Rehabilitation

**Richard S. Materson, M.D.
Medical Director and Vice President
National Rehabilitation Hospital**

**Dinner Address
September 26, 1990**

What role will physicians play in developing health services research? This is a question I wondered about as I thought of what to say to you. Most of the introductory material I received pointed out that medical rehabilitationists don't know very much about health services research. If we agree with this assessment, my contribution, perhaps, can be to free-associate about some of the things that I wonder about as I go about the business of providing medical rehabilitation services to my patients.

Physicians learn many things from their patients. One patient who caused me to think about a great many things is the young mother of an illegitimate son born with severe physical disabilities. This young mother's parents disowned her for the sin of premarital sex; she lost her job (and her health benefits) because she missed a lot of work taking care of the child; she hated the intrusive interactions with the social worker. Everyone in the medical and social services community warned her that institutionalization was her only recourse – that nothing could be done for the child.

Against all these odds, the mother held on. She refused to believe that her child would have no life. She wouldn't accept the harsh pronouncements of the world, and she gave the child all the love and attention she could. Slowly the child improved – not dramatically but more than anyone had predicted. When I saw the mother, she was looking for help with a locomotion setup because the seating device she had sawed out of wood for the plain stroller she had rigged no longer worked.

My questions have to do with the future for this woman and her son. Where will this child get the testing, treatment, therapy he will need to approach his maximum potential? Who will pay for the equipment he is sure to need or the drugs for the likely-to-come seizures? What chance does this child have to get an education or vocational training? Will he and his mother even have a place to live or food to eat? What will happen to the child as he grows to adulthood and his mother ages and may no longer be able to care for him?

There are other examples from my patient care experiences that make me wonder about rehabilitation goals, about rehabilitation's place in a society which does not provide easy answers for persons who have limited resources, about quality-of-life issues for persons who survive serious injuries.

I wonder about the lessons to be learned from the quadriplegic young man who wanted to commit suicide; but who, with rehabilitation help, found a purpose in life, a vocation, and a family, only to suffer a second injury which forced him to give up his vocation. He didn't give up and found the strength to start over again, develop another vocation, and continue to live a meaningful life. Where did this strength come from? What role did medical rehabilitation play in his recovery? How did society respond to this person's needs?

These cases illustrate the real human aspects of the questions facing those of us who work in medical rehabilitation and those who want to set the policy agenda. I want to challenge health service policy researchers to define our mission and to develop baseline information by which to evaluate our interventions. We must define clearly who we mean by "disabled persons" and obtain accurate demographic information on disability groups. We must understand the typical life history of the disease for each disability subgroup. We must examine the goals of the rehabilitation process and frame these goals in terms of quality of life.

One method of measuring quality of life for disabled persons is a life scale, a hierarchy of needs. This hierarchy builds on survival and includes medical rehabilitation, functional independence, functional independence within the family setting, reintegration into society, and human creativity. We should determine what interventions can be made at each point of the life scale of the individual with disabilities to enhance function, decrease care-giver burden, and increase quality of life. We should measure each individual intervention for its efficacy, efficiency, and effect on the whole life course.

A greater emphasis on quality of life would help us move from a narrow focus on rehabilitation medicine to examination of other issues affecting life quality. We would be compelled, for instance, to evaluate the status of primary health care for disabled people and determine how best to provide this care. We would start to answer questions such as whether primary care doctors should be trained in the special medical problems that face the disabled community. Alternatively, should rehabilitation medicine professionals be trained so that they can provide primary care as well as rehabilitative care?

There are many other pressing disability and rehabilitation concerns which deserve the attention of health policy researchers. I am going to put forth a list of

these concerns as a challenge for this audience, as it formulates the goals of disability-related health policy research.

Were we, as a country, correct in linking health insurance for disabled people to the Medicare system which was designed predominantly for the aged?

Does it make any sense to have a two-year waiting period for disabled persons to become eligible for Medicare, thereby losing the golden period of opportunity to reverse impairment and prevent disability?

Was it logical for the federal government to abandon oversight over the insurance industry to the states, resulting in a patchwork of eligibility for rehabilitation, other medical services, and durable medical equipment?

Why don't we have a national universal health insurance program that provides risk pooling and public payment for indigent people, a benefit package focused toward disability prevention; and catastrophic care coverage including medical supplies, durable medical equipment and attendant care?

Why don't we enforce truth in advertising for the insurance industry and thus prevent the selling of insurance policies that hide non-coverage of services that persons with disabilities require?

How can we get medical schools to establish departments of physical medicine and rehabilitation that teach new strategies for dealing with chronic care, preventing disability, and enhancing function?

Can we develop a national study group consisting of informed physicians and other health care practitioners to prevent HCFA from developing arbitrary policy decisions that limit services and physician visits unnecessarily?

Can we provide rural areas the same intensity of rehabilitation service as urban centers? Do we need to provide rehabilitation through a regional approach which will enable rural residents to receive comparable rehabilitation care?

What items of durable medical equipment facilitate function and quality of life?

What are the special problems of the aging disabled; what strategies are successful in maintaining function and keeping people out of institutions and facilitating independent living?

How can we best prevent chronic disability? We need sound parental education, prenatal care, adequate maternal and infant nutrition, prompt vaccination, avoidance of toxins and tobacco, modest use of alcohol, good hypertension control, and adoption of sensible lifestyles.

We now have the brilliant shining light of the Americans with Disabilities Act, but we must continue to advocate, legislate, and implement its regulations. I dislike the term "disabled community." I believe that instead we should call those who have been rehabilitated the "enabled community." Our greatest failure is the single individual who does not have the opportunity to express his unique human creativity. Our mission must be to unchain each person's human potential.

An Independent Living Perspective on Health Services Research

**Judith Heumann, MPH, Director
World Institute on Disability**

**Luncheon Address
September 27, 1990**

The independent living (IL) movement was created during the late 1960s and early 1970s during a time of wide social ferment and change. Groups of disabled individuals had become more and more dissatisfied with the service delivery systems that had been designed to serve them. We shared the belief that the systems themselves were not designed to meet our objective to become integrated members of our communities. We didn't want to be seen as "special people," but instead as people with special needs, much like the elderly who need a variety of health care services or students who need financial assistance. Each service supports the right of each person to live a healthy, quality life.

Along with members of other political movements for social change, such as women and people of color, we experienced a growing dissatisfaction with the professionals who delivered the services to us, the individuals who did the research about us, and the persons who were trying to help us advance into the mainstream. We didn't see ourselves included in the process of providing services, deciding on research questions and design issues, and working towards political change that would allow us to move into the mainstream.

An important expression of our dissatisfaction was the formation of disabled student programs in the late 1960s and independent living centers in the 1970s. These institutions were created with the conviction that the system was not listening to our demands. We were saying that to be able to function in the community and live healthy, quality lives, we needed some basic services. We needed a wheelchair-accessible environment, personal assistance services, help in finding accessible places to live, mechanical and technological equipment and places to repair it when it broke, as well as health services – all provided in a comprehensive way.

During the early years of the IL movement, there was little interest in keeping a dialogue between the professional community and the IL community. Many professionals perceived the IL leadership as militant, unbending, and speaking for a very small percentage of the disabled population. Some professionals viewed them as ungrateful for the services provided them by the rehabilitation and special

education systems. Since then, more and more professionals have found the IL perspective valuable in helping make the dream of integration come true.

Some Research Issues

At this juncture, now a full 20 years after the beginning of the IL movement, it is time for the rehabilitation research field to advocate that the lessons of the IL movement be incorporated fully into the health services research agenda. While I believe that this conference represents a very strong beginning towards reaching this goal, let's also recognize that much more needs to be accomplished, and that our task today is to look toward the next steps. An important first step which many of you could take is to promote the inclusion of disability and rehabilitation issues into existing undergraduate and graduate curricula and programs. Training the next generation of disability researchers is a responsibility we all share. Specific research issues should be those that are defined as vital to the well-being of persons with disabilities.

The Role of IL Centers in Health Maintenance

One of the first topics for a health services research agenda should be more outcome studies on the role of IL centers in helping to maintain the health of disabled people. The IL perspective maintains that IL centers have been effective institutions for improving the quality of life for disabled individuals. IL centers have solved problems by using methods that should be documented and replicated in other settings. An important result of outcome research on the effectiveness of IL centers might be the justification to create more IL centers. We have a very small number of IL centers in the United States compared to what we need.

Personal Assistance Services

A second topic for research is the area of personal assistance services. The need does not have to be justified; we already know this is something we need. We should examine the characteristics of different programs to predict what type of programs would benefit specific populations. For example, we need to know the characteristics of persons who require a trained assistant and those who do not. If indeed a person needs a trained personal assistant, then what type of training does that assistant need?

It was a source of disappointment for many leaders of the IL movement that the rehabilitation community was silent when the Pepper Commission, in putting forward its bill to provide funds for personal assistance services, required that every personal assistant undergo a mandatory training program. Every home care agency

that believed that it could make money training a personal assistant testified at the Pepper Commission hearings that their clients were going to get hurt if personal assistants were not trained. The rehabilitation community should have been present telling officials that not everybody providing personal assistance should have to be trained.

Also, the appropriate level of pay for personal assistants, and mechanisms for financing assistance, need to be researched. We know that an underpaid worker is a very undervalued worker.

Benefits Programs

A third topic for research is whether disabled persons should receive a basic income allowance, regardless of their employment status. Income benefits, as well as many other benefits, are available to disabled veterans in the U.S. and to disabled civilians in several industrialized European nations. In these European nations, disabled persons are given income, health, and other service benefits solely because they have a disability, regardless of employment status.

In the U.S., only disabled veterans receive these types of benefits, such as mobility allowances, personal assistance services allowances, and basic income allowances. Disabled veterans continue to receive these benefits even if they return to work. The value of these benefits for veterans is rarely questioned; we believe they deserve these benefits. I, too, believe these benefits are appropriate, but why aren't they available for disabled civilians as well? I'd like to see a study that assesses the effectiveness of the Veterans Administration benefits program for disabled veterans and its potential applicability to non-veterans.

Disability Prevention

It has troubled me that some participants in this conference have emphasized the need to prevent disability. I find this personally insulting, given that the implication of this statement is that as a disabled person myself "I should have been prevented." I agree that we need airbags in cars and that people need to receive appropriate health care, including prenatal care for women who are pregnant. But we need these services not to prevent disability, but to enable people to live a healthy, quality life.

If, in fact, some of us do acquire disabilities – as many of us will in our lifetimes – then we have to determine how to receive the services we need to live well. If the primary goal is the prevention of disabilities, then persons with disabilities will constantly be viewed as failures of the system. And I really don't

want anyone talking about how I could have been prevented or how my life would be better if I did not have a disability. One of the lessons of this conference should be a recognition that most disabled persons in this room feel fine about being disabled. To the extent that we don't feel fine about who we are, it is mainly because of the failures of the system.

Dissemination of Research in the IL Community

It would be useful for researchers to attend the annual National Council on Independent Living (NCIL) meetings to work with persons with disabilities to determine appropriate research questions. When researchers publish an article in scientific journals, it would be worthwhile to disseminate a version of it to the directors of the IL centers. This would help get a meaningful dialogue going between the research community and the IL community.

In Conclusion

We have a long way to go. You are the movers and shakers in the rehabilitation field. I believe that the primary goal of all of us in this room should be to help empower all people with disabilities and without current disabilities to recognize that disability is not a tragedy. Our goal in life should not be to prevent disability, but to ensure that all people have the right and the ability to live a healthy, quality life regardless of their race, creed, socio-economic status, or their physical functioning status.

That is our challenge. The IL movement has been in the vanguard of moving us toward these goals. We want very much to work more closely with the professionals in the field. While we have gotten to where we are today substantially on our own, in the future we'd like to be able to achieve progress more in coalition with other people. But with you or without you, we are not going to stop, because we are fighting for our own lives.

CHAPTER III

PANEL SESSION:

The Role of Key Components in Developing a HSR Capacity

A panel consisting of representatives of the various key components that might contribute to the development of a comprehensive HSR capacity in physical disability and rehabilitation addressed the role of each component. The panelists were:

J. Paul Thomas, Ph.D., Director of Medical Sciences of the National Institute on Disability and Rehabilitation Research, who spoke on "The Role of NIDRR";

Stephen C. Crane, Ph.D., Deputy Director of the Association for Health Services Research, who spoke on "The Role of the Health Services Research Community";

J. Michael Fitzmaurice, Ph.D., Director, Office of Science and Data Development of the Agency for Health Care Policy and Research, who spoke on "The Role of the Agency for Health Care Policy and Research";

Marcus J. Fuhrer, Ph.D., Professor, Baylor College of Medicine, and Vice President for Research at The Institute for Rehabilitation and Research, who spoke on "The Role of the Rehabilitation Research Community";

Lynn Gerber, M.D., Chief of the Department of Rehabilitation Medicine of the National Institutes of Health, who spoke on "The Role of NIH";

Mary Jane Owen, M.S.W., Executive Director of Disability Focus, Inc., who spoke on "The Role of Disability Organizations";

Randy Davis, Program Associate with The Dole Foundation, who spoke on "The Role of the Foundation Community."

The Role of the National Institute on Disability and Rehabilitation Research

**J. Paul Thomas, Ph.D.
Director of Medical Sciences
NIDRR, U.S. Department of Education**

Medical rehabilitation is at a crossroads. The pioneering spirit that helped create rehabilitation over the last 40 or 50 years now is brushing up against the realities of a very competitive health care economy. Medical rehabilitation is going to need good health services and policy research if it is to thrive in a more competitive environment. In fact, health services research speaks to the very heart of what rehabilitation is all about when it addresses issues related to the economics of disability, service delivery, and service outcomes.

NIDRR'S Commitment to HSR

Does NIDRR have a commitment to HSR? Very strongly! Its commitment is evident in its funding of this conference. We would not have supported this conference if we did not intend to follow up on the agenda established by it. This conference provides an opportunity to evaluate the explosion of new interest in HSR and to chart new activity.

NIDRR's interest is also evident in its recent *Federal Register* notice (August 5, 1990) announcing a priority for HSR and policy research related to inpatient medical rehabilitation. The agency's focus on inpatient medical rehabilitation is not intended to preclude front-end issues related to acute care or back-end issues related to community health care. However, because the reimbursement and payment policy issues confronting medical rehabilitation loom so large today, we believe they deserve special consideration at this time.

Background on NIDRR

NIDRR has its origins in the 1954 amendments to the Rehabilitation Act, the act which authorized the federal-state vocational rehabilitation program. The 1954 amendments were the first authority for research and demonstration projects and for training projects. The agency was formally established in 1978 as part of the Department of Education and was known originally as the National Institute on Handicapped Research (NIHR). In 1986, Congress changed the agency's name to the National Institute on Disability and Rehabilitation Research.

NIDRR is engaged in three main types of activity: (1) support of extramural research, (2) research dissemination, and (3) participation in federal interagency coordination of related activities. The agency's FY 1991 budget is expected to be \$74 million which covers not only NIDRR's various research and center grant programs but also grants under the state technology program. Thus, NIDRR is only a fraction of NIH's size. However, unlike NIH, which is divided into 13 institutes representing specific disease categories and organ systems, NIDRR must look at the *whole* person with a disabling condition that frequently is severe or catastrophic.

Clinical versus Health Services Research

Medical rehabilitation research traditionally has focused on the clinical course of disability including the prevention of complications and the evaluation of new rehabilitation modalities. HSR entails a very different view of health issues facing persons with disabilities. HSR is concerned not only about the efficacy of individual procedures, but also about the manner in which health services are delivered and financed.

Developing an HSR Capacity

This audience probably represents the nation's best hope for the development of an effective and purposeful HSR program related to rehabilitation. To develop this capacity, I believe we need to move on several fronts that require a long-term commitment, not a quick fix. For example:

1. Research planning

Research planning begins with the identification of research issues and the framing of research questions. Good research cannot proceed without the considerable intellectual rigor that we must bring to the issues of service delivery, outcomes, and costs.

2. Research training

The type of research training that is needed will depend on whether new health service researchers in disability and rehabilitation come mainly from outside rehabilitation or from within. Those health service researchers from outside rehabilitation already possess many of the needed skills. However, they know little about substantive disability and rehabilitation issues and may not be acquainted with some of the measurement tools used in rehabilitation such as specific functional assessment instruments. These folks need little methodological

training but do need a better understanding of disability and rehabilitation. Those within rehabilitation are not as likely to have the same level of methodological sophistication but are more likely to have a good grasp of the substantive issues. Those with mainly clinical backgrounds may need to develop a systems perspective to augment their clinical perspective.

3. Graduate and professional education

I believe that too much of our graduate and professional training in rehabilitation is focused on narrow clinical issues related to impairment and disability. It fails to impart an adequate understanding of the larger American health care system of which we are all a part. If we evaluate the efficacy of our clinical efforts without considering the larger health care system, much of our work may become irrelevant and of little use to our clientele.

4. Continuing professional education

I would like to make an important distinction between training and retraining. I think we have had as much training as we can stand. We are pretty well burned out and do not have much time or funding for more training. However, we do need the kind of retraining and retooling that will enable rehabilitation professionals to be proficient in dealing with health policy issues.

5. Supporting HSR at home

The development of an HSR capacity requires the nurturing of support back at the place where you work. You need to encourage HSR and HSR planning in your own environment so that you will have the support and infrastructure you need to participate in HSR. Local commitment is important to potential funding from foundation and government sources.

6. Dissemination/utilization

Another important element of an HSR capacity is the ability to disseminate research findings and encourage their utilization. Research has little meaning unless it is shared through various forms of dissemination and utilization. Effective dissemination and utilization will be fostered in part through our enthusiastic commitment to policy research and its application to rehabilitation.

