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**Report of the Advisory Committee
to the Director, National Institutes of Health**

Medical Rehabilitation Research

**January 26, 1990
Bethesda, Maryland**

**Report of the Advisory Committee
to the Director, National Institutes of Health**

Medical Rehabilitation Research

**January 26, 1990
Bethesda, Maryland**

***Summary of the 60th Meeting of the
Advisory Committee to the Director
National Institutes of Health***

January 26, 1990

Medical Rehabilitation Research

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EXECUTIVE SUMMARY

The Advisory Committee to the Director, National Institutes of Health (NIH), joined by representatives of the National Advisory Councils of the NIH institutes, met on January 26 to review the Report of the Panel on Physical Medicine and Rehabilitation Research. The Panel was constituted as an ad hoc group of consultants to the Advisory Committee to the Director, NIH (ACD), to review and consider the concerns of the medical rehabilitation research community, to assess the current administration of medical rehabilitation research at the NIH, and to develop suggestions for approaches to assure continued progress in this area of research. During its review, the Committee heard presentations by nine members of the Panel, including its Chairman. The individual presentations by members of the Panel focused primarily on the perceived need to create a Center for Rehabilitation Sciences at the NIH. The Director of the National Institute on Aging also shared his views on this issue.

After the Panel presentations, the Committee members and Council representatives discussed the report, inviting comments and further clarification from the Panel members present. In the course of their deliberations, the Advisory Committee members and Council representatives concluded that an immediate effort to create a Center for Rehabilitation Sciences, as recommended by several of the Panel members, is premature and advised great caution in pursuing an organizational restructuring in addressing the concerns of this particular research community. At the same time, the Advisory Committee members and Council representatives agreed that activities related to medical rehabilitation research should be strengthened at the NIH. They were also in agreement with the Panel's recommendations regarding the importance of the development of a research agenda and mission statement for this area of medical research and

the creation of a transgovernmental entity to coordinate medical rehabilitation research within the Federal sector. Committee members and Council representatives voiced unanimous agreement with Panel recommendation 6: "The Director, NIH, as an interim step, create an entity that includes the following elements: a long-range plan for rehabilitation research that can be implemented; a central focus for rehabilitation; an advisory body (to include people with disabilities); and a way to coordinate and promote rehabilitation research throughout the NIH."

INTRODUCTION

The Panel on Physical Medicine and Rehabilitation Research was established by the NIH in response to legislative interest in medical rehabilitation research and the NIH commitment to review comprehensively the needs and concerns of the medical rehabilitation research community. The Panel was constituted as an ad hoc group of consultants to the ACD to receive testimony from the medical rehabilitation research community and other interested parties and organizations, and to develop a report and recommendations for consideration by the Advisory Committee. The mandate of the Panel was to review and consider the concerns of the medical rehabilitation research community, to assess the current administration of rehabilitation research at the NIH, and to develop suggestions for approaches to assure continued progress in this area of research. The Panel met in public sessions on November 20-21, 1989. On November 20, the Panel heard presentations on scientific and policy issues related to medical rehabilitation research from invited experts from the National Institute for Disability and Rehabilitation Research (NIDRR), the NIH, the Centers for Disease Control (CDC), and the medical rehabilitation research community. It also heard public testimony from interested organizations and scientific societies. On the second day of the meeting, the Panel began its deliberations and the drafting of a report.

The ACD, joined by representatives of the National Advisory Councils of the NIH institutes, met on January 26 to consider the report of the Panel on Physical Medicine and Rehabilitation Research and to provide the Acting Director, NIH, with the Committee's conclusions relative to the content and recommendations contained in the report of the Panel on Physical Medicine and Rehabilitation Research.

SUMMARY OF PRESENTATIONS BY INDIVIDUAL MEMBERS OF THE PANEL ON PHYSICAL MEDICINE AND REHABILITATION RESEARCH

A summary of the report of the Panel on Physical Medicine and Rehabilitation Research and the deliberations leading to the Panel's recommendations were presented to the Advisory Committee and Council representatives by the Chairman of the Panel. Individual members of the Panel also had been invited by the Acting Director, NIH, to attend the Advisory Committee meeting and to address the Committee at its meeting to provide further insight into the deliberations of the Panel. Nine of the twelve Panel members present at the meeting made brief statements that explained their position on the Panel's recommendations. With two exceptions, Panel members providing individual statements emphasized their support for the Panel's recommendation to create a Center for Rehabilitation Sciences at the NIH. The remaining two Panel members, while not precluding the possibility for the eventual establishment of such a center, supported a more measured approach beginning with the development of a long-range plan for medical rehabilitation research.