NIDRR Funding Mechanisms

All of these efforts require long-term planning and training. NIDRR has several funding mechanisms that can facilitate planning and training efforts. These include (a) research and training centers, (b) field-initiated research, (c) innovation grants, (d) the Switzer Fellowship program, (e) research training for new scientists, and (f) the regional model spinal cord and brain injury center programs. NIDRR staff such as myself would be delighted to discuss our various grant programs and how they might support a health services and health policy research agenda. I can be reached at (202) 732-1194.

The Role of the Health Services Research Community

Stephen C. Crane, Ph.D.
Deputy Director
Association for Health Services Research

My task this morning is to describe the potential role of the health service research community in developing a comprehensive health services research capacity for physical disability and rehabilitation research. As I am sure the other panelists also have found, this is both challenging and perhaps presumptuous, since it is difficult to represent adequately the diverse community of people who call themselves health services researchers and all of the many varied resources that they have available for you.

I propose a reformulation of the issue. If I might borrow an idea from John F. Kennedy's inaugural address, the question is not what the field of health services research can do for you in developing this research capacity, but what you can do to help develop the field of health services research. A good capacity for research on physical disability and rehabilitation issues already exists within the general field of HSR, though more could be done. A most important challenge for you is to use existing resources in the general health services research field to solve issues in physical disability and rehabilitation research.

The two basic questions that I want to address are: (1) what are the resources of the general health services research system that would benefit disability and rehabilitation research, and (2) how can these resources be mobilized effectively?

The Role of Health Services Research

Clearly, many resources already are available. Universities, independent research institutes, hospitals, academic health centers, and private consulting firms have well-established research programs that could address the issues of physical disability and rehabilitation. The Association for Health Services Research (AHSR), which I represent, maintains a directory of most of these major institutions. Many of these research sites also have a variety of training programs that can prepare people for careers in physical disability and rehabilitation research.

Specialized training and fellowship programs, such as The Robert Wood Johnson Clinical Scholars program, the Pew Health Policy Doctoral Program, and

The Robert Wood Johnson Health Policy Fellowship, target individuals interested in policy and management issues. Getting people from the disability field into these programs is an excellent way to mainstream research interests and build a capacity for future research.

The field of general health services research offers a knowledge base and a set of research tools that are directly and immediately applicable to disability and rehabilitation research. If you are interested in the organization, financing, and delivery of health care services, as well as the cost, quality, and availability of these services, well-established literatures and methodologies exist for answering questions in these areas.

It is particularly important to participate early in efforts to develop better health outcome measures. There also are many data bases which, while not specifically directed at physical disability and rehabilitation, can provide important contextual information about the incidence and prevalence of disability-related problems and the use of health services.

The world of general health services research has established connections with Congress, the executive branch, and other users and funders of research. These connections and the credibility that comes along with them may be some of your most important resources.

The Role of AHSR

As many of you know, AHSR is the only national membership organization formed exclusively to promote the field of health services research. It has over 1,500 individual members and almost 1,000 institutional members. AHSR can offer several highly visible public forums for discussion of physical disability and rehabilitation issues. It has, for instance, several publications, including the *Journal of Health Services Research*; *HSR Reports*, a newsletter which updates members on news in the domestic field of health services research; *Bridge*, which provides the same information for health services researchers internationally; and *Focus*, a newsletter which emphasizes issues of mental health research. Through its other activities, AHSR can serve further as an information clearinghouse on research on disability and rehabilitation.

Most importantly, AHSR can focus on disability and rehabilitation research as part of its overall mission of promoting public support for health services research through agencies such as AHCPR and the VA. Linking physical disability and rehabilitation research to the general field of health services

research can enhance its visibility and strengthen its overall place in the general field of health services research.

Integrating Disability and Rehabilitation Research

I think the best way to increase the capacity for research in this important area is to make disability and rehabilitation research a part of the general health services research field. You will find an audience that is willing to learn from you and in turn is willing to help you move your research agenda forward as rapidly as possible.

The Role of the Agency for Health Care Policy and Research

**J. Michael Fitzmaurice, Ph.D., Director
AHCPR, Public Health Service
U.S. Dept. of Health and Human Services**

The Agency for Health Care Policy and Research is the newest of the eight agencies in the Public Health Service. The agency's purpose is "to enhance the quality, appropriateness, and effectiveness of health care services, and access to such services, through (1) the establishment of a broad base of scientific research and (2) the promotion of improvements in (a) clinical practice and (b) the organization, financing, and delivery of health care services."

The mission of AHCPR's Office of Science and Data Development (OSDD) is to undertake research, coordination, and standard setting efforts that will make more and better health care data available to HSR generally and medical effectiveness researchers specifically.

AHCPR's Mandate

Medical effectiveness research is the study of what works in the community's practice of medicine, or the projected outcomes of alternative treatment choices for given areas of illness. The agency's mandate certainly includes research into the utilization and effectiveness of services used by people with disabilities. The Secretary of HHS is required by Congress, through AHCPR, to develop:

- 1) *uniform definitions* of data to be collected and used in describing a patient's clinical and functional status;
- 2) *common reporting formats and linkages* for such data; and
- 3) *standards* to assure the security, confidentiality, accuracy, and appropriate maintenance of such data.

New Opportunities for HSR in Disability and Rehabilitation

The rehabilitation community can address several areas of health services research:

We need new scientifically-credible measures of functional capacity.
Under the newly enacted Americans with Disabilities Act, employers are expected

to make reasonable accommodations on behalf of disabled applicants or employees. Moreover, when an impaired individual's ability to perform a particular job is questioned by an employer, the ADA places increased responsibility on the employer to demonstrate that the individual is unable to do so. These expectations of the Act heighten the need for objective and scientifically credible assessment tools that can measure the functional status of individuals in a variety of settings such as the workplace.

We need to know the effectiveness of rehabilitation services.

Functional status measures are important in identifying those rehabilitation services that are most effective in helping disabled people qualify for employment and thus avert the need for income assistance. However, functional status measures have utility well beyond issues related to employment. They also can serve as important measures of outcome and effectiveness for a whole range of health care services. Thus, the development of functional status measures could drive a number of government-sponsored research and training programs such as those funded by AHCPR.

We need to expand well beyond the simple concepts of ADL and IADL and to validate numerous other functional measures, including quality of life. Measures are needed that relate not only to how a person's joint moves, but also to how the limitation of motion impedes the worker's ability to function and relate in the workplace. As Dr. Materson pointed out, we need to look at the "life picture" of the person with a disability.

We need instruments for assessing children's ability to function in a normal environment. With the Zebley decision (Zebley vs. Sullivan, 1990), children applying for SSA disability benefits must now be retested according to how they react to the environment, not on the type of impairment. This will require an individualized functional assessment. Many instruments do exist, but which ones should be used remains an open question.

We need to make existing data sources more accessible, to help guide future decisions. AHCPR, working with other PHS agencies and others, will compile existing knowledge and develop an agenda aimed at developing, evaluating, and making operational a scientifically-based series of functional measures which could influence the basis for SSA disability determinations. This presents an unusual opportunity for researchers to use and explore SSA's unique data base for the purposes of epidemiologic tracking and characterizing the American disabled population.

We need to access existing data bases that can inform us about health services needs for people with disabilities. In 1987, AHCPR conducted the *National Medical Expenditure Survey (NMES)* on a total sample of 15,000 households and 36,400 persons to investigate their utilization of health services, their expenditures, and their financing sources. An institutional population component of that survey covered 10,000 persons in nursing homes and homes for persons with mental retardation. The survey also includes information about developmental disabilities, functional status for individuals with ADL/IADL limitations, possible change in functional status of the individual, and caregiver experiences.

Actions to Take

There is tremendous pressure on Congress to reduce the federal deficit; thus one should not underestimate the difficulty of obtaining expansions in funding for rehabilitation health services research. Yet, I am optimistic that research on the alleviation of an impairment, disability, or handicap could be expanded.

We need to enhance the scientific soundness of rehabilitation research grant proposals. Scientifically sound hypotheses and good data upon which to test these hypotheses are needed to: (1) develop and validate appropriate measures of functional status, residual functional capacity, and quality of life; (2) document what works in the treatment of disabilities; (3) demonstrate how to increase access to primary care services for the disabled; (4) evaluate the effectiveness of primary care; (5) document the utilization of health services and the substitutability of health services for disabled people; and (6) evaluate alternatives to hospitalization for delivery of care (e.g., home care). With our new agency there is new opportunity for addressing these health policy issues. We need your help in developing rehabilitation research priorities. This fine conference will be extremely valuable for focusing attention on the types of research that should have high priority.

In Closing

In my personal observation, health services research priorities are set by a variety of mechanisms: participation in conferences such as this; involvement of health policy decision makers, such as our Assistant Secretary for Health, Dr. James Mason; direction of Congress through direct appropriations for general HSR and rehabilitation-specific HSR; authorization of a program in rehabilitation HSR; expression of Congressional interest in committee reports; and discussions

between agency program staff and Congressional staff. Agenda-setting conferences such as this one contribute. Most importantly, research priorities can be influenced by the submission of high-quality research grant proposals in this area.

I am talking about health services research that is not only directed at the level of impairment or disability, to use the ICIDH terminology, but also at the level of handicap. "Handicap" involves the interaction between a person's disability and the environment. A handicap may be resolved not only by restorative services but also by changing the environment. Thus, not only must there be research on reducing disabilities, there also must be research that extends to the quality of life and considers the environment in which the disabled person lives and works.

The Role of the Rehabilitation Research Community

Marcus J. Fuhrer, Ph.D.
Professor, Baylor College of Medicine
Vice-President for Research
The Institute for Rehabilitation and Research

As we develop a rehabilitation-relevant research agenda for the 1990s, I suggest that we consider using the term "rehabilitation services research" in place of "health services research." In my view, it is important to emphasize that rehabilitation services, in both the hospital and community setting, include health services, but are not solely health services.

As a starting point, let's turn to three recommendations made by Batavia and DeJong (1990) regarding what the rehabilitation research community can do to develop a rehabilitation-relevant health services research capacity:

- 1) impart to the wider HSR community the need for research on the organization, provision, and financing of health care services for persons with physical disabilities;
- 2) devise an HSR research agenda to inform prospective researchers about the type of studies that are needed;
- 3) advise NIDRR, other public sector agencies funding disability-related research, and private organizations on ways to develop and organize a comprehensive HSR capacity in physical disability and rehabilitation.

The first recommendation acknowledges the existence of a pool of appropriately trained health services investigators outside the rehabilitation research community and suggests that our task is to stimulate them to turn their attention to rehabilitation-relevant issues. I have relatively little to add to that perfectly reasonable suggestion. This conference is a splendid example of outreach to the HSR community. We can help multiply this example by taking the initiative to interact with health services researchers by inviting them to participate in our national rehabilitation conferences and attending their meetings as well. It is also critical that we take the initiative to publish our rehabilitation services research studies in mainline health services research journals, an example being DeJong, Batavia and Griss (1989).

The second recommendation encourages the formulation of thoughtful research agendas. Some of us in this room are having the remarkable experience this year of participating in formal research planning efforts sponsored by an array of federal agencies, including NIDRR, the Department of Veterans Affairs' Rehabilitation Research and Development Service, the National Institutes of Health, and the Centers for Disease Control. In each and every one of these planning efforts, research issues are being highlighted that are precisely of the kind that we have been dealing with during this meeting. There seems to be a new day dawning for medical rehabilitation research, and rehabilitation services research will certainly be a central element of that promising effort.

However, I must express at least mild skepticism about the current preoccupation with research agendas. All of us are aware of highly significant research that has been done without any available, overarching research agenda, at least as defined by a granting agency. It is important to remember that highly elaborate research agendas hardly assure that the requisite research is going to get done without the imagination, technical expertise, and resources that are brought to bear by committed investigators.

The third recommendation advises cooperation among funding organizations. It is no accident that this conference includes invited participants from NIDRR, NIH, CDC, HCFA, and the Agency for Health Care Policy and Research, as well as The Dole Foundation and Paralyzed Veterans of America. We hope they leave this conference feeling well advised about contributions their agencies can make to promoting rehabilitation services research.

In addition to these recommendations, I would like to remind those of us who comprise the rehabilitation research community that we should get on with the job of conducting some of the needed research. After all, our community is by no means bereft of rehabilitation services researchers, witness the published contributions of attendees at this very meeting, including Bob Keith, Harriet Aronow, Denise Tate, Mark Johnston, Byron Hamilton, and certainly the NRH Research Center group.

In my experience, an important way to get on with the task of doing some of the needed rehabilitation-relevant research is to work at developing productive collaborations at our home institutions. Many of us are situated in major medical centers that have schools of public health with faculty members and graduate students who are expert in the core disciplines of HSR (e.g., epidemiology, health care economics, and biostatistics). I am confident they will not kick us out of their offices if, as rehabilitation researchers, we take the initiative of approaching them with the possibility of undertaking collaborative research. I have had the

distinct pleasure of collaborating through the years with a group of applied mathematicians on problems of benefit-cost analysis and have been struck with how readily members of such a seemingly distant discipline can become interested and productively engaged in a rehabilitation-related effort.

In closing, I'd like to suggest a final contribution that we can make to the effort of getting on with rehabilitation services research. We need to recruit to our faculties, or to the staffs of our free-standing rehabilitation research programs, some of the appropriately trained health services researchers who, in collaboration with us, can conduct the needed research. This strategy will become increasingly realistic as interest grows on the part of funding agencies that support rehabilitation services research.

The Role of the National Institutes of Health

Lynn Gerber, M.D.
Chief, Department of Rehabilitation Medicine
NIH, Public Health Service
U.S. Department of Health and Human Services

My observations are tempered by three different perspectives. The first perspective is the larger and official NIH view and, in this sense, I serve as an NIH spokesperson. The second perspective is the view of a hands-on clinician, administrator, and researcher in an NIH-based clinical medical rehabilitation program. In addition, I have been an advocate of disabled children who have been an important part of my professional life. All three of these perspectives shape my remarks.

NIH's Increased Interest in Disability and Medical Rehabilitation

Two factors have heightened NIH's interest in disability and medical rehabilitation. First is the passage of the Americans with Disabilities Act which has served to signal the fact that consumers are organized and that NIH needs to respond in some manner to the needs expressed by this segment of society. NIH's strong emphasis on scientific merit has made it reluctant to acknowledge that special interests shape its research agenda. Second is the possible development of a medical rehabilitation research center within the NIH system. As you know, legislation to this effect is currently pending.

Scope of NIH Funding and Activity in Medical Rehabilitation

As a result of these two factors, NIH recently took inventory of its current efforts in medical rehabilitation research. By taking a very broad, if not loose, definition of medical rehabilitation, NIH estimates that it currently spends \$120 million on medical rehabilitation-related research. The Institutes that have been most important include the National Institute of Child Health and Human Development (NICHD); the National Institute of Arthritis, Musculoskeletal, and Skin Disease (NIAMS); the National Institute of Neurological Disorders and Stroke (NINDS); the National Institute on Deafness and other Communication Disorders (NIDCD); the National Cancer Institute (NCI); and the National Institute on Aging (NIA).

Most NIH-sponsored research is focused quite narrowly on physiological, biochemical, and biophysical processes. By going well beyond biomedical

research, NICHD is perhaps the most broadly focused of the National Institutes. It also addresses functional problems that stem from physical, behavioral, and cognitive impairments and, to some extent, is concerned with environmental modifications that can enhance function. Similarly, NIAMS has been a leader in functional assessment and the development of outcome measures. By contrast, NINDS is still very much focused on pathophysiology and physiological processing problems associated with the central nervous system. NCI's interest in rehabilitation has been mainly in the area of education and dissemination of information.

Most NIH research is extramural. However, I also should mention NIH's intramural program in medical rehabilitation which I represent as Chief of the Department of Rehabilitation Medicine. While we do not have a research budget in the strict sense of the term, our department's research effort is probably in the order of \$150,000 per year (+/- \$25,000).

In short, there are a number of NIH-sponsored activities on which an HSR agenda can build, particularly those activities that involve the development of functional assessment and outcome measurement tools. However, the focus of NIH has been primarily on impairment and disease processes. In terms of the World Health Organization framework of pathology → impairment → disability → handicap, NIH is at the pathology and impairment end of the continuum.

Congressional Interest

This is likely to change given Congressional interest in having NIH become more involved in rehabilitation. As a result, NIH has established a number of working panels that are developing an agenda for rehabilitation research. Following the NIH tradition, most of the panels are disease- or problem-specific. Once rehabilitation research gets underway at NIH, I believe that we can obtain a better scientific understanding of various rehabilitation modalities in terms of what works, why it works, and how it works. This scientific knowledge base will be essential to health services research which is very much concerned with the efficacy and cost-effectiveness of medical treatment.

Future Growth of Medical Rehabilitation

I believe that in the decade ahead, medical rehabilitation will enter a log phase of growth. It will become a more mature discipline as its scientific basis becomes better understood. Unlike many other medical specialties, medical rehabilitation's growth will require contributions from many disciplines including

many nonmedical ones such as engineering and the social sciences. Its growth as a field also will require contributions from, and the insights of, people with disabilities and their families.

Medical rehabilitation cannot grow unless various scientific communities, including various biomedical communities, are willing to shed some of their parochial interests. In my view, there is clearly an overlap between what is learned at the bench, in clinical trials, and in health services research. Although not a lead agency, NIH is clearly allied with HSR-type research. This is especially the case with medical rehabilitation.

The Role of Disability Organizations

Mary Jane Owen, M.S.W.
Executive Director
Disability Focus, Inc.

What a challenge to be asked to address ways in which disability organizations can add to the development of an HSR agenda. In my view, disability organizations can offer suggestions about research relevance, research utilization, and the dissemination of results. The diversity of disability organizations leads me to reflect further on these issues in terms of the themes of paradox, parable, and paradigm.

A Troublesome Paradox

The annual success of the Jerry Lewis Telethon in raising research funds for the Muscular Dystrophy Association is a troublesome paradox in the disability community. Although the financial benefit of the Telethon is immense, the image of persons with disabilities as pathetic individuals and objects of pity and charity is extremely troublesome, especially to disability organizations that are so committed to public education efforts that stress the potential productivity of all people with disabilities.

Last year I wrote an open letter to Mr. Lewis, which has since been published in several national publications. I wrote it in response to the annual Telethon event, and the discussion of his imagined feelings at being a child with a disability which had been published in a *Parade Magazine* article. Mr. Lewis had said he would be terrified as a "crippled" child, feeling himself to be imprisoned in a wheelchair, facing a world filled with barriers to normal services and opportunities, unwilling to play with other "cripples," and *assigned* to living half a life. I asked him to reconsider the new and evolving ideas about disability which are being forged with the passage of such legislation as the American with Disabilities Act, the Fair Housing Amendments Act, and the Air Carriers Access Act. Each of these laws affirms the civil right of people with disabilities to be included in life's mainstream.

The paradox is that although the Telethon strategy still works for raising very large sums of money – very much needed by disability organizations – it is unacceptable within the current social context in which disabled people no longer accept the pity models of the past. The new issues are quality of life and civil rights. The implications of this paradox for the private funding of health services

research is straightforward. Although the pity appeal may help raise funds, at the same time it undermines the egalitarian assumptions about disabled people that should guide health services research.

An Amusing Parable

Several years ago, Barbara Bush invited some of the leaders of disability organizations to the White House on the day that turned out to be the start date for her treatment for Grave's Disease. On my ride to 1600 Pennsylvania Avenue, thinking of what I might say in the reception line, I remembered my own treatment for Graves Disease a few years before. I thought it would be fine to let Mrs. Bush know I shared a common medical experience and had done just fine. As you can see, I am a blind, hearing-impaired wheelchair user. As I rolled up to shake Mrs. Bush's hand, I began juggling my long white cane and my hearing device.

With the best of intentions, I said to her, "It's such a pleasure to shake your hand again And I wanted to let you know that thirty years ago, I had Grave's Disease too, but I elected to have surgery . . . and Mrs. Bush, I hope your recovery is every bit as successful as mine." With no thought to the possible implications of this wish, I turned to roll away. Then I heard her clear her throat. "You certainly are an enthusiastic woman," she said. "Yes, that's true," I agreed and turned again to leave. Suddenly, I realized why my remark might have flustered the unflappable Mrs. Bush!

Every parable has a point. There was no thought on my part that I was a pitiful social burden or in a particularly difficult circumstance. In my mind, I was nothing less than a happy, reasonably successful woman who could, with high quality medical care and sufficient help from others, overcome any barriers to a full, productive life. I merely hoped Mrs. Bush would be just as healthy as I was thirty years down the road. And this self-assessment is not unique, as many of the disabled persons in this room can attest. With appropriate health services, social resources, and a barrier-free environment, persons with disabilities can live full lives and experience great personal satisfaction. The task for health service researchers is to discover how to make this possible in an effective and cost-efficient manner.

The Promising Paradigm

Persons with disabilities, many of us advocates for self-empowerment, are often puzzled and sometimes offended by the research questions selected or data

collected by disability and rehabilitation-oriented researchers. Advocates often feel that they were never asked about what sort of information people with disabilities need or want. During the 1960s, when I taught in the university, students insisted on the relevance of knowledge. We began research classes with the following questions: "What social problems are you interested in? What bugs you about the system today? What information do you need to demonstrate the need to change the system?" Only then would we turn our attention to a semester-long discussion about hypothesis testing and the use of research instruments.

The task of developing a research agenda in physical disability and rehabilitation issues reminds me of that academic exercise I engaged in with students over two decades ago. The issue is relevance. We are seeing innovations in rehabilitation technology and improved social strategies that make it possible for individuals to continue to live productively with disabilities. The research community is responding to this promising and relevant focus by developing an agenda that includes the relevant issues of quality of life and civil rights.

As disabled persons enter the social mainstream in larger and larger numbers, we are in a position to observe the impact of this minority group on the larger social system. For example, for the first time in American history, during the Dukakis/Bush presidential campaign, we found that pollsters were tracking disabled voter preference. Both political parties were informed of a Louis Harris finding that disabled people wanted to know about a candidate's position on disability policy. According to the polls, Dukakis had the disability vote in his pocket at the beginning of the race. But each time George Bush asserted his intent to bring disabled Americans into the mainstream, a sizable proportion of disabled voters turned toward him. Dukakis chose not to articulate publicly any concern to integrate people with disabilities into the social mainstream. After the campaign was over, officials of the Harris Poll suggested that fully one half of the Bush margin of victory could be credited to the disability votership which shifted away from the democratic candidate.

Another example of the potential effect of disabled persons on the larger social system is in the commercial marketplace. As greater numbers of disabled persons enter the social mainstream, we will find that their need for inexpensive assistive devices and products (heretofore classified as "medical supplies/equipment") will finally be met by the competitive marketplace. Those of us who have needed to buy adaptive equipment, such as wheelchairs or canes, have known that the price for these items is inflated, due to the relatively small number of companies that manufacture these products. As more and more

disabled consumers demand these products, we will find the cost for purchasing assistive devices, such as talking and listening computers, or attractive, efficient mobility aids, will be lowered. This will help make these products more available to many other members of our society, including the elderly and the temporarily disabled as well as the long-term disabled. The use of these items will slowly lose its social stigma, and they will acquire the status of convenience items.

Research Dissemination

As a spokesperson for disability organizations, I urge all disability researchers to make efforts to popularize their research results in consumer-oriented publications and the national media, if possible. Dissemination of research should include as wide an audience as possible. Individuals who are a part of disability organizations want solutions to those problems which "bug" them. Communication is the key to linking persons with disabilities to the disability research community.

The Role of the Foundation Community

Randy Davis
Program Associate
The Dole Foundation

I'm pleased to work for the Dole Foundation, an organization that does much to promote the dignity, worth, value, and productivity of people with disabilities everywhere. It is my hope that more organizations, foundations, and other bystanders will realize that people with disabilities have much to contribute, as well as much to receive – like all of us.

The Dole Foundation was set up explicitly to provide funding for *employment* projects for people with disabilities – to help get persons with disabilities back into the workplace. In 1989, the Dole Foundation funded a project in Atlanta that offered early intervention vocational training, independent living skills, and vocational readjustment preparation for people who had recently incurred spinal cord injuries.

There have been other foundation-funded service delivery projects for persons with disabilities. The On Lok Clinic in San Francisco, funded by The Robert Wood Johnson Foundation, utilized health service delivery mechanisms aimed at removing distinctions between long-term care and acute care and thus providing for more holistic care for people with disabilities.

I know of no foundation that has provided general research funds for health policy research in rehabilitation. Because private foundations differ in location, philosophy, and funding priorities, it is not easy to say collectively what foundations should do. Foundations cannot be the rescuers or the saviors of the financial needs of the rehabilitation and health care community, but they can fill gaps in health policy research, health care research, and rehabilitation research.

In future years, foundations of various sorts should have a much better understanding of disability in all its aspects – and understand that disability is not just about employment or health care, but about all our lives – the potentially disabled. Foundations must be made to understand why it is important for all segments of society to prepare for disability: we are all going to grow old; we are all going to lose, in some shape, form or fashion, a degree of our physical capacities.

It is important that foundations and other organizations help us plan for that future. To accomplish this we must recognize that a mutual give-and-take process is required; a process of educating foundations on the one hand and a process of learning about funding priorities and how foundations work on the other. Working with foundations – educating them about how disability issues fit within their own priorities – could enhance funding for research in disability and rehabilitation. New partnerships could be forged between foundations and disability interests. Foundations could play an important role in educating the rest of society to disability issues.

In sum, don't be discouraged by current priorities and limitations of foundations. The foundation world needs to be educated by and involved with people such as yourselves. I encourage you to think about ways to work with foundations to agree on mutually beneficial outcomes and methods of increasing rehabilitation and disability research.

CHAPTER IV

THE WORKSHOP SESSIONS:

Guidelines and Recommendations

This section presents the guidelines and recommendations which were developed in the eight concurrent workshops held during the conference. The workshops were comprised of experts in the following areas:

- Trauma care (two groups)
- Rehabilitation services – financing (two groups)
- Rehabilitation services – organization (two groups)
- Personal assistance services
- Institutional long-term care

Trauma Care

Moderators: Wayne Copes, Ph.D.
Ruth Brannon, M.S.P.H.

Recorders: Barbara Faigin, M.A.
William Sacco, Ph.D.

Guideline 1: Expansion of Trauma Measurement to Include Long-term Outcomes

Current assessments of trauma outcome focus on patient survival, not on long-term outcomes such as the likelihood of disability. As a result, trauma center staff may not be adequately aware of the rehabilitation potential of trauma patients and may not make appropriate referrals to rehabilitation.

Recommendation 1.1

Expand trauma registries to include, at a minimum, information on (1) whether the trauma patient had a rehabilitation consultation; (2) if appropriate, whether the patient was referred to rehabilitation; and (3) long-term outcome measures such as patient living arrangement, employment status, and functional level at discharge from acute care.

Recommendation 1.2

Develop a scale for measuring the likelihood of disability from individual injuries and injury combinations. Investigate the efficacy of linking existing trauma severity measures such as the Abbreviated Injury Scale with measures of functional outcome such as the Functional Independence Measure (FIM).

Recommendation 1.3

Develop model systems for diagnostic groups such as burns, orthopedic injury, and amputation, modeled after the SCI and TBI systems, to ensure early provision of rehabilitative care and to facilitate the movement of patients from acute care to medical rehabilitation settings.

Recommendation 1.4

Construct "severity indices" (e.g., for head injury) that relate injury type to expected treatment requirements and likelihood of long-term disability.

Guideline 2: Measures to Evaluate Trauma Interventions

Current measures of the outcomes of trauma care primarily assess the potential for survival. More refined measures are needed to allow fuller evaluation of trauma interventions.

Recommendation 2.1

Conduct studies to quantify the magnitude of post-trauma disability and to determine changes in the organization or provision of trauma care needed to reduce disability.

Recommendation 2.2

Conduct comparative studies of the long-term functional outcomes of trauma center and non-trauma center patients.

Recommendation 2.3

Compare outcomes, as measured by survival and functional assessment, of patients treated in model trauma care systems with those of patients not treated in model systems.

Guideline 3: Alternative Service Delivery/Decision-Making Models

Referral from the trauma setting frequently is conducted by the discharge planner, with guidance from the physician and some family input. Resources may be used more efficiently if each patient's care is coordinated by a case manager through all levels of recovery, from acute to rehabilitative care. The outcome of such coordination through case management should be evaluated.

Recommendation 3.1

Compare the cost effectiveness of various case management approaches (e.g., insurance company, life coach, team approach).

Recommendation 3.2

Conduct studies to determine how families should be integrated into the decision-making process so they can best contribute to care decisions and prepare for long-term consequences (e.g., financial, medical, psychosocial) of injury.

Recommendation 3.3

Conduct studies to identify what determines functional outcome other than trauma care delivery (e.g., patient beliefs and attitudes, family and social support structure, urban vs. rural setting). Use this information to construct care plans that account for those determinants.

Recommendation 3.4

Investigate the impact on the referral process of various factors including (1) funding sources and payor policies, (2) availability of health care facilities, and (3) caregiver and family attitudes.

Recommendation 3.5

Establish protocols to guide referral from acute care to rehabilitation settings, including ethical considerations (e.g., when should active treatment be discontinued for patients remaining in coma).

Guideline 4: Financing Trauma/Rehabilitation Care

As health care costs continue to increase, the financing of trauma care and rehabilitation has received much attention. Researchers should consider how limitations imposed by payors affect access to care.

Recommendation 4.1

Determine whether there are treatment differences for "paying" and non-paying trauma patients, specifically how payor source affects likelihood of receiving rehabilitation services.

Recommendation 4.2

Determine whether different financing mechanisms result in outcome differences for "similar" trauma patients.

Recommendation 4.3

Develop and test innovative financing sources for uninsured or underinsured persons.

Recommendation 4.4

Compare the cost and efficacy of model system versus non-system care. Test the hypothesis that, in non-system care, available funds are often consumed by acute care, leaving little for rehabilitation.

Guideline 5: Improving Disability Awareness Among Trauma Center Staff

Trauma center personnel need to understand better the long-term disability potential of traumatic injuries. Improved understanding may lead to earlier provision of rehabilitative care in acute care settings.

Recommendation 5.1

Educate trauma and non-trauma center personnel in how to minimize the disabilities associated with non-life threatening injuries (e.g., minor head injuries).

Recommendation 5.2

Determine how to motivate the early and continued collaboration of trauma care and medical rehabilitation personnel.

Recommendation 5.3

Assess the role of nursing in mitigating secondary disability. Develop interventions for trauma nurses to prevent secondary disability.

Recommendation 5.4

Assess the role of social workers in training family members and significant others to assist with care in the hospital/home setting and to provide advocacy for patients in a trauma care/rehabilitation setting.

Guideline 6: Needs of Special Populations

Special populations may require unique service delivery models to facilitate movement from trauma to rehabilitation settings. Environmental characteristics such as rural setting or urban drug culture may be important factors in creating viable treatment plans for trauma survivors with long-term treatment needs.

Recommendation 6.1

Conduct studies of how trauma care/rehabilitation systems can best respond to the needs of special segments of the population. For instance, what are the unique problems of patients in rural settings or urban areas with high levels of violence and drug usage?

Rehabilitation Services – Financing

Moderators: Harriet Aronow, Ph.D.
Douglas Fenderson, Ph.D.

Recorders: Mark V. Johnston, Ph.D.
Scott Osberg, M.A.

Guideline 1: Current and Alternative Payment Systems

While much research has been conducted on the financing of acute health care services, relatively little is known by health services researchers or policy makers about the financing of medical rehabilitation services.

Recommendation 1.1

Examine further current models of financing rehabilitative care to understand better the eligibility, coverage, and payment policies of rehabilitation payors and to identify which services needed by disabled persons are unfunded (see Batavia, 1989).

Recommendation 1.2

Examine specifically which types of insurance policies and programs exclude coverage for medical rehabilitation and other services for persons with disabilities, and determine how to enhance the level of coverage.

Recommendation 1.3

Conduct demonstration projects on alternative means of financing rehabilitative services, including prospective payment systems, to determine their effect on access, quality, costs, and patient outcomes (see Batavia, 1988).

Recommendation 1.4

Examine whether payment for medical rehabilitation should be linked in whole or part to patient functional outcomes and/or other health outcome measures, and how this can be achieved best using currently available measures of functional status.

Recommendation 1.5

Examine alternative means of controlling the costs of rehabilitative care while maintaining access and quality of care for disabled persons.

Recommendation 1.6

Conduct research on the impact of current HCFA rules such as cost screens, PRO regulations, and pre-admission certification systems on access to services, containment of costs, and patient outcomes.

Guideline 2: Inefficiency and Discontinuity

The fragmentation of the U.S. health care financing system has induced inefficiency and discontinuity in the provision of rehabilitation and other health care services, as well as poor functional and health outcomes for people with disabilities.

Recommendation 2.1

Examine the sources of inefficiency and discontinuity between the public and private sectors, and between federal and state programs, in the financing of medical rehabilitation and other services for persons with disabilities.

Recommendation 2.2

Examine the extent to which "cost shifting" from acute care providers to rehabilitation providers exists, and whether it results in quicker acute care discharges and sicker rehabilitation patients.

Recommendation 2.3

Examine institutional policies affecting referral patterns to understand better the impact of financing mechanisms on decisions concerning discharge from acute care, admission to rehabilitation, and discharge from rehabilitation.

Recommendation 2.4

Develop more rational financing approaches that integrate the funding of vocational and medical rehabilitation, as well as funding for post-discharge independent living (e.g., independent living centers).

Guideline 3: Financing and Access to Care

Access to comprehensive, coordinated, and continuous rehabilitation and other health care services for people with disabilities is impeded by financial barriers.

Recommendation 3.1

Conduct research and demonstration projects on competing provider arrangements (HMOs, PPOs, IPAs, etc.) to determine which offer the greatest access and highest quality of comprehensive, coordinated, and continuous care to disabled persons.

Recommendation 3.2

Conduct cost-effectiveness and cost-benefit research on which levels and settings of care (e.g., inpatient vs. outpatient, SNF vs. comprehensive inpatient rehabilitation hospital) are most appropriate for different categories of patients.

Recommendation 3.3

Conduct research on how financing mechanisms and methodologies affect the supply of different types of personnel who provide services needed by persons with disabilities, how pay scales vary by geographic region and by urban/rural factors, and how these factors influence the availability of rehabilitation and related services.

Recommendation 3.4

Conduct research on "adverse selection" by disabled persons and "preferred risk selection" by third-party payors to understand better how to create a more "level playing field" among payors and to prevent discrimination against disabled persons.

Recommendation 3.5

Establish who should determine the need for rehabilitation services and who should design and direct these services (including models of consumer input and control), and examine the effects of alternative means of control on access, quality, costs, and outcomes of care.

Recommendation 3.6

Conduct research on the extent of financial coverage for rehabilitation services and the effects of financial coverage on delivery of rehabilitation services across racial, ethnic, and geographic groups.