Several common themes emerged in the presentations of Panel members who supported the creation of a separate center for medical rehabilitation research. Panel members repeatedly stressed that establishing such a center at the NIH would place this research at the site of the highest realm of scientific endeavor in the country; it would provide a means of legitimizing rehabilitation research; and it would foster superior research in the

medical rehabilitation sciences. It was stressed further that, as a group of disciplines committed to excellence in rehabilitation, the medical rehabilitation research community wished to embrace the NIH system of training basic and clinical scientists, as well as its peer review system. Establishment of a center with authority for training and research grant awards was seen as the most direct route to these goals.

The timeliness of establishing an entity for medical rehabilitation research at the NIH was another theme repeated in presentations of Panel members supporting the creation of a center. It was noted that the recognition by the public of the need for improving the lot of the disabled and the awareness of the professional community of the need for expanded scientific effort and leadership in medical rehabilitation have never been higher. Furthermore, the field of rehabilitation has never been as strong and has within its ranks a surplus of bright young researchers. Also, the recently introduced Americans with Disabilities Act, the initiatives of the Institute of Medicine and the CDC related to disability issues, and the independent living movement were all indications that the concerns of and issues affecting persons with disabilities are receiving increased national attention.

Presentations by Panel members supporting the creation of a center also addressed issues related to the allocation of resources for medical rehabilitation research across several NIH institutes and the potential impact a new organizational entity would have on the continued support for individual institute activities in this area of medical research. It was stressed that the establishment of a center at the NIH would not threaten the rehabilitation research activities of other institutes. Rather, creation of a principal focus and authority should increase awareness of medical rehabilitation research in each institute. It was noted also that while the 1978 legislation authorizing the NIDRR was a model of comprehensiveness, coordination and interagency communication related to medical rehabilitation is but one of five areas of concentration at the NIDRR. Furthermore, medical and scientific leadership, as well as continuity of overall leadership in medical rehabilitation research, has been lacking at the NIDRR.

Individual Panel members supporting the creation of a center addressed additional issues related to the establishment of a Center for Rehabilitation Sciences. It was emphasized that establishing a center with the authority to award gap-filling and cross-cutting grants could support research that might otherwise go unsupported. Also highlighted was the need to place a high priority on input to the center from persons with

disabilities and the importance of involving an extensive cross-section of the disability community in the activities of the center, since different disability groups may have unique medical and quality-of-life problems.

Panel members who supported a phased approach in addressing the medical rehabilitation research issue urged that, as a first step, a coordinated research agenda be defined for this area of medical research that draws upon the strength of the coordinated research environment of the NIH. The healthiest growth for the medical rehabilitation research field would be assured by moving with some degree of caution, but with a dedication to broadening both the amount and the nature of support related to furthering progress in rehabilitation medicine. While physicians trained in physical medicine are not likely to move rapidly into areas of basic research, but rather will focus on more clinical and applied research, the NIH model involves the coexistence of, and relationship between, pertinent bodies of information encompassed in the basic sciences and one or more clinical sciences. The inclusion of medical rehabilitation research in such relationships is highly desirable, but will require time to develop and become productive.

SUMMARY OF PRESENTATION BY THE DIRECTOR OF THE NATIONAL INSTITUTE ON AGING

Directors of NIH institutes, centers, and divisions in attendance at the Advisory Committee meeting were invited to comment on the Panel's report and recommendations by the Acting Director, NIH. Consequently, in a statement to the Committee, the Director of the National Institute on Aging (NIA) noted that medical rehabilitation is at the core of geriatric medicine, which has the goal of restoration and maintenance of function and independence. Other components of the NIH also have a stake in medical rehabilitation research. As a modification to several Panel members recommending the creation of a center with grant-making authority, he suggested that a center or office be established that has a strong coordinating function and that receives funds and establishes research priorities. Other institutes could then be challenged to propose activities that would address the established priorities. This approach would have an incentive-producing impact on institutes with a stake in the area of medical rehabilitation research without requiring the establishment of an entirely new and separate funding mechanism. The NIA Director also stressed the great need for trained researchers in the different disciplines relevant to medical rehabilitation research and emphasized the need for imaginative ways to provide good research training, both at the pre- and postdoctoral levels, that would incorporate the goals of rehabilitation. He cited as an example of an innovative approach, the joint Ph.D. program of the Department of Physiology and the Department of Physical Therapy at the University of Texas Health Sciences Center at San Antonio, which has a basis in physiology, but incorporates the perspective and goals of physical therapy.

DELIBERATIONS OF THE MEMBERS OF THE ADVISORY COMMITTEE AND THE COUNCIL REPRESENTATIVES

Following the presentations by members of the Panel on Physical Medicine and Rehabilitation Research and the statement by the NIA Director, the Committee members and Council representatives began a comprehensive review of the report and the recommendations. Some questions about the report were directed to the Panel Chairman and comments and further clarification were also invited from all of the Panel members present. The recommendations put forward by the Panel during its November meeting served as a framework for the deliberations of the members of the Advisory Committee and the Council representatives.