Guideline 4: Need for a Common Terminology

The lack of common terminology concerning rehabilitation financing hinders meaningful discourse among rehabilitation and health services researchers, health care providers, and third-party payors.

Recommendation 4.1

Adopt the World Health Organization taxonomy of International Classification of Impairments, Disabilities, and Handicaps (ICIDH), and educate researchers, providers, and third-party payors on the common use of terminology under that nomenclature.

Recommendation 4.2

Adopt uniform measures of functional assessment that can be used to provide a scientific basis for evaluating interventions associated with the management of impairments, disabilities, and handicaps.

Recommendation 4.3

Develop uniform measures of social support that can be used to evaluate its impact on long-term functional capacity, productivity, and living arrangement.

Recommendation 4.4

Develop better protocols for ICDA9 coders to enhance the reliability and validity of these data for use by health services researchers in physical disability and rehabilitation.

Recommendation 4.5

Apply provisionally accepted "quality of life" measures (e.g., Katz, Flanagan) for use in rehabilitation services outcome studies, and develop improved quality of life measures for rehabilitation.

Guideline 5: Need for Sound Cost and Utilization Data

The lack of valid and reliable data on the costs of physical disability and rehabilitation hinders understanding of current health service utilization patterns and development of demonstration projects on innovative financing arrangements.

Recommendation 5.1

Examine the relationship between costs and charges to determine whether charges are an adequate proxy for costs in rehabilitation, and, if not, investigate alternatives to using charges in rehabilitation cost accounting systems.

Recommendation 5.2

Conduct longitudinal research on the direct post-acute costs of physical disability and rehabilitation, including professional fees.

Recommendation 5.3

Conduct research to determine the relationship between cost components and patient outcomes, as well as the relationship between minutes of therapy to patient outcomes.

Recommendation 5.4

Examine inter-institutional differences in efficiency (cost/functional change) to determine why there is substantial variation, and identify factors associated with more efficient models of rehabilitative care.

Recommendation 5.5

Conduct research on predicting length of stay (LOS) and charges/costs using type and extent of impairment, severity, disability level, and type and frequency of complications.

Guideline 6: Need for Education and Training

Adequate support for the financing of rehabilitation services is contingent upon a heightened awareness of the efficacy of rehabilitation among employers, third-party payors, health policy makers, foundations, health care providers, and disabled consumers and their advocates. Many employers, third-party payors, and policy makers do not understand the purpose of rehabilitation.

Recommendation 6.1

Educate the above groups about the role of rehabilitation in restoring function and preventing medical complications, subsequent loss of function, and concomitant handicaps.

Recommendation 6.2

Foster better coordination concerning support of health services research in rehabilitation between public agencies and private foundations.

Recommendation 6.3

Conduct longitudinal studies on years of productivity lost due to physical disability versus cost of rehabilitative care to demonstrate the economic benefits of rehabilitation.

Recommendation 6.4

Conduct research on ethical/philosophical bases for resolving financing issues relating to the special needs of persons with disabilities for comprehensive, coordinated, and continuous rehabilitative services.

Guideline 7: Work Disincentives

Despite recent legislation by Congress, the current health care financing system in this country continues to foster disincentives to work for persons with disabilities.

Recommendation 7.1

Examine the effects of the Medicare buy-in provision and other recent efforts by Congress to eliminate work disincentives.

Recommendation 7.2

Conduct demonstration projects to develop and test means of overcoming disincentives to employment associated with access to health care.

Rehabilitation Services – Organization

Moderators: Marcus Fuhrer, Ph.D.
Robert Keith, Ph.D.

Recorders: Don Galvin, Ph.D.
Deborah Wilkerson, M.A.

Guideline 1: Rehabilitation Capacity, Access, and Utilization

We have little benchmark data by which to determine an ideal medical rehabilitation capacity in a given geographic area. Nor do we have a good understanding about future rehabilitation needs relative to the changing profile of the disabled population. We need to develop an epidemiology of disability that will enable health planners and health providers to define the kind of rehabilitation capacity that is desired. Moreover, we need to determine (a) whether persons who need rehabilitation in fact have access to it, and (b) the rate at which various subpopulations actually use inpatient and outpatient rehabilitation.

Recommendation 1.1

Conduct a comprehensive survey of the disabled population, as was done recently in Great Britain and Canada, to ascertain the prevalence of disability and types of persons who may need rehabilitation. Such a survey should go well beyond other national surveys such as the National Health Interview Survey and the Survey of Income and Program Participation in which persons with disabilities are only a minor subgroup within the larger survey.

Recommendation 1.2

Develop an epidemiologic model where the service needs of major impairment groups are identified. Such a model should serve as a planning aid for providers, sponsors, and regulators of health services.

Recommendation 1.3

Conduct surveys to develop a more specific characterization of existing rehabilitation service capacities, both inpatient and outpatient. Special efforts should be made to determine the kinds of outpatient services available currently.

Guideline 2: Optimal Organization and Service Delivery

We need to identify the parameters that define the optimal organization and delivery of rehabilitative care beyond those specified by accrediting organizations. These parameters include, for example, ideal facility and program sizes (economies of scale), the ideal mix of rehabilitation professionals needed to serve a particular group, ideal staff/patient ratios, and other factors. Existing data sources can be used to help define optimal organizational strategies for inpatient rehabilitation, but little data are available to define optimal strategies for outpatient services. Little is known about how different models of rehabilitation services organization affect outcomes and costs. We need to obtain a better understanding of how the type, intensity, and setting of rehabilitation services affect rehabilitation costs and outcomes.

Recommendation 2.1

Conduct follow-up studies in which cohorts of newly impaired persons are tracked at regular intervals for periods of three to five years post-onset. Such studies should be designed to ascertain (a) patterns of recovery, (b) optimal patterns of service utilization (both acute and rehabilitative services), (c) service outcomes, and (d) service costs. Such studies should also evaluate the continuity of services and identify the types of individuals who fail to receive the services they need.

Recommendation 2.2

Link existing acute care and rehabilitation data bases in order to identify patterns of service utilization and outcomes.

Recommendation 2.3

Conduct multi-site collaborative research to evaluate the relative effectiveness and efficiency of different service delivery systems. Federal funding sources should encourage multi-site collaboration. Multi-site research also is needed to obtain adequate sample sizes of patients in target groups.

Recommendation 2.4

Evaluate the relative costs and outcomes of current methods of providing rehabilitation services. Outcome should include consumer satisfaction; cost should include the use of post-rehabilitation services.

Recommendation 2.5

Conduct studies to assess the outcomes and costs of service delivery programs with different organizational characteristics, e.g., evaluate the costs and outcomes of freestanding facilities versus those of rehabilitation units in acute care settings.

Guideline 3: Alternative Delivery Models

Personnel shortages and increased medical rehabilitation costs may require the consideration of alternative modes of rehabilitation service delivery such as the increased use of outpatient services, use of home-based rehabilitation services, use of paraprofessional staff, and less reliance on the team approach in inpatient rehabilitation.

Recommendation 3.1

Conduct demonstration projects in which one or more alternative modes of rehabilitation service delivery can be tested. Compare outcomes and costs with more traditional modes of rehabilitation service delivery.

Guideline 4: Impact of External Factors

Many factors in the larger health care economy have an effect on the costs and outcomes of rehabilitation services that cannot be controlled by rehabilitation providers. These include payment ceilings such as TEFRA limits, length-of-stay limits, minimum service requirements, and other factors over which providers have little control and which may result in suboptimal outcomes.

Recommendation 4.1

Determine the impact of payment and reimbursement systems on rehabilitation outcomes and costs. Specifically, examine whether TEFRA payment limits affect the use of rehabilitation resources and how managed care systems are affecting rehabilitation utilization, outcomes, and costs.

Recommendation 4.2

Evaluate the impact of mandated guidelines such as the "three-hour rule" on rehabilitation costs and outcomes.

Recommendation 4.3

Evaluate the probable impact of "manpower" shortages in nursing, physical therapy, and occupational therapy.

Guideline 5: Efficacy and Effectiveness of Interventions

We need to establish the efficacy and effectiveness of interventions. We must distinguish between "efficacy" – for the purpose here, the power of treatment in the hands of highly capable people under ideal circumstances – and "effectiveness" – used here to mean the routine use of that same treatment in the hands of those in the usual facility with the usual mix of patients. Efficacy is what is possible in the controlled clinical environment, and effectiveness is what happens in the natural environment, or the "real world." Some maintain that controlled clinical trials to establish efficacy do not address the issue of effectiveness very well. The efficacy and effectiveness of rehabilitation should be ascertained by using all relevant research tools available currently to health service and clinical researchers including controlled clinical trials, program evaluation, cost-benefit analysis, cost effectiveness analysis, and differential clinical research.

Recommendation 5.1

Use research designs and methods, such as clinical trials and cost-effectiveness studies, already developed for other health services to establish the efficacy of rehabilitation treatment.

Recommendation 5.2

Examine ways in which rehabilitation efficacy and effectiveness vary at different levels of analysis, i.e., how efficacy and effectiveness vary depending on whether one is examining (a) a specific treatment procedure, (b) a type of rehabilitation program, or (c) an entire rehabilitation delivery system.

Recommendation 5.3

Develop quantitative indices that reflect sensitively the key attributes of specific rehabilitation services when determining the efficacy and effectiveness of services.

Guideline 6: Effects of Consumer Characteristics on Outcomes

Targeting appropriate and responsive rehabilitation services to different population subgroups can increase the cost-effectiveness of rehabilitation services. Little is known about how the individual characteristics of consumers affect their utilization of rehabilitation services and the outcomes that are achieved.

Recommendation 6.1

Ascertain both the provider-assessed service needs and expressed demands of persons with disabling impairments when determining the need for, and the effect of, rehabilitation services.

Recommendation 6.2

Assess ways in which rehabilitation service needs and outcomes vary by individual differences among consumers such as age, gender, and ethnicity.

Guideline 7: Quality of Care and the Measurement of Outcomes

The health care industry is focusing increasingly on definitions of quality care. There is a corresponding need to define quality rehabilitative care. This entails establishing outcome norms, developing and validating relevant measures, defining practice guidelines, identifying acceptable practice variations, and other quality-of-care criteria. Moreover, rehabilitation needs to develop outcome and quality-of-care criteria that are responsive to new patient groups such as those with traumatic brain injury.

Recommendation 7.1

Continue development of outcome measures that are sensitive to patient change in functional independence, satisfaction, and quality of life. Address validity, reliability, sensitivity, and uniformity of tools.

Recommendation 7.2

Develop functional status tools and outcome measures that are responsive to the needs of patients with cognitive deficits, such as patients with traumatic brain injury (e.g., tools to measure social interaction skills, behavioral control, cognitive function, and communication skills).

Recommendation 7.3

Develop outcome and quality-of-care guidelines that go beyond traditional functional status measures by addressing issues such as the prevention and management of medical complications, post-rehabilitation hospitalizations, independent living arrangements, productivity, consumer satisfaction, and quality of life.

Recommendation 7.4

Conduct studies to investigate the validity of patient and family self-report as a method of outcome measurement.

Recommendation 7.5

Develop a consensus on the most relevant sets of outcome measures and indicators of quality care.

Personal Assistance Services

Moderator: Margaret Nosek, Ph.D.

Recorder: Gerben DeJong, Ph.D.

Guideline 1: Models of Personal Assistance

Personal assistance services in the United States have been organized and provided under two competing models. Under the traditional home health or medical model, services are directed by medical personnel. Under the independent living (IL) model, services are directed by the user. Disabled persons associated with the IL movement believe strongly that the IL model is more responsive to their needs and value system.

Recommendation 1.1

Identify the benchmark characteristics of the medical and IL models that can be used to evaluate personal assistance service programs.

Recommendation 1.2

Develop an inventory of federal, state, and local personal assistance programs, and determine the extent to which they conform mainly to the medical or to the IL model or to some hybrid.

Recommendation 1.3

Monitor and evaluate IL-oriented personal assistance programs.

Guideline 2: Measuring Need/Demand for Personal Assistance

There is considerable confusion as to the need and demand for personal assistance services. Estimates range from a few hundred thousand to more than several million potential users, depending on how the target population is defined. Policy makers fear that the latter figure may result in budget-busting levels of spending with uncertain results. Health services researchers, epidemiologists, and demographers need to develop a consensus as to the numbers of people who require personal assistance.

Recommendation 2.1

Conduct secondary analyses of existing survey data as to the numbers of people who need various forms of personal assistance and the amount they are likely to need on a daily or weekly basis. National survey data should include, but not be limited to, the National Health Interview Survey, the Survey of Income and Program Participation, and the National Medical Care Expenditure Study.

Recommendation 2.2

Determine whether the numbers of ADLs (activities of daily living) and IADLs (instrumental activities of daily living) in which people need assistance, as reported in national survey data, are a good proxy for the actual amount of assistance a person may need on a daily or weekly basis. If not, propose new survey language to gauge the amount of assistance people need.

Guideline 3: Measuring Individual Need for Personal Assistance

To administer a personal assistance program both equitably and efficiently, there must be (1) tools or instruments by which individual needs can be assessed objectively and (2) persons who are skilled in assessing more subjective factors such as the influence of environmental barriers and living arrangements.

Recommendation 3.1

Determine the extent to which existing functional assessment instruments such as the Functional Independence Measure and the Katz Scale predict the hours and minutes of daily and weekly assistance that an individual might need (predictive validity). If predictive, encourage the use of such instruments in the assessment of individual need in determining eligibility and level of service.

Recommendation 3.2

Develop a checklist of environmental, lifestyle, and living arrangement factors that should be taken into account when evaluating individual need including needs apart from the home environment such as work or school.

Recommendation 3.3

Identify the types of professional persons and disabled persons who would be best equipped to assess individual need on behalf of a personal assistance program.

Recommendation 3.4

Identify ways in which assistive technology can be used to reduce the need for personal assistance, consistent with an individual's overall lifestyle including employment and school.

Guideline 4: Funding and Financial Eligibility Criteria

The mechanisms by which services are funded have a major impact on their delivery and effectiveness. One of the unresolved debates in American public policy is whether, and the extent to which, a person's income and resources should be taken into account when determining if he or she should be eligible to participate in a publicly supported program.

Recommendation 4.1

Determine how federal regulations under Titles XIX and XX of the Social Security Act can be made more responsive to the IL model of personal assistance services.

Recommendation 4.2

Evaluate the merits of financing personal assistance services from existing funding sources versus new funding authorities. Determine how existing funding mechanisms can facilitate more community-based versus institution-based forms of personal care.

Recommendation 4.3

Evaluate the merits of taking versus not taking into account a person's financial resources when determining eligibility for personal assistance services. In such an evaluation, consider the following factors: overall program costs, the cost of administering financial eligibility criteria, program equity, congruence with other income-tested benefits, and the effect on gainful work. Evaluate alternative approaches to user financial participation.

Recommendation 4.3

Evaluate how other nations address financial factors when determining eligibility for personal assistance services.

Recommendation 4.4

Evaluate the extent to which the Aids and Attendants Allowance program of the Department of Veterans Affairs (which is administered without regard to financial eligibility) affects individual decisions in becoming gainfully employed.

Guideline 5: Determining the Scope of Personal Assistance Services

One unresolved issue in establishing a personal assistance policy is the scope of services to be included in the package of personal assistance services. The particular bundle of services may also determine which of several existing or new funding sources should be used to pay for personal assistance services.

Recommendation 5.1

Determine the extent to which persons with disabilities need personal assistance services in places apart from the home environment, such as on the job or in school. Estimate the numbers of persons who may require out-of-home assistance on a regular basis.

Recommendation 5.2

Evaluate the extent to which reader services for blind people and interpreter services for deaf persons should be integrated into an overall national policy for personal assistance services. Evaluate whether reader and interpreter services should be funded apart from, or in concert with, services geared more toward personal care.

Recommendation 5.3

Analyze existing in-home service programs to determine the extent to which distinctions between medical and nonmedical, and skilled and unskilled, services are made in long-term care policy. Evaluate the appropriateness of such distinctions in developing a national personal assistance policy designed to meet the needs of persons with long-term impairments.

Guideline 6: The Role of Professional Providers

This nation already has a substantial network of agencies and professionals that provide in-home support services directed by providers, not consumers. Some providers view the IL model as inconsistent with the demands for public

accountability and quality assurance. Some IL advocates insist that provider organizations have no role in the delivery of self-directed personal assistance services.

Recommendation 6.1

Determine if there are any aspects of personal assistance delivery that could be provided by professional home care providers without violating the self-directed nature of personal assistance services in the IL model (e.g., evaluation of need, eligibility determination).

Guideline 7: Personal Assistance Across Different Age Groups

Because the quest for functional independence is relevant to all age groups, some disability advocates have urged that personal assistance services not make distinctions based on age. Others have noted the need to train disabled children in becoming adept at learning to manage their own personal assistance.

Recommendation 7.1

Evaluate the merits of developing a unified national personal assistance policy across age groups. Determine the administrative, political, and economic factors that should be considered in using age as a factor in developing national policy.

Recommendation 7.2

Determine ways in which the IL model of personal assistance can be adapted to meet the different needs of children, adolescents and older adults. Conduct demonstration and research projects in which children and adults learn to become increasingly independent in managing their own personal assistance.

Guideline 8: Personal Assistance for Persons Who Have Cognitive Impairments or Limitations in Self-direction

The IL model of personal assistance originated with a population of disabled persons who demonstrated considerable self-determination. The application of the IL model to less self-directed persons is not always straightforward.

Recommendation 8.1

Develop innovative models in which persons with cognitive impairments (e.g., mental retardation, brain injury) can become maximally independent in managing their own personal assistance.

Recommendation 8.2

Evaluate the impact of new service delivery models on individuals with cognitive impairments in terms of their need for supervision and their ability to function in other spheres of life (e.g., work).

Guideline 9: Supply and Recruitment of Personal Assistants

Insufficient attention has been given to the supply side of the personal assistance market. Many users of personal assistance services report that they are unable to find an adequate supply of willing and dependable assistants.

Recommendation 9.1

Conduct surveys of users of personal assistant services to determine their experience in locating a steady source of personal assistants. Identify barriers to recruitment and possible new sources of attendants.

Recommendation 9.2

Conduct market research on potential suppliers of personal assistance services (e.g., students, immigrant groups, persons with cognitive impairments, retired persons) to determine the conditions under which they would be willing to work as assistants.

Recommendation 9.3

Review proposals for a "national service corps" of volunteers to determine how personal assistant services might be included in such a national program.

Recommendation 9.4

Conduct a demonstration program using a computerized "multiple listing service" for personal assistance services in which suppliers and users express their preferences with respect to factors such as time of day, wage rates, location, gender, and live-in status. Use a multiple listing service to evaluate local market conditions and provide wage data for rate-setting purposes.

Guideline 10: Training

Many users of personal assistance services who subscribe to the IL model believe strongly that they are best able to train their own assistants, and that regulatory training requirements are designed to satisfy professional misconceptions of what is needed. However, others believe that training would enhance the job status of assistants and provide opportunities for professional growth. In addition, some consumers need training on how best to organize and manage personal assistants.

Recommendation 10.1

Survey users and assistants to determine whether they believe that "outside" training, prior to becoming an assistant, would have benefited them.

Recommendation 10.2

Determine whether and how potential assistants might benefit from some formal training before and while serving as assistants.

Guideline 11: Job Satisfaction and Retention of Assistants

Many users of personal assistance services report high turnover of assistants.

Recommendation 11.1

Question users and assistants about the factors that contribute to assistant turnover. Determine the extent to which turnover is inherent in the population groups that work as assistants.

Recommendation 11.2

Identify the factors that contribute most to job satisfaction and retention of assistants.

Guideline 12: Consumer/User Involvement

Through experience, many users of personal assistance services have developed ideas about what makes for an excellent personal assistant service arrangement. Their ideas should inform the research process. Research findings with respect to personal assistance services need to be made more accessible to persons with disabilities.

Recommendation 12.1

Develop consumer-based quality assurance standards for the evaluation of personal assistance services.

Recommendation 12.2

Involve users of personal assistance services in the development and design of research related to personal assistance services.

Recommendation 12.3

Make research findings pertaining to personal assistance "user-friendly" for consumers of personal assistant services.

Institutional Long-term Care

Moderator: Joshua Wiener, Ph.D.

Recorder: Naomi Naierman, M.P.A.

Guideline 1: Perceptions about Long-term Care Facilities and their Residents

Our understanding about long-term care institutions and their residents contains major gaps. All too often, public perceptions and attitudes about the quality of life available in long-term care institutions are based on stereotypes. That a large variety of institutions exist (e.g., supervised and unsupervised group homes, nursing homes, and day care facilities) is not well understood. The variety of people who use long-term institutional care also is overlooked. Utilization data (e.g., length of stay and health outcomes) are inadequate for sound policy planning. A public education program is needed to facilitate more informed decisions about institutional care policy in the nation.

Recommendation 1.1

Collect data on the types of services available and quality of life in institutions for elderly/non-elderly physically disabled, mentally disabled, and mentally ill persons, using available national data bases, such as the National Medical Care Expenditure Survey and the Brookings National Nursing Home Survey.

Recommendation 1.2

Conduct public opinion surveys about attitudes toward these institutions for selected subgroups of users, including questions about public versus private responsibilities, insurance payment for long-term care services, and additional taxes. Several subgroups of the general public should be queried, including persons with disabilities, their caregivers, and government officials.

Recommendation 1.3

Conduct descriptive studies to gather basic demographic and health status data on users of long-term care institutions, length of stay, discharge status, and hospitalization rate.

Recommendation 1.4

Conduct analytic studies to determine what proportion of the institutionalized population is and is not living in the least restrictive and appropriate environment. Generate projections about the costs of more appropriate placement in several regional settings.

Recommendation 1.5

Develop and implement a public education strategy that includes the dissemination of research-based information on (a) the types and characteristics of various long-term care facilities, (b) the characteristics of residents living in long-term care facilities, (c) public perceptions about long-term care facilities and their residents, and (d) the accuracy of such perceptions.

Guideline 2: The Potential Impact of Related Services

The availability of other services such as medical rehabilitation, independent living, and day care services can affect the utilization and impact of institutional services. The impact of these services is not well understood.

Recommendation 2.1

Conduct outcome studies to evaluate the impact of pre-institutionalization medical rehabilitation services on institutional use and length of stay.

Recommendation 2.2

Conduct qualitative and quantitative studies to document the events which precipitate institutionalization. Include data on caretakers' health and emotional status.

Recommendation 2.3

Conduct studies to evaluate the role of independent living centers in the prevention of institutionalization. Examine how decisions on whether to use long-term institutional care affect, and are affected by, individual preference, quality of life for individuals and families, functional status, and costs. Determine how IL centers can help to (a) avert institutionalization and (b) facilitate deinstitutionalization for those who were institutionalized for lack of community-based alternatives in earlier years.

Recommendation 2.4

Conduct studies to evaluate the role of day care services in the prevention of institutionalization. Examine issues of individual preference, quality of life for individuals and families, functional status, cost, and mortality rates. Use experimental, control-group studies comparing day care service users versus institutionalized versus at-home populations.

Recommendation 2.5

Examine cross-national comparisons of institutional versus community-based alternatives for selected groups such as persons with physical disabilities, mental illness, and mental retardation among both elderly and non-elderly populations. Conduct cross-national comparative studies where major comparisons currently are not available.

Guideline 3: Quality of Care

The quality of care available to non-elderly users of long-term care institutions is not well understood. Non-elderly users of long-term institutional care are a minority and their characteristics and special needs have been neglected.

Recommendation 3.1

Conduct qualitative and quantitative studies of the quality of life for non-elderly users of long-term care institutions. Stratify the study group by type of impairment and functional status.

Recommendation 3.2

Compare elderly and non-elderly users of long-term care institutions in terms of their quality of life, level of impairment, and functional status.

Guideline 4: The Financing of Institutional Long-term Care

A national consensus on the financing of institutional long-term services has yet to be reached. A disability and rehabilitation perspective on the financing of institutional services needs to be developed.

Recommendation 4.1

Conduct descriptive studies on the use of rehabilitation services in long-term care institutions to answer the questions of who pays, how much, and for what services.

Recommendation 4.2

Conduct analytic studies to compare the outcomes and costs of rehabilitation services rendered in skilled nursing homes versus those rendered in short-term comprehensive inpatient rehabilitation centers. Identify alternative methods for financing rehabilitative care rendered in skilled nursing facilities.

Recommendation 4.3

Evaluate the role of the Medicaid spend-down's impact on the financial status of non-elderly disabled individuals and their families.

Recommendation 4.4

Investigate the role of private and public long-term care insurance in financing long-term care services.

Recommendation 4.5

Develop a cross-national perspective on the public financing of long-term care services for both elderly and non-elderly persons.

CHAPTER V

Closing Remarks

Gerben DeJong, Ph.D., Director
National Rehabilitation Hospital Research Center

September 27, 1990

Four Research Communities

This conference represents the conjunction of four different research communities: (1) rehabilitation research, (2) health services research, (3) injury and trauma research, and (4) long-term care/gerontology research. This probably is the first conference in which all four communities have been represented.

The interaction of these four research communities is noticeable increasingly in our respective professional organizations. For example, the American Public Health Association now has its Caucus on Disablement, chaired by Dr. MacKenzie, who is a participant in this conference. Likewise, the American Congress of Rehabilitation Medicine is giving increasing attention to health services research issues under the rubric of "administration."

Research Infrastructure

Each of the four research communities has its own array of research instruments, data bases, research training capacities, and professional journals for research dissemination. Thus, research capacities vary widely within each of these four communities. While each community has a cadre of skilled researchers, the *skill mix* is different within each community. The rehabilitation community and the long-term care/gerontology community are strong in conceptualizing and measuring functional status; the HSR community has a strong network of health economists and other social scientists; and the injury and trauma research community has a strong nucleus of epidemiologists.

The development of an HSR capacity in physical disability and rehabilitation will require a great deal of cross-fertilization among various disciplines. For example, disability researchers need to recruit more epidemiologists and health economists from the ranks of the HSR community,

and health services researchers need to recruit more experts in functional measurement from the disability research community. I believe that our respective research communities have much to offer one another.

Unfortunately, our research communities are too balkanized. Each is dependent on its own network of graduate programs and funding sources. Fortunately this is changing, as funding sources such as the Centers for Disease Control, the National Institutes of Health, and the Agency for Health Care Policy and Research become more interested in disability issues.

Other Major Themes

Over the last two days we have heard several major themes. I would like to cite some of them. My list is not exhaustive but does cut across each of the four major content areas of the conference.

Changes in health care delivery

One recurring theme is that we are living through a very fluid time in American health care. While this could be said for almost any era in American health care, we are in a transition between (1) a decade of entrepreneurial medicine and managed care and (2) a decade of debate on health outcomes, practice guidelines, and rationing. There is a sense that the growth of health care services of the last decade cannot be sustained without creating serious distortions elsewhere in the American economy. There is considerable concern about how the health care needs of disabled persons will be addressed in the decade ahead. This is one reason why an HSR capacity in physical disability and rehabilitation is needed. Without this capacity, there will not be an adequate research community to back up and affirm the claims of disabled persons for a more accessible health care system that can meet their needs.

Americans with Disabilities Act

The ADA is having a pervasive effect on how this nation views disability. It is shaping the consciousness of many decision makers in both the public and private sectors. Take note of the references to the ADA in Dr. Mason's keynote address and in presentations made by other participants. One way or another, the policy assumptions that fostered the ADA will spill over into the delivery of health care services.

Outcomes

Health outcomes and assessment of outcomes have been important themes at this conference. Outcomes research has become a major focus of federal interest. However, in the context of disability research, health outcomes mean functional status and independence for persons with disabilities. I believe that the disability research community has much to offer investigators in other research communities who are trying to conceptualize and measure outcomes that relate to functional well-being. In health services research and bioethics, there has been increasing discussion about concepts such as quality-of-life-adjusted years of life as an outcome to be used when evaluating the efficacy of a given medical procedure. I believe that the disability research community – and I include persons with disabilities in that community – has much to offer toward conceptualization and measurement of health outcomes apart from those related to medical rehabilitation.

Continuity of care

By sorting ourselves into specific segments of the health care system – trauma care, rehabilitation, primary care, long-term care – we develop a very discontinuous view of the health care needs of people with disabilities. By bringing researchers and practitioners from all segments of the health care system into one place, this conference has enhanced our understanding of the need for continuity of care if the health and well-being of disabled persons are to be advanced. This concept of continuity is central to the model regional brain and spinal injury systems sponsored by NIDRR. I believe that there is much we can learn from these systems that can be applied elsewhere.

Health care financing and the shaping of human behavior

One important theme in this conference has been the notion that provider and consumer behavior is shaped in large part by how we finance health care services. Our system of health care finance contains major economic incentives that may compromise important outcomes and may not always be in the best interest of persons with disabilities. Too often we accept our system of health care finance as a given and fail to taken into account the nature of our system when attempting to explain outcomes.

Need for multi-site research and interagency collaboration

This conference has underscored the fact that sound health services research often requires large patient populations at multiple sites. Often it is the differences in health service delivery at each site that are of specific interest.

Accordingly, an HSR capacity in disability requires the cooperation of multiple institutions.

Additionally, HSR issues in disability often cut across the domains of several funding sources and require considerable interagency collaboration. In some instances, one funding source may be better able to fund the planning and pilot phase of a study while another may be better suited to fund the full-scale implementation of a study.

Involvement of persons with disabilities

One recurring theme in our deliberations has been the need to involve people with disabilities. However, it is my view that involving people with disabilities in various advisory committees and in the peer review process is not enough. In some cases, a fetish commitment to involve persons with disabilities who are not themselves researchers may undermine the scientific merit review process. Instead, I believe that we need to recruit and train people with disabilities as health services researchers. We need to make people with disabilities an integral part of the disability and HSR community. This is one important way we can assure that our research will be relevant to the needs of persons with disabilities.

References

- Acton JD. *Measuring the Social Impact of Health and Circulatory Disease Programs: Preliminary Framework and Estimates*. Rand Report R-1967. Santa Monica: The Rand Corporation, 1975.
- Batavia AI. *The Payment of Medical Rehabilitation Services: Current Mechanisms and Potential Models*. Chicago: American Hospital Association, 1988.
- Batavia AI & DeJong G. Developing a Comprehensive Health Services Capacity in Physical Disability and Rehabilitation. *Journal of Disability Policy Studies*, 1990; 1(1):37-61.
- Champion HR & Mabee MS. *An American Crisis in Trauma Care Reimbursement*. Washington, DC: Washington Hospital Center, 1990.
- Chirikos TN. Aggregate Economic Losses from Disability in the United States: A Preliminary Assay. *The Milbank Quarterly*, 1989; Vol. 67, Suppl 2, Pt 1, pp 59-91.
- Cooper B & Rice DP. The Economic Cost of Illness Revised. *Social Security Bulletin*, 1976; 39:21-36.
- DeJong G & Batavia AI. Toward a Health Services Research Capacity in Spinal Cord Injury. *Paraplegia*, 1991; 29(6):373-389.
- DeJong G, Batavia AI & Griss R. America's Neglected Health Minority: Working-age Persons with Disabilities. *The Milbank Quarterly*, 1989; Vol. 67, Suppl 2, Pt 2; pp 311-350.
- Landefeld J & Seskin E. The Economic Value of Life: Linking Theory to Practice. *American Journal of Public Health*, 1982; 72(6):555-566.
- Lubeck DP & Yelin EH. Question of Value: Measuring the Impact of Chronic Disease. *The Milbank Quarterly*, 1988; 66(3):444-464.
- Luchter S. *The Use of Impairment for Establishing Accident Injury Research Priorities*. SAE 871078. Society of Automotive Engineers, 1987.

MacKenzie EJ, Siegel JH, Shapiro S, Moody M & Smith RT. Functional Recovery and Medical Costs of Trauma: An Analysis by Type and Severity of Injury. *Journal of Trauma*, 1988; 28:281-97.

Rice DP. Estimating the Cost of Illness. *American Journal of Public Health*, 1967; 57:424-440.

Rice DP, MacKenzie EJ & Associates. *Cost of Injury in the United States: A Report to Congress*. San Francisco: Institute for Health and Aging, University of California and Injury Prevention Center, Johns Hopkins University, 1989.

APPENDICES

APPENDIX A

Conference Participants

Barbara M. Altman, Ph.D., Service Fellow
Agency for Health Care Policy and Research

N. Jeanne Argoff, Ph.D., Director
Grant Program
The Dole Foundation

Harriet Udin Aronow, Ph.D.
Visiting Assistant Researcher, UCLA
Multicampus Division of Geriatric Medicine and Gerontology

Andrew Batavia, J.D., M.S.
Associate Director for Health Services Research
National Rehabilitation Hospital Research Center

Sherrie L. Bordon, M.H.S., P.A.-C.
Assistant Director of Government Affairs
National Association of Rehabilitation Facilities

Laurence G. Branch, Ph.D., Professor
Boston University School of Medicine

Ruth Brannon, M.S.P.H., Senior Research Associate
National Rehabilitation Hospital Research Center

Arlene Bruhn, Administrative Officer
Medical and Research Affairs Department
Paralyzed Veterans of America

Wayne Copes, Ph.D., Vice President
Tri-Analytics, Inc.

Julia F. Costich, Ph.D., Department Administrator
Department of Rehabilitation Medicine
University of Kentucky Medical Center

Stephen Crane, Ph.D., Deputy Director
Association for Health Services Research

Gerben DeJong, Ph.D., Director
National Rehabilitation Hospital Research Center
Professor, Department of Community and Family Medicine
Georgetown University School of Medicine

Alice M. Demichelis, Legislative Liaison
National Head Injury Foundation, Inc.