The initial phase of the discussion focused on the first three recommendations of the Panel:

- That the Director, NIH, appoint a panel consisting of experts in rehabilitation research and persons with disabilities to define a research agenda with priorities, time lines to complete research, and dollars needed. Such a research agenda should include short- and long-term elements and include a plan for developing a larger number of experts in rehabilitation research relative to the NIH mission.
- That the mission of any rehabilitation administrative entity should be to foster research and research training in rehabilitation

sciences and to promote all aspects of rehabilitation research within the mission of the NIH.

- That the Director, NIH, work through appropriate channels to create a high-level transgovernmental entity to monitor and coordinate rehabilitation research in all Federal agencies, to identify unserved rehabilitation research needs and opportunities, and to stimulate programs in appropriate agencies to address these needs and opportunities.

In response to requests from Council representatives for clarification about the recommended research agenda and mission statement, the Panel Chairman pointed out that a primary objective underlying the Panel's recommendation to define a research agenda was the need to determine the aspects of rehabilitation research that fall within the mission of the NIH and to identify gaps in medical rehabilitation research at the NIH. It was not the purpose of the recommendation to define rehabilitation research itself or to differentiate between the types of rehabilitation research that should be conducted by the different NIH institutes. The Panel Chairman also noted that an important element in the mission statement was the need to foster and improve research and research training in medical rehabilitation. Furthermore, the focus on research training is not to be construed to be restricted to clinical research, but should reflect training as it is broadly defined by the NIH.

During the discussion, both Advisory Committee members and Council representatives noted the difficulty in considering medical rehabilitation research as a discrete entity. One Council representative observed that, to those not in the field, medical rehabilitation research appears to encompass the whole range of biomedical research and that the establishment of a separate organizational entity would pose problems. The Acting Director, NIH, interjected that while some would call for more NIH support for medical rehabilitation research, the individual activities in this area are appropriately linked to the individual institutes. Dislodging these activities has, therefore, been viewed as undesirable. At the same time, the Committee noted that the Panel did not advocate the accumulation of all rehabilitation research activity in a new and separate entity. It appeared, rather, that there is a need to capitalize on the strengths of the NIH and its ongoing programs, while taking further steps to meet perceived unmet needs.

Council representatives also requested clarification about the focus of the NIH research agenda in this area and the research mission of the NIDRR in medical rehabilitation research. In responding to this, one of the Panel members and a former Director of NIDRR noted that the NIDRR has the legislative authority to undertake all of the activities advocated by the Panel, but is hampered by limited funding, a lack of medical and scientific leadership, and a very broad research mission. The U.S. Office of Education, within which NIDRR is located, also does not provide a setting that promotes the scientific rigor and collegiality needed to foster medical rehabilitation research. While NIDRR has implemented some valuable programs—its spinal cord injury centers were cited as an example—its training program has had limited capacity and funding. Furthermore, only very recently has funding for field-initiated research, comparable to the NIH R01 grant awards, been available to the NIDRR. It was also noted that any potential overlap in rehabilitation research activities of NIH and NIDRR or any other Federal agency could be addressed by the transgovernmental entity recommended by the Panel in recommendation 3.

During the discussion, one Council representative inquired whether the primary problem of medical rehabilitation research involved difficulties in securing peer review or was associated with the need for increased training opportunities. In responding to this issue, Panel members concurred that both peer review and increased training opportunities were perceived as areas of concern. Yet another concern of the medical rehabilitation research community that was highlighted at this point was the perception by the community that important areas in medical rehabilitation research were not being addressed by the NIH or by any other research organization.

Panel members also were asked by the Acting Director, NIH, about the amount of time that would be needed for the development of a research agenda. Several Panel members responded by acknowledging that this task was not likely to be accomplished quickly. They noted that consensus is lacking within the field, and that this in itself would preclude devising a research agenda within a short period of time. Furthermore, the quality of the research agenda developed would strongly influence the success of any activities emanating from it. Accordingly, the developmental process should be a careful and deliberative one.

Following this discussion, the Committee focused on the following two recommendations of the Panel:

- That a Center for Rehabilitation Sciences be created, either free-standing or integrated into an existing institution, to contain the following elements:
 - training grant authority,
 - gap-filling and cross-cutting award authority,
 - a long-range plan for rehabilitation research that can be implemented,
 - a central focus for rehabilitation,
 - an advisory body (to include people with disabilities), and
 - a way to coordinate and promote rehabilitation throughout the NIH.
- That the Director, NIH, as an interim step, create an entity, that includes the following elements:
 - a long-range plan for rehabilitation research that can be implemented,
 - a central focus for rehabilitation,
 - an advisory body (to include people with disabilities), and
 - a way to coordinate and promote rehabilitation throughout the NIH.