James N. Eastham, Jr., Sc.D., Chairperson
Department of Emergency Health Services
University of Maryland, Baltimore County
Maryland Institute for Emergency Medical Services Systems

Edward Eckenhoff, M.H.A., President
National Rehabilitation Hospital

Diana Elmes, J.D., Director
Quality Assurance and Risk Management
National Rehabilitation Hospital

Robert Enteen, Ph.D., Director
Health Research and Policy Programs
National Multiple Sclerosis Society

Barbara M. Faigin, M.A., Economist
Office of Plans and Policy
National Highway Traffic Safety Administration
Department of Transportation

Douglas A. Fenderson, Ph.D., Professor
Department of Family Practice and Community Health
University of Minnesota

Thomas W. Findley, Jr., M.D., Ph.D.
Director of Research
Kessler Institute for Rehabilitation

J. Michael Fitzmaurice, Ph.D., Director
Office of Science and Data Development
Agency for Health Care Policy and Research

Marcus Fuhrer, Ph.D., Professor
Department of Rehabilitation and Psychiatry
Baylor College of Medicine

Donald E. Galvin, Ph.D., Director
Institute for Rehabilitation and Disability Management
Washington Business Group on Health

Lynn Gerber, M.D., Chief
Department of Rehabilitation Medicine
National Institutes of Health

Dorothy L. Gordon, D.N.Sc., R.N., Associate Professor
Director, Acute Care Program and Rehabilitation
Elsie M. Lawler Chair in Nursing
Johns Hopkins University School of Nursing

Wayne A. Gordon, Ph.D.
Associate Professor/Associate Director
Department of Rehabilitation Medicine
Mount Sinai School of Medicine
Mount Sinai Medical Center

Patricia A. Grady, Ph.D., Health Scientist Administrator
Division of Stroke and Trauma
National Institute of Neurological Disorders and Stroke

Philip Graitcer, D.M.D., M.P.H., Medical Epidemiologist
Division of Injury Control, Center for Environmental Health and
Injury Control
Centers for Disease Control

William H. Graves, Ph.D., Director
National Institute on Disability and Rehabilitation Research
U.S. Department of Education

David Bertsch Gray, Ph.D., Health Scientist Administrator
National Institute of Child Health and Human Development

Robert Griss, M.A., Disability Policy Analyst
World Institute on Disability

Lawrence D. Haber, Research Director
L. D. Haber Associates

Evan C. Hadley, M.D., Chief
Geriatrics Branch
National Institute on Aging
National Institutes of Health

Marnie Hall, Ph.D., Social Science Research Analyst
Office of Research and Demonstrations
Health Care Financing Administration

Lauro S. Halstead, M.D., Director
Post-Polio Program
National Rehabilitation Hospital

Byron B. Hamilton, M.D., Ph.D., Director
Uniform Data System for Medical Rehabilitation, Data
Management Systems
Clinical Associate Professor
Department of Rehabilitation Medicine
State University of New York at Buffalo

Mary F. Harahan, Director
Division of Disability, Aging and Long-term Care
Office of the Secretary/Assistant Secretary for Planning and
Evaluation
Department of Health and Human Services

Allen W. Heinemann, Ph.D., Associate Professor
Department of Rehabilitation Medicine
Northwestern University Medical School
Director, Rehabilitation Services Evaluation Unit
Rehabilitation Institute of Chicago

Judith E. Heumann, M.P.H., Director
World Institute on Disability

Lenore Hildebrandt, M.Ed.
Data Base Specialist, Program Evaluation
National Rehabilitation Hospital

Barbara Howard, Ph.D., Director of Research Programs
Medlantic Research Foundation

John Hudson, M.S.W., Assistant Director
Social Work Service
National Rehabilitation Hospital

Mark V. Johnston, Ph.D., Director of Outcome Research
Kessler Institute for Rehabilitation

Judith Miller Jones, M.A., Director
National Health Policy Forum
George Washington University

Ruth Katz, Policy Analyst
Office of Assistant Secretary for Planning and Evaluation
Department of Health and Human Services

Robert Allen Keith, Ph.D., Director
Rehabilitation Research and Planning Center
Casa Colina Hospital

Mitchell P. LaPlante, Ph.D., Assistant Research Sociologist
Disability Statistics Program, Institute for Health and Aging
University of California at San Francisco

Toby Lawrence, P.T.
Rehab Program Specialist
U.S. Department of Education
Office of Special Education and Rehabilitation Services
National Institute on Disability and Rehabilitation Research

Stephen Luchter, B.S., Chief
Planning and Policy Development
National Highway Traffic Safety Administration

Ellen J. MacKenzie, Ph.D., Assistant Director
Health Services Research and Development Center
Professor, Department of Health Policy and Management
Johns Hopkins University School of Hygiene and Public Health

Marsha Marshall, M.P.A., Research Associate
Department of Community and Family Medicine
Georgetown University School of Medicine

James Mason, M.D., Assistant Secretary for Health
U.S. Department of Health and Human Services

Richard S. Materson, M.D.
Vice President, Medical Affairs, and Medical Director
National Rehabilitation Hospital

Karen Rittinger Matherlee, M.A., Deputy Director
National Health Policy Forum

Frederick M. Maynard, Jr., M.D., Associate Professor
Department of Physical Medicine and Rehabilitation
University of Michigan Medical Center

Marsha G. Meehan, Research Assistant
National Rehabilitation Hospital Research Center

Allan R. Meyers, Ph.D., Associate Dean/Associate Professor
Boston University School of Public Health

Ted R. Miller, Ph.D., Senior Research Associate
The Urban Institute

Malcolm H. Morrison, Ph.D., Director of Research and
Program Development
National Association of Rehabilitation Facilities

Timothy C. Muzzio, Ph.D., Director of Education and Training
National Rehabilitation Hospital

Naomi Naierman, M.P.A.
Independent Consultant, Long-term Care Issues
National Rehabilitation Hospital Research Center

Patricia Neuman, M.H.S., Professional Staff Member
Subcommittee on Health
U.S. Committee on Ways and Means

Margaret A. Nosek, Ph.D., Assistant Professor
Department of Rehabilitation
Baylor College of Medicine

J. Scott Osberg, M.A., Research Associate
Medical Rehabilitation R&T in Rehabilitation and
Childhood Trauma
New England Medical Center Hospitals

Mary Jane Owen, M.S.W., Director
Disability Focus, Inc.

Seymour Perry, M.D., F.A.C.P., Professor and Chairman
Department of Community and Family Medicine
Georgetown University School of Medicine

Penelope Pine, Statistician
Office of Research
Health Care Financing Administration

Peter Reinecke, Associate Staff Director for Health Policy
Senate Subcommittee on Disability Policy

James B. Reswick, Sc.D., Associate Director
Division of Research Sciences
National Institute on Disability and Rehabilitation Research
U.S. Department of Education

Grace S. Rozycki, M.D.
Deputy Director, Trauma Services
Surgical Director, MEDStar
Washington Hospital Center

William J. Sacco, Ph.D., President
Tri-Analytics, Inc.

Jessica Scheer, Ph.D.
National Institute on Aging Postdoctoral Fellow
National Rehabilitation Hospital Research Center

Kay Fletcher Schriner, Ph.D., Editor
Journal of Disability Studies
Department of Rehabilitation Education and Research
University of Arkansas

Katherine D. Seelman, Ph.D., Research Specialist
National Council on Disability

Raymond Seltser, M.D., M.P.H., Consultant
Agency for Health Care Policy and Research
Center for General Health Services Extramural Research

Donald Shriber, Counsel
House Energy and Commerce Committee

John H. Siegel, M.D., Professor of Surgery
University of Maryland Medical Systems and Johns Hopkins
University
Deputy Director, Emergency Medical Services
Maryland Institute for Emergency Medical Services Systems

Linda A. Siegenthaler, M.A., Economist
Agency for Health Care Policy Research
Center for General Health Services Extramural Research

Susanne R. Sonik, M.A., Director
Section for Rehabilitation Hospitals and Programs
American Hospital Association

Margaret G. Stineman, M.D., Assistant Professor
Department of Physical Medicine and Rehabilitation
University of Pennsylvania

Samuel L. Stover, M.D.
Professor and Chairman of Rehabilitation Medicine
Spain Rehabilitation Center
University of Alabama at Birmingham

Thomas E. Stripling
Associate Director for Health Studies and Analysis
Paralyzed Veterans of America

Denise G. Tate, Ph.D., Assistant Professor
Department of Physical Medicine and Rehabilitation
University of Michigan Medical Center

Daniel Thomas, Assistant Director
Insurance Managed Care and Provider Relations Division
Health Insurance Association of America

J. Paul Thomas, Ph.D., Director
Medical Sciences Programs
National Institute on Disability and Rehabilitation Research
U.S. Department of Education

Joan Van Nostrand, M.P.A.
Coordinator of Data on Aging
National Center for Health Statistics

Sara D. Watson, M.P.P., Associate Director
Institute for Rehabilitation and Disability Management
Washington Business Group on Health

Joshua M. Wiener, Ph.D., Senior Fellow
Department of Economics
The Brookings Institution

Norman Weissman, Ph.D., Director
Center for General Health Services Extramural Research
Agency for Health Care Policy Research

Deborah Wilkerson, M.A., Program Evaluation Manager
National Rehabilitation Hospital
Director, Program Evaluation and Outcome Studies
National Rehabilitation Hospital Research Center

Cynthia Perry Zejdlik, R.N.
Disability Consultant

APPENDIX B

Conference Planning Committee

Andrew I. Batavia, J.D, M.S.
Principal Investigator/Conference Director

Gerben DeJong, Ph.D.
Co-Principal Investigator

Jessica Scheer, Ph.D.
Conference Coordinator

Marsha G. Meehan
Conference Assistant

APPENDIX C

Developing a Comprehensive Health Services Research Capacity in Physical Disability and Rehabilitation

Andrew I. Batavia

Gerben DeJong

*National Rehabilitation Hospital Research Center
Georgetown University School of Medicine*

JOURNAL OF DISABILITY POLICY STUDIES
Volume 1 Number 1 Spring 1990

ABSTRACT

The lack of an adequate capacity for policy-oriented disability research in the United States has hampered decision making in all aspects of disability policy. This article considers the development of a comprehensive Health Services Research (HSR) capacity in physical disability and rehabilitation, which would examine the organization, provision, and financing of health care services for persons with physical disabilities. Despite the substantial health care needs of such individuals, there have been relatively few HSR studies on the health care issues that affect their lives. This article considers why this is the case, and suggests a strategy for developing a comprehensive HSR/disability capacity. It further presents an agenda for HSR in the areas of trauma care and post-trauma acute care, medical rehabilitation, post-rehabilitation primary care, and long-term support services for persons with physical disabilities.

In recent years, the field of disability research has made significant advances in understanding the etiology of physical impairments and resulting disabilities. The field of medical rehabilitation research has been successful in developing effective therapies and other interventions to reduce the functional limitations of persons with disabilities and to enhance their abilities to live independently. However, much of this work has been clinical in nature. Relatively little emphasis has been placed on the broader social, political, economic, and legal issues that are essential to developing informed public and private disability policy (Fuhrer, 1988; DeJong, Batavia, & Griss, 1989).

The paucity of policy-oriented disability research has hampered decision making in all aspects of disability policy: employment, health care, housing, personal assistance, recreation, and transportation (DeJong & Lifchez, 1983; National Council on Disability, 1988). This article specifically considers the development of a comprehensive capacity for disability policy research in the areas of health care and health-related support services—a health services research capacity. It also has important implications for research in the other areas of interest to persons with physical disabilities. For example, a health services research capacity would address such issues as transportation to health care providers and disincentives to work associated with access to adequate health insurance.

In addressing the development of a health services research capacity in

physical disability and rehabilitation, this article considers primarily the specific health care needs of persons with mobility impairments. These include persons with:

- major amputations
- cerebral palsy
- major head injury
- Friedreich's ataxia
- muscular dystrophy
- spina bifida
- amyotrophic lateral sclerosis
- cystic fibrosis
- spinal cord injury
- multiple sclerosis
- post-polio syndrome
- stroke

We emphasize the needs of persons with mobility impairments because they face certain common problems, such as high susceptibility to pressure sores (i.e., decubitus ulcers), urinary tract infections, respiratory infections, and scoliosis; high rates of health care utilization, including emergency room visits, hospitalization and other forms of institutionalization; and poor access to many health care providers. This emphasis on mobility impairment, therefore, is valuable for purposes of illustration. However, in actually developing a health services research capacity in physical disability, emphasis also must be placed on persons with other physical, physical/cognitive, and sensory disabilities, such as persons with hearing, speech, or visual impairments.

What Is Health Services Research?

The field of Health Services Research (HSR) systematically examines the organization, provision, and financing of health care services (Flook & Sanazaro, 1973). HSR draws on the skills of many disciplines, including biostatistics, health care economics, epidemiology, health care finance, health policy, health law, political science, and medical sociology. Health services researchers commonly consider such issues as access, cost, efficiency, effectiveness, and quality of health care services.

Among the research issues that have been addressed by the field of HSR are the effects of volume of various types of high-risk surgery in hospitals on the costs and mortality rates of surgery; the effects of health maintenance organizations (HMOs) on the cost and quality of health care services; the effects of the Medicare Prospective Payment System, which is based on diagnosis related groups (DRGs), on the cost and quality of inpatient hospital services; and the effects of socio-economic factors on health and access to health care services.

Although there have been several isolated HSR efforts concerning persons with physical disabilities, there currently is no comprehensive, well-integrated HSR capacity in physical disability and rehabilitation. As a result, many difficult health policy decisions that affect millions of disabled people and billions of federal, state, local, and private dollars often are made with insufficient knowledge. In an era of budget deficits and increasing health care costs, it is essential to develop a comprehensive HSR capacity to address the needs of populations at high risk of health problems, such as many persons with physical disabilities.

How Are HSR and Disability Research Related?

The field of HSR was established in the 1960s, and has since built an enormous body of studies concerning the organization, provision, and financing of a broad scope of health care services (Flook & Sanazaro, 1973). The field of disability research also began its significant development in the 1960s and gained maturity in 1978 with the establishment of the National Institute on Handicapped Research (NIHR), recently renamed the National Institute on Disability and Rehabilitation Research (NIDRR). Yet, since their beginnings, there has been very little interaction between the HSR and disability research communities, and there have been relatively few HSR studies on physical disability and rehabilitation.

The lack of HSR in physical disability contrasts starkly with the extensive HSR capacity in the areas of general acute care and psychiatry/mental illness. Due to the strong emphasis on acute medical services in the U.S. health care system, this country's HSR capacity in acute care is the strongest in the world. In addition to libraries of books on HSR in acute care, several widely respected journals have been established specifically to address these issues (e.g., *The Milbank Quarterly*, *Health Services Research*, *The Journal of Health Politics, Policy, and Law*, *The American Journal of Public Health*, *Health Affairs*, *Inquiry*, and *The American Journal of Law and Medicine*). Although these journals now are also addressing long-term care issues, it is rare to see an article on physical disability or medical rehabilitation.

Similarly, researchers in the field of psychiatry and mental illness have conducted many HSR studies. That field is in many ways analogous to medical rehabilitation and physical disability in that it addresses the func-

tional limitations and health care needs of a population of persons with functional limitations and uses a specialized set of providers and institutions to meet their needs. Yet, we know much more about the provision, organization, and financing of health care services for persons with mental disabilities in this country than we know about health care services for persons with physical disabilities. There are several journals dedicated to HSR issues in psychiatry/mental illness.

In contrast, the fields of physical disability and medical rehabilitation have a much smaller number of journals that only occasionally publish HSR studies. In a content study of all articles published in 1986 in the most widely circulated rehabilitation journal, the *Archives of Physical Medicine and Rehabilitation*, Fuhrer found that only ten of the 168 articles (6%) were in the area of HSR (Fuhrer, 1988).

Why Has a Comprehensive HSR/Disability Capacity Not Developed?

Thus, HSR in this country has not focused on the health care needs of people with physical disabilities. While the HSR community *has* addressed the concerns of various other subpopulations with special needs such as elderly persons, indigent persons, and persons living in underserved geographical areas, it largely has ignored the physically disabled population. To the extent that the HSR community has addressed physical disability, it has considered primarily disabled children and the elderly. Yet, there also is a real need for HSR to focus its efforts on the needs of working-age persons (ages 18–65) with physical disabilities—the disabled population growing at the fastest rate (DeJong, 1987; DeJong, Batavia, & Griss, 1989).

The primary reason for the dearth of HSR on physical disability and rehabilitation is that the rehabilitation research community is comprised largely of professionals who traditionally have not addressed issues of HSR: physicians, allied health professionals, psychologists, and social workers. While these researchers may have a role to play in the development of an HSR/disability capacity, they are not trained in the disciplines that specifically examine the broad organizational and financing issues that HSR addresses. There is a notably short supply of disability and rehabilitation researchers who are trained in the disciplines that comprise the core of HSR (DeJong, Batavia, & Griss, 1989). We must then ask why health services researchers have not been drawn to issues of physical disability.

One reason for this neglect is that the physically disabled population is a relatively small minority and some researchers may believe that disability issues are not sufficiently significant to warrant their efforts. However, it is essential to recognize that the disabled population is growing much more rapidly than the general population (see DeJong, 1987), and is estimated to comprise over 37 million persons. Even more significantly, disabled persons use a disproportionate share of health care services, and therefore account for a substantial percentage of the nation's health care costs (Zook & Moore, 1980; Zook, Savickis, & Moore, 1980). Therefore, persons with physical disabilities must be regarded as an important population for HSR study.

A more disturbing explanation for the neglect of HSR/disability issues is that persons with physical disabilities in our society traditionally have been a socially devalued population. This is reflected in the use of such demeaning terms as "invalids" and "cripples" in referring to them. Researchers, therefore, may have received the implicit message from society that the disabled population is not worthy of serious academic research. Fortunately, this negative attitude toward persons with disabilities (and the pejorative terminology associated with it) now is changing. The development of a comprehensive HSR/disability capacity will further "legitimize" the disabled population by stating implicitly to society that persons with disabilities are worthy of serious study.

Who Would Benefit from an HSR/Disability Capacity?

The beneficiaries of an HSR capacity in the areas of physical disability and rehabilitation would include consumers, providers, and payors of rehabilitative care and other disability-related health care services. In fact, all persons involved in the formulation and implementation of health policies that affect persons with disabilities would benefit from analyses conducted objectively by trained health services researchers, and would therefore benefit from the development of a comprehensive HSR capacity in these areas. Without such objectively-conducted analyses by qualified researchers, policy makers often must rely exclusively on the self-serving claims of provider advocates, disability advocates, and other interested parties.

Disabled persons, as consumers of health care services, need the results of HSR studies to better understand the highly complex health care system

they must confront in attempting to maintain their health. Providers, such as trauma surgeons, physiatrists (rehabilitation physicians), therapists, hospital administrators, and suppliers of assistive devices need to understand how to organize and provide their services in a cost-effective manner, and how to ensure that they are paid equitably for their services. Payors, such as the Medicare program, the Medicaid program, workers' compensation programs, Blue Cross/Blue Shield, and other commercial insurers, need to understand how to encourage the efficient provision of services and how to contain their costs.

Why Is It Timely to Develop an HSR/Disability Capacity?

The development of a comprehensive HSR capacity in physical disability and rehabilitation is particularly timely due to relatively recent changes in the clinical management of disability, changes in the expectations of persons with disabilities, and changes in the financing and provision of health care services generally. Such changes, described below, call for creative approaches to meeting the health care needs of persons with physical disabilities. Collectively, these changes provide an important historical perspective on why an HSR capacity in physical disability is long overdue.

Prior to the 1940s, the main issue in the clinical management of physical disability often was mere survival. For example, persons who sustained a spinal cord injury (SCI) often would survive the original trauma, but later would die because of secondary complications (such as urinary and respiratory tract infections). The introduction of the sulfa drugs in the late 1930s, and penicillin later, dramatically improved the ability to medically control the complications of disability. With the establishment of the specialty of physical medicine and rehabilitation in the late 1940s, the medical profession began to focus on reducing the functional limitations of persons with disabilities and increasing their capacities to live independently and productively.

However, even in the 1950s, most rehabilitation patients were discharged to highly restrictive settings that limited their opportunities for independent and productive lives. Their ongoing health care and personal assistance needs usually were managed in institutional settings. The situation began to improve in the 1960s as rehabilitation facilities incrementally improved the prospects for their patients to live independently. More than any

other factor, however, the independent living (IL) movement of the 1970s radically altered our expectations about the opportunities available to persons with physical disabilities. The movement was initiated by persons with disabilities who sought to remove environmental barriers that reduced their capacity for self-direction, independence, and productivity (DeJong, 1979). It gave persons with disabilities a vision of how they could direct their own lives.

In altering the expectations of disabled persons, the IL movement also reshaped the relationships between physician and patient, and between rehabilitation professional and disabled consumer. With the advent of the movement, disabled persons served notice that they want to direct their health care on their own terms (DeJong, 1981). In particular, they have sought to manage their primary health care untethered to large medical centers. This often has proven difficult, however, due to the relatively few primary care providers who are familiar with the health care needs associated with physical disability. Consequently, disabled persons often seek the expertise of rehabilitation hospital outpatient clinics for primary care, even though such clinics were designed to provide rehabilitation services, not primary care (Batavia et al., 1988).

As these changes in clinical practices and societal expectations were taking place, particularly in the past decade, substantial changes have occurred in the delivery and financing of health care in this country. These changes fall into two categories. *First*, there are many new models of payment for health care services such as capitation payment, diagnostic related groups (DRGs), preferred provided arrangements (PPAs), and other payment mechanisms (Batavia, 1988). *Second*, these alternative methods of health care payment often are accompanied by new health care delivery systems such as various types of health maintenance organizations (HMOs), preferred provider organizations (PPOs), and other systems of managed care (Batavia et al., 1989).

Clearly, the past few years have been an unusually fertile time for innovation and experimentation in health care. The challenge for the HSR and disability research communities is this: How can we take advantage of these changes in health care financing and delivery to accommodate the health care needs and expectations of persons with disabilities? We must evaluate different models of health care delivery and financing with respect to their ability to meet the needs and expectations of disabled persons. New approaches should be tested before new political and economic constraints emerge that may limit the options available to persons with disabilities.

Components of a Comprehensive HSR/ Disability Capacity

Although there currently is no *comprehensive* HSR capacity in physical disability and rehabilitation, several important HSR studies in these areas have been conducted. Such studies have been sponsored by a variety of public funding agencies such as NIDRR, the Rehabilitation Services Administration (RSA), the U.S. Health Care Financing Administration (HCFA), the U.S. Administration on Aging (AoA), the Social Security Administration (SSA), and private organizations such as The Robert Wood Johnson Foundation (RWJF) and Paralyzed Veterans of America (PVA). However, too few of such studies have been funded, and those that have been funded have not been coordinated as part of a comprehensive, integrated HSR/disability research agenda.

An understanding of the research that has been conducted to date is essential to the efficient development of a comprehensive HSR/disability research capacity. NIDRR has sponsored by far the greatest number of HSR studies in physical disability and rehabilitation through its Mary E. Switzer fellowships, its work on rehabilitation outcome measurement, its efforts in developing the Congressionally-mandated study on health insurance for disabled persons, its work on aging with a disability, and its international fellowship program.

HCFA funded the Medical College of Wisconsin/Rand study on prospective payment for medical rehabilitation services (Hosek et al., 1986). SSA has funded a study by the National Rehabilitation Hospital on work disincentives associated with poor access to private health insurance for disabled Medicare and Medicaid beneficiaries (NRH, 1988). AoA and other agencies concerned with the aging population have sponsored studies and demonstration projects on the organization and financing of care for elderly disabled persons, especially in the area of community-based, long-term care services (Zawadski et al., 1985).

However, the public sector agencies and the private organizations that address issues of disability often are not fully aware of what each other is doing. The Interagency Committee on Disability Research—a committee consisting of representatives of the major federal agencies—was established by NIDRR to coordinate disability research policy. While it has been instrumental in coordinating disability research generally, it has not focused on HSR issues to any substantial extent. It is important that coordinating

committees such as the Interagency Committee address issues of HSR. It also would be valuable for NIDRR to develop a master list of HSR studies being conducted (and studies completed) and to place such studies in a comprehensive HSR framework.

What are the components that should comprise an HSR capability in physical disability and rehabilitation? We would like to suggest the following:

1. A core group of researchers trained in several HSR-related disciplines (such as those stated above) and committed to researching disability issues; and
2. Longitudinal data bases that can track patient resource utilization, patient progress, functional status, and patient outcome well into the post-rehabilitation period.

This, of course, will require substantial resources. Qualified health services researchers have skills that are developed only after extensive training (and many have terminal academic degrees), and longitudinal studies are labor intensive and require extended periods of time to conduct.

It should be recognized that part of the second component already exists. Specifically, there already are various longitudinal data bases that sprinkle the medical rehabilitation landscape (Sonik, 1988). In addition, various medical rehabilitation facilities have emerging data bases within their respective program evaluation systems. The critical element—and the one most frequently missing—is the acquisition of post-discharge outcome and health utilization data. However, the element of a HSR/disability capacity in shortest supply is researchers trained in the disciplines of HSR.

There are a variety of possible approaches to developing an HSR capacity in physical disability and rehabilitation. However, any approach should include NIDRR funding, RSA funding, and collaborative arrangements among the various agencies and organizations that address issues of physical disability and rehabilitation. One possible approach would include the following components:

A. NIDRR Funding

1. Research & Training Center in HSR
2. HSR Research & Development Projects
3. HSR Field-Initiated Research Projects
4. HSR Innovation Grants
5. HSR Research Fellowships

B. RSA Funding

1. Short-term and Long-term HSR Training Grants
2. Research grants focusing on HSR as it relates to vocational rehabilitation services

C. Collaborative arrangements

1. National Center for Health Services Research (NCHSR)
2. Health Care Financing Administration (HCFA)
3. Social Security Administration (SSA)
4. Administration on Aging (AoA)
5. Veterans Administration (VA)
6. National Institutes of Health (NIH) (e.g., National Institute on Aging (NIA))
7. Private Foundations and Organizations
 - a. The Robert Wood Johnson Foundation
 - b. The Pew Memorial Trust
 - c. The Dole Foundation
 - d. Paralyzed Veterans of America
 - e. Provider Organizations (AHA, ASHA, NARF, etc.)
 - f. Payor Organizations (Blue Cross/Blue Shield, other commercial insurers).

An Agenda for Health Services Research in Physical Disability and Rehabilitation

To the extent that an HSR capacity in physical disability currently exists, it consists primarily of researchers in the areas of trauma care and medical rehabilitation. However, because persons with disabilities now are living longer than ever before, it is not sufficient to focus research primarily on health care provided to save their lives at the time of the disabling event, or to restore functional capacity shortly thereafter. A broad HSR capacity should be developed to evaluate not only trauma care and medical rehabilitation, but also the ongoing health care needs of disabled persons well after their rehabilitation. These individuals have a specific constellation of ongoing health problems that are not being addressed by the mainstream of the American health care system, and that demand the attention of the HSR community.

An agenda for HSR in physical disability might be organized according to the following four general areas of health care for persons with disabilities:

1. Trauma care and post-trauma acute care
2. Medical rehabilitation
3. Post-rehabilitative primary health care services
4. Long-term care and support services (including personal assistance services, assistive devices, and institutional care).

Each of these areas is addressed in the following sections, and a list of potential HSR issues is delineated for each area. Although these lists are by no means exhaustive, they offer a valuable point of departure for identifying and prioritizing issues in this emerging field.

Trauma care and post-trauma acute care

For many persons with disabilities, the initial point of entry into the health care system is some form of trauma care. This may be administered in a variety of settings from the emergency room of a small rural hospital to a highly triaged, Level I trauma center at a large urban medical complex. The field of traumatology recently has emerged as a recognized discipline with a budding research capacity. Trauma researchers have developed a variety of tools with which to measure the severity of an injury, such as the Injury Severity Score (Baker et al., 1974) and the Revised Trauma Score (Champion et al., 1981). In evaluating the outcomes of trauma care, such researchers seldom look beyond the patient's discharge from an acute care setting. Moreover, they typically limit their outcome analyses to whether the patient lived or died.

However, as indicated above, it is important to look beyond the mere survival of persons with disabilities. Researchers have yet to examine how trauma care affects residual disabilities and functional losses. Thus, from the standpoint of an HSR capacity in physical disability, the impact of trauma care should be evaluated in terms of:

- how advances in emergency medical management, trauma care, and post-trauma acute care are changing the chances of survival for a person with a disability for a given level of injury severity;
- how trauma care is affecting the degree of residual disability among survivors, especially among recent severe spinal cord and head injury survivors who earlier would have died;

- how trauma care is altering the mix of disabled patients seen by medical rehabilitation, such as the proportion of patients who require permanent use of a ventilator; and
- how trauma care and post-trauma acute care may be reshaping the post-rehabilitation health care needs of survivors with selected disabilities.

To answer these kinds of questions, it is important that health services researchers in the field of trauma care collaborate with researchers in the field of medical rehabilitation. Each will benefit from the other's tools. For example, trauma researchers are largely unfamiliar with the functional status measures commonly used in medical rehabilitation research. Likewise, most rehabilitation researchers are not adequately familiar with injury severity measures used in trauma research.

Medical rehabilitation

Medical rehabilitation is the field of health care that seeks to enhance the functional abilities of persons with physical disabilities through a variety of therapies, patient education, and other clinical interventions (England, 1986). Different types and intensities of medical rehabilitation services are offered by a wide variety of health care providers. Rehabilitation hospitals and rehabilitation units in acute care hospitals provide by far the most intensive and coordinated medical rehabilitation services. However, acute care hospitals, skilled nursing facilities, intermediate care facilities, long-term hospitals, and several different types of outpatient providers also offer medical rehabilitation services (England, 1986; Batavia, 1988).

At the risk of great oversimplification, two categories of research have dominated the medical rehabilitation literature: (1) research related to physical restoration of patient functional capacity; and (2) research related to psychosocial rehabilitation. Thus, although there has been considerable research in the field of medical rehabilitation, there have been relatively few studies in Health Services Research (Batavia, 1988). Those HSR studies that have been conducted have been limited largely to issues of costs and cost-effectiveness. While these efforts have been significant in their own right, their findings remain less than fully conclusive (Johnson & Keith, 1983).

Recently, a few substantial studies have considered payment for medical rehabilitation services (NARF, 1985; Hosek et al., 1986; McGinnis et al., 1987; Batavia, 1988, 1989). However, many other HSR issues in medical rehabilitation have been largely overlooked or simply unfunded (Fuhrer,

1988). These include issues of access to medical rehabilitation services, the relative effectiveness of various inpatient and outpatient treatment modalities, and the impact of health maintenance education on subsequent health care utilization (Batavia, 1988). Although there have been occasional references to some of these topics in the medical rehabilitation literature, it is difficult to discern a committed HSR capacity with which to address these kinds of issues.

Batavia, in his study on payment models for medical rehabilitation services, indicated several issues that should be addressed by health services researchers in the area of medical rehabilitation (Batavia, 1988). These include:

- What are the optimal eligibility, coverage, and payment policies for medical rehabilitation?
- What are the costs and benefits of the various medical rehabilitation services?
- Are patients entering rehabilitation hospitals "quicker and sicker" than ever before (as alleged by some rehabilitation industry representatives)?
- What is the optimal geographic distribution of rehabilitation providers?
- What are the perceptions of medical rehabilitation by the acute care medical community and the public?
- What are the trade-offs between inpatient and outpatient rehabilitation?
- To what extent is medical rehabilitation being provided in skilled nursing facilities (SNFs), intermediate care facilities (ICFs), and home settings?
- What is the quality of services provided in different rehabilitation settings and by different rehabilitation providers?
- What are the current patterns of referral and transfer to and from the rehabilitation provider, and the resultant effects on costs and rehabilitation outcomes?
- What are the relationships between the short-term and long-term goals and outcomes of rehabilitation?
- Are there differences in goals at different points in the rehabilitative process?
- What are optimal utilization patterns for rehabilitative care that is disrupted by an acute episode?
- What are the optimal length of stay, intensity of services, and point of discharge for patients with different disabilities?

Post-rehabilitative primary care

Clearly, there still is much HSR that must be conducted in the areas of trauma care and medical rehabilitation. However, these areas of care for persons with disabilities have at least the beginnings of an HSR capacity; other areas have barely been considered by health services researchers. Among the most neglected health care needs of disabled persons are those that surface after discharge from rehabilitation. At present, there is no system of primary care that is responsive to the particular constellation of health care problems commonly experienced by disabled persons. Once a person with a disability completes medical rehabilitation, he or she has an "orphaned condition" that is not the province of any one medical discipline (Batavia et al., 1988).

The provision of post-rehabilitation health care services for persons with physical disabilities has lagged behind the progress made by these individuals in living independently and becoming informed consumers of health care services. Prior to the independent living movement, when disabled persons remained primarily in institutional settings, the institution constituted the framework in which the person's health care needs were addressed. No comparable community-based framework has surfaced to meet the health care needs of persons with disabilities now that they routinely are living in community settings.

Several important sub-areas have been identified within the general area of post-rehabilitation primary care services for disabled persons (DeJong et al., 1989; Burns et al., 1990). These include (1) the high rate of re-hospitalization among certain physically disabled populations, such as persons with SCI (Burnside & Cook, 1976; Young & Northup, 1979; Young et al., 1982; Meyers et al., 1985, 1987, 1988); (2) problems associated with aging with a physical disability (Ohry et al., 1983; Trieschmann, 1987); (3) poor access to primary care practitioners knowledgeable of disability (Batavia et al., 1988, 1989); and (4) problems associated with the financing and organization of primary care services for persons with physical disabilities (DeJong et al., 1987; Batavia et al., 1988, 1989; DeJong, Batavia, & Griss, 1989).

Among the post-rehabilitation primary care issues that must be addressed by health services researchers are:

- What factors affect the post-rehabilitation health status of persons with different physical disabilities?
- What factors in the health care system are responsible for the

high rate of rehospitalization among certain populations of persons with disabilities?

- What are the effects of aging for persons with different physical disabilities, and what are the implications for health care delivery and financing;
- Are current health care *delivery* systems addressing the post-rehabilitative health care needs of the disabled population, and if not, how can this be achieved most effectively?
- Are current health care *financing* systems addressing the post-rehabilitative health care needs of the disabled population, and if not, how can this be achieved most effectively?
- What factors impede access to primary care and other post-rehabilitation health care services for persons with physical disabilities?

Long-term care and support services

Many persons with physical disabilities require assistance in the activities of daily living to compensate for their lost functional capacities. Such support may be in the form of (1) personal assistance services including attendant services, (2) assistive devices, and (3) institutional care for disabled persons who are not capable of living in the community. These constitute the major "long-term care" issues for the physically disabled population.

Personal assistance services Many persons with disabilities in this country require some form of personal assistance services to compensate for their functional limitations. The World Institute on Disability estimates that over 3.8 million persons require such services (Litvak, Zukas, & Heumann, 1987). The term "personal assistance" encompasses a broad range of different services needed by persons with different disabilities. Persons with mobility impairments may require the services of personal attendants; individuals with hearing impairments may require sign language interpreter services; and those with visual impairments may require reader services.

Because this article focuses primarily on persons with mobility impairments, this section specifically considers attendant services to assist mobility-impaired individuals in personal care and various other in-home activities. Without the services of an attendant, the alternative for many of these persons would be institutional care. Accordingly, attendant services is the premier long-term care issue for the population of persons with mobility impairments (DeJong & Wenker, 1983; Litvak, Zukas, & Heumann, 1987). We estimate that there are approximately 1.8 million persons with substantial limitations in their abilities to conduct physical activities who would

require the services of a paid attendant under a national attendant services program (Batavia, DeJong, & McKnew, 1990).

In using the term "attendant services" or "attendant care," we refer to a very specific model of in-home services that must be understood and distinguished from other types of in-home services. In the attendant care model, the user of the service (i.e., a person with a disability) manages and directs his or her own attendant care employment relationship. The attendant is accountable to the consumer of the service, not to an outside agency as in the case of home health care. The attendant is not an extension of a home health agency, which is usually managed by nurses who direct care in accordance with a physician's plan of treatment. The attendant is, in a real sense, an extension of the disabled person, and does for the disabled person what the disabled person ordinarily would do for himself or herself (if not for the person's functional limitations).

This conception of attendant services would appear to place such services outside the boundaries of health care and thus beyond the scope of HSR. However, we believe that attendant care is as much a health services issue as it is a social services issue for three reasons. *First*, attendant care is, as noted above, a type of long-term care issue that is widely viewed as a health service alternative to institutional care. *Second*, attendant care often is financed using health-related payment systems such as Medicaid. And *third*, an attendant also is an important aid to the user in carrying out health maintenance regimes and in detecting health problems at an early stage. Thus, attendant care must be viewed as an important adjunct to the user's overall program of health maintenance. It should be noted that personal assistance services (e.g., interpreter and reader services) for other disabled populations also are important to providing adequate access to health care services.

Despite the rather straightforward nature and scope of attendant services and other personal assistance services, this nation has yet to develop a coherent personal assistance policy that can address the varied needs of persons with different disabilities. Instead, we have a needlessly complex patchwork of programs that are extensions of various health and social service programs, and that typically are not responsive to the needs of persons with disabilities. In some states, disabled persons have no access to personal assistance at all unless they can afford to purchase such services with their own resources (Litvak, Zukas, & Heumann, 1987).

A major problem in the development of a coherent national personal assistance services policy is the absence of good national and regional research bases on users of the services. We believe that the various compo-

nents that make up the HSR capacity in this country can significantly advance the nation's policy agenda with respect to personal assistance services. The development of a national policy will require an aggressive HSR agenda that effectively can define the parameters of the debate with respect to the future of attendant services (Litvak, Zukas, & Heumann, 1987; Batavia, DeJong, & McKnew, 1990).

Several major research questions remain to be addressed in the area. For example:

- How many and what types of persons need *and* want user-directed personal assistance services?
- Can a user-directed model of personal assistance services foster a more independent and productive lifestyle?
- Does a user-directed model of personal assistance services foster health maintenance behaviors that help avert complications leading to emergency room visits and hospitalizations?
- Can user-defined criteria be developed by which (a) the quality of personal assistance service programs can be evaluated and (b) alternative models can be critiqued?
- How do eligibility and income requirements for personal assistance services create disincentives for work, and how can such disincentives be averted?
- How should personal assistance services be financed? For example, should they be financed within the framework of a health maintenance plan?
- How much money will a national personal assistance program cost?

Assistive devices In addition to personal assistance services, modern technology can assist persons with physical disabilities to compensate for their functional limitations. Although robotic arms, environmental control units (ECUs), sophisticated wheelchairs, telecommunication devices for the deaf (TDDs), and Kurzweil reading machines typically cannot substitute completely for personal assistance services, they can be important supplements. Because a pressure sore is estimated to cost an average of \$50,000 in intensive health care services, a wheelchair cushion, designed to reduce susceptibility to the sores and costing a few hundred dollars, could have a direct and dramatic affect on health care utilization and costs. Other assistive devices have a more or less direct affect on health.

As in the case of research on medical services for disabled persons, research on assistive devices has focused on clinical issues (as well as basic engineering issues). Relatively little research has been conducted on

broader policy issues. There have been some studies on the financing of assistive devices and other aspects of technology transfer (Reeb, 1987a, 1987b, 1987c, 1987d). There has also been some work on evaluating assistive devices, including the criteria used by consumers to evaluate their own devices (Batavia & Hammer, 1989). However, much work remains to be done on the organization, provision, and financing of assistive devices. Some of this research could be included within the auspices of an HSR capacity in physical disability.

Among the policy-related issues that should be researched on assistive devices are:

- What are the effects of different assistive devices on health, health care utilization, and independent living outcomes?
- Which types of devices should be financed as part of the health care financing system (Medicare, Medicaid, private insurance, etc.), and what alternative financing systems are available for other types of devices?
- Is the current delivery system for assistive devices meeting the needs of the disabled population, and if not, how can the delivery system be improved?
- How should assistive devices be evaluated, and how should the evaluations be used for decisions on certification of manufacturers and suppliers, and on the provision and financing of devices.

Institutional care It appears that relatively few persons with physical disabilities prefer long-term institutional care to living in the community (often with the help of personal assistants). However, institutional care is the only alternative for some disabled persons with substantial cognitive impairments or major daily medical needs. This is particularly true now that more persons with severe head injuries are surviving with substantial medical and personal assistance needs. Therefore, while we do not believe an HSR research capacity in physical disability and rehabilitation should primarily emphasize long-term institutional care, research on institutional care should be a component of such a capacity.

Among the HSR issues that should be examined regarding institutional care for persons with disabilities are:

- Which types of physical disabilities require long-term institutional care, and what types of care do they need?
- How are different types of long-term care institutions currently meeting the needs of physically disabled persons?

- Are transitional institutional settings an option for some disabled persons who require institutional care?
- How does the current health care financing system affect care for disabled persons at long-term care institutions, and what alternative financing approaches are available?

A major emphasis in this area should be to ensure that disabled persons who are capable of living independently, and who want to, are given support to live in the community by the institutions (and by the health care community generally).

In Closing

This article identifies a major void in the fields of disability research and Health Services Research—the lack of a comprehensive HSR capacity in physical disability and rehabilitation. In order to fill this void, the disability research community must take a leadership role in:

- imparting to the general HSR community the need for research on the organization, provision, and financing of health care services for persons with physical disabilities;
- devising an HSR research agenda, and thereby informing prospective researchers of the types of studies that need to be conducted; and
- advising NIDRR, other public sector agencies funding disability-related research, and private organizations that address disability issues on ways in which to develop and organize a comprehensive HSR capacity in physical disability and rehabilitation.

The HSR issues in the area of physical disability and rehabilitation are compelling. Studies in this field will form the basis for health care policies and disability policies that allocate billions of dollars and affect millions of lives. We believe that once researchers are exposed to these issues, they will develop an enduring commitment to addressing them. Of course, they will require the financial resources necessary to pursue such a commitment. Financial support is essential from federal, state, and local government, and from the philanthropic, provider, and payor communities. This article has suggested a general approach and an agenda to organize an HSR capacity in physical disability and rehabilitation.

Perhaps most important to the development of a comprehensive HSR/disability capacity is funding specifically earmarked to attract health services researchers to this field. There are too few trained disability re-

searchers in HSR disciplines such as biostatistics, health economics, epidemiology, health care finance, health policy, health law, medical sociology, political science, and social psychology. Therefore, with respect to research funding sources, there is a need for individual dissertation grants, post-doctoral fellowships, research fellowships, visiting senior scientist awards, and other awards directed to attract individual investigators trained in HSR to the disability field. The Mary E. Switzer Research Fellowship Program of NIDRR is one example of such a program.

It is particularly important that persons with disabilities, who have direct personal experience in HSR/disability issues, be involved in researching those issues. Thus, we believe that the disbursement of investigator awards should take into account a person's disability status as one relevant indicator of expertise. Moreover, financial support should be offered specifically to encourage disabled persons to pursue HSR careers. Dissertation support for disabled persons trained in HSR disciplines would be one way to foster the intellectual commitment needed to make a significant contribution to HSR in physical disability and rehabilitation.

As more and more persons survive injuries and diseases with resulting physical disabilities and choose to live in their communities, it will become increasingly essential to understand the health care services they need and how to provide such services efficiently and equitably. Issues such as access to adequate health insurance, access to health care providers knowledgeable about physical disability, and access to affordable personal assistance services will influence whether they will be able to live independent, productive lives. It is the task of health services research, and disability research generally, to conduct the studies needed to shape the agenda that will resolve these issues.

Andrew Batavia, J.D., M.S., is Associate Director for Health Services Research at the National Rehabilitation Hospital Research Center (NRH-RC) and Adjunct Assistant Professor of Community and Family Medicine at Georgetown University School of Medicine.

Gerben DeJong, Ph.D., is Director of NRH-RC and Professor of Community and Family Medicine at Georgetown University School of Medicine.

REFERENCES

- Baker, S. P., O'Neill, B., Haddon, W., & Long, W. B. (1974). The injury severity score: A method for describing patients with multiple injuries and evaluating emergency care. *The Journal of Trauma*, 14(3), 187.

- Batavia, A. I. (1988). *The payment of medical rehabilitation services: Current mechanisms and potential models*. Chicago: American Hospital Association.
- Batavia, A. I. (1989). *The payors of medical rehabilitation: Eligibility, coverage, and payment policies*. Washington, DC: National Association of Rehabilitation Facilities.
- Batavia, A. I., DeJong, G., Burns, T. J., Smith, Q. W., Melus, S., & Butler, D. (1989, January). *A managed care program for working-age persons with physical disabilities: A feasibility study*. National Rehabilitation Hospital Office of Research, Washington, DC.
- Batavia, A. I., DeJong, G., Halstead, L., & Smith, Q. W. (1988). The primary medical needs of people with disabilities. *American Rehabilitation*, 14(4), 9-12.
- Batavia, A. I. & Hammer, G. (1989). Consumer criteria for evaluating assistive devices: Implications for technology transfer. *Proceedings of the 12th Annual Conference of the Rehabilitation Engineering Society of North America*, RESNA, Washington, DC.
- Batavia, A. I., DeJong, G., & McKnew, L. (1990). Toward a national attendant services program: Home-based long-term personal assistance for persons with physical disabilities. Manuscript submitted for publication.
- Burns, T. J., Batavia, A. I., Smith, Q. W., & DeJong, G. (1990). The primary health care needs of persons with physical disabilities: What are the research and service priorities? *Archives of Physical Medicine and Rehabilitation*, 71(2), 138-143.
- Burnside, I. D., & Cook, J. B. (1976). Factors influencing readmission to hospital. *Paraplegia*, 14, 220-224.
- Champion, H. S., Sacco, W. J., Carnazzo, A. J., Copes, W. S. & Fouty, W. J. (1981). Trauma score. *Critical Care Medicine*, 9, 9.
- DeJong, G. (1979). Independent living: From social movement to analytic paradigm. *Archives of Physical Medicine and Rehabilitation*, 60, 435-446.
- DeJong, G. (1981). *Environmental accessibility and independent living outcomes: Directions for disability policy and research*. East Lansing, MI: Michigan State University, University Center for International Rehabilitation.
- DeJong, G. (1987). Number of adults with severe disabilities has grown. *Business and Health*, 4, 22.
- DeJong, G., Batavia, A. I., & Griss, R. (1989). America's neglected health minority: Working-age persons with disabilities. *Milbank Quarterly*, 67(Supp. 2, Pt. 2).
- DeJong, G., Batavia, A. I., Smith, Q. W., Burns, T. J., Scheer, J., Brannon, R., Naierman, N., & Butler, D. (1989). Meeting the primary health care needs of persons with disabilities: Setting the agenda. *Proceedings of the NRH National Invitational Conference on Primary Care and Disability*. National Rehabilitation Hospital Research Center, Washington, DC.

- DeJong, G., & Lifchez, R. (1983). Physical disability and public policy. *Scientific American*, 248(6), 40-49.
- DeJong, G. & Wenker, T. (1983). Attendant care as a prototype independent living service. *Caring*, 2(2), 26-30.
- DeJong, G., Osberg, J. S., McGinnis, G. E., Seward, M. L., Branch, L. G. & Campion, L. G. (1986, October). Rehospitalization following rehabilitation, Part II: Findings and analysis. Paper presented October 20, 1986, at the Annual Meeting of the American Congress of Rehabilitation, Baltimore, MD.
- England, B. (Ed.). (1986). *Medical rehabilitation services in health care institutions*. Chicago: American Hospital Association.
- Flook, E. E., & Sanazaro, P. J. (Eds.). (1973). *Health services research and R & D in perspective*. Ann Arbor, MI: Health Administration Press.
- Fuhrer, M. J. (1988). Rehabilitation research in the 1980s. In Eisenberg, M. G., & Grzesiak, R. C. (Eds.), *Advances in clinical rehabilitation: Volume II*. New York: Springer.
- Hosek, S., Kane, R., Carney, M., Hartman, J., Reboussin, D., Serrato, C., & Melvin, J. (1986). *Charges and outcomes for rehabilitative care: Implications for the prospective payment system*. Santa Monica, CA: Rand.
- Johnson, M., & Keith, R. A. (1983). Cost-benefits of medical rehabilitation: Review and critique. *Archives of Physical Medicine and Rehabilitation*, 64, 147-154.
- Litvak, S., Zukas, H., & Heumann, J. E. (1987). *Attending to America: Personal assistance for independent living*. Berkeley, CA: World Institute on Disability.
- McGinnis, G. E., Osberg, J. S., DeJong, G., Mae, M., Seward, L., & Branch, L. E. (1987). Predicting charges for inpatient medical rehabilitation using severity, DRG, age, and function. *American Journal of Public Health*, 77(7), 826-829.
- Mahoney, C. W., Estes, C. L., & Heumann, J. E. (1986). *Toward a unified agenda: Proceedings of a national conference on disability and aging*. San Francisco: Institute For Health and Aging, University of California at San Francisco.
- Meyers, A. R., Feltin, M., Masters, R. J., Nicastro, D., Cupples, A., Lederman, R. I., & Branch, L. G. (1985). Rehospitalization and spinal cord injury: Cross-sectional survey of adults living independently. *Archives of Physical Medicine and Rehabilitation* 66, 704-708.
- Meyers, A. R., Cupples, A., Lederman, R. I., Branch, L. G., Feltin, M., Master, R. J., Nicastro, D., Glover, M., & Kress, D. (1987). A prospective evaluation of the effect of managed care on medical care utilization among severely disabled independently living adults. *Medical Care* 25(11), 1057-1068.
- Meyers, A. R., Cupples, A., Lederman, R. I., Branch, L. G., Feltin, M., Master, R. J., Nicastro, D., Glover, M., & Kress, D. (1988). The epidemiology of medical care utilization by severely disabled independently-living adults. *Journal of Clinical Epidemiology* 41(2), 163-172.

- National Association of Rehabilitation Facilities (NARF). (1985). *NARF position paper on a prospective payment system for inpatient medical rehabilitation services and a study regarding a prospective payment system for inpatient medical rehabilitation services: Final report*. (Study conducted by Coopers and Lybrand).
- National Rehabilitation Hospital (NRH). (1988). *Health insurance coverage for SSDI beneficiaries*. (Social Security Grant # 12-D-70288-3-01).
- National Council on Disability. (1988). *On the threshold of independence*. Washington, DC: National Council on Disability.
- Ohry, A., Schemesh, Y., & Rozin, R. (1983). Are chronic spinal cord injured patients prone to pre-mature aging? *Medical Hypotheses* 11, 467-469.
- Reeb, K. G., Jr. (1987a, July). *Private insurance reimbursement for rehabilitation equipment*. Washington, DC: Electronic Industries Foundation Rehabilitation Engineering Center.
- Reeb, K. G., Jr. (1987b, September). *Final report of the national task force on third party payment for rehabilitation equipment*. Washington, DC: Paralyzed Veterans of America and Electronic Industries Foundation.
- Reeb, K. G., Jr. (1987c). *Procurement of durable medical equipment under the medicare part B program*. Washington, DC: Electronic Industries Foundation Rehabilitation Engineering Center.
- Reeb, K. G., Jr. (1987d, June). *Revolving loan funds: Expanding equipment credit financing opportunities for persons with disabilities*. Washington, DC: Electronic Industries Foundation Rehabilitation Engineering Center.
- Sonik, S. (1988, June). *Medical rehabilitation hospitals and units: A summary and comparison between 1984 and 1986 surveys*. (Conducted by the American Hospital Association Section for Rehabilitation Hospitals and Programs and the Hospital Data Center). Chicago: American Hospital Association.
- Trieschmann, R. B. (1987). *Aging with a disability*. New York: Demos Publications.
- Young, J. S., Burns, P. E., Bowen, A. M., & McCutchen, R. (1982). *Spinal cord injury statistics: Experience of the regional model spinal cord injury systems*. Phoenix, AZ: Good Samaritan Medical Center, National Spinal Cord Injury Data Research Center.
- Young, J. S. & Northup, N. E. (1979). Rehospitalization in years two and three following spinal cord injury. *SCI Digest* 1, 21-26.
- Zawadski, R., Shen, J., Yordi, C., & Hansen, J. C. (1985). *On Lok's community care organization for dependent adults: Research and development project—final report (1978-1983)*. San Francisco: On Lok Senior Health Services.
- Zook, C. J. & Moore, F. D. (1980). High cost users of medical care. *The New England Journal of Medicine* 302, 996-1002.
- Zook, C. J., Savickis, S. F., & Moore, F. D. (1980). Repeated hospitalizations for the same disease: A multiplier of national health costs. *Milbank Memorial Fund Quarterly* 58(3), 454-471.

ACKNOWLEDGMENT

This article was supported in part by a grant from the National Institute on Disability and Rehabilitation Research.

Requests for reprints should be sent to Andrew Batavia, NRH-RC, 102 Irving St., N.W., Washington, D.C. 20010-2949.

NATIONAL REHABILITATION HOSPITAL RESEARCH CENTER

The National Rehabilitation Hospital Research Center (NRH-RC) provides research leadership on many of the major clinical and policy issues facing persons with disabilities and providers in the medical rehabilitation industry. The Center tests new rehabilitative interventions, evaluates the financing and delivery of medical rehabilitation services, and seeks better ways in which to deliver and pay for the ongoing health care needs of persons with disabilities. Facilitated by its location in the nation's capital, the Center also conducts research on major public policy issues that affect the well-being of persons with disabilities.

The NRH-RC is staffed with persons skilled in research design, data analysis, statistics, health services research, and policy analysis. Current areas of research include neurotrauma rehabilitation, health services research, aging with a disability, program evaluation, and patient outcome studies. The Center is supported by grants from sources such as the National Institute on Disability and Rehabilitation Research, The Robert Wood Johnson Foundation, the Centers for Disease Control, the National Institute on Aging, and the Social Security Administration.