The first issue addressed in this portion of the deliberations was related to a concern that had emerged earlier in the discussion, that is, the difficulty that may be anticipated in developing an implementable research agenda given the heterogeneity of the research issues relevant to medical rehabilitation research. One Advisory Committee member expressed doubt that, given this potential difficulty, agreement could be reached about an implementable research agenda and asked who would be responsible for assessing

whether the agenda that emerges is sufficiently implementable to proceed. In responding to this, the Acting Director, NIH, indicated that the NIH could move immediately to set in motion a process to develop a research agenda and, furthermore, could provide the type of assistance needed to ensure that the proposed research agenda could also be implemented. He noted, however, that if significant changes in organizational structure were required, congressional or Presidential approval would be needed.

Some Committee members voiced the opinion that, given the current lack of a research agenda for medical rehabilitation research, it would be premature at this juncture to attempt to initiate the creation of a center containing the elements recommended by the Panel. They emphasized that the establishment of staff and an advisory panel to initiate a planning process to develop a research agenda for medical rehabilitation should receive priority before considering a new center. It was suggested that an appropriate mechanism within the Director's office could be established immediately to develop short- and long-term priorities, to assess types of research and training that are needed in medical rehabilitation research, and to determine the relationship between any proposed future entity and existing NIH institutes.

Several Committee members and Council representatives also expressed the concern that centralizing medical rehabilitation research may not lead to the primary goal of expanding the research enterprise and increasing training in this area. It was noted that at the NIH, centralization of research activities in a particular area has sometimes lead to reduced rather than expanded resources. The fact that medical rehabilitation research deals with the outcomes of many different disease processes also was seen as a reason for adoption of a decentralized approach to ensure input from a variety of fields. However, such an approach would require rigorous oversight and coordination to ensure that important gaps would be addressed. If a coordinating body for medical rehabilitation research were established, it would have some responsibility in the distribution of funds to the various institutes.

Prior to concluding the meeting, the Acting Director, NIH, asked the Advisory Committee members and Council representatives present at the

meeting to provide him with individual summary comments on the organizational options under discussion. All members expressed agreement that implementation of Panel recommendation 6 would well serve the medical rehabilitation research community. Furthermore, while the Committee members recognized that a center could eventually emerge as a result of implementing this recommendation, they also submitted that the development of a research agenda may conceivably be all that is needed to initiate the desired improvements in the quality and quantity of medical rehabilitation research and research training. Several members also suggested that an analytical framework needed to be developed to evaluate progress made by the coordinating mechanism in the Office of the Director, NIH, in accomplishing desired goals, and to assess if developments warranted the creation of a separate medical rehabilitation sciences center or institute. In addition, Committee members urged that this initiative be implemented with all possible speed, that the process and timetable for implementation be made public, and that the results of this undertaking be reported at a future meeting of the ACD.

SUMMARY AND CONCLUSION

The Advisory Committee to the Director, NIH, together with representatives of the National Advisory Councils of the NIH institutes, met on January 26 to review the Report of the Panel on Physical Medicine and Rehabilitation Research. The Advisory Committee heard presentations by nine of the twelve members of the Panel present at the meeting as well as a presentation by the Director of the National Institute on Aging. In the course of their deliberations, the Advisory Committee members and Council representatives agreed that activities related to medical rehabilitation research should be strengthened at the NIH and were also in agreement with the Panel's recommendations regarding the development of a research agenda and mission statement for medical rehabilitation research, and the creation of a transgovernmental entity to coordinate medical rehabilitation research. However, Committee members and Council representatives believed that an immediate effort to create a free-standing center was premature and could dilute, rather than enhance, medical rehabilitation research efforts at the NIH. Advisory Committee members and Council representatives were in unanimous agreement with recommendation 6, that "The Director, NIH, as an interim step, create an entity that includes the following elements: a long-range plan for rehabilitation research that can be implemented, a central focus for rehabilitation, an advisory body (to include people with disabilities), and a way to coordinate and promote rehabilitation research throughout the NIH."

Appendix A

Agenda

AGENDA

***60th Meeting of the Advisory Committee to the Director
National Institutes of Health***

REPORT OF THE PANEL ON STRENGTHENING THE SCIENTIFIC REVIEW PROCEDURES OF THE NIH INTRAMURAL RESEARCH PROGRAM

and

REPORT OF THE PANEL ON PHYSICAL MEDICINE AND REHABILITATION RESEARCH

Friday, January 26, 1990

***Shannon Building, Wilson Hall
National Institutes of Health
Bethesda, Maryland***

- 8:30-8:45 Opening Remarks Dr. Raub
- Status Report on Activities Following the
 May 19, 1989, Meeting of the Advisory
 Committee to the Director, NIH, on
 Biomedical Research: The Next Generation of
 Scientists
 - Topic I-Strengthening the Scientific Review
 Procedures of the NIH Intramural Research
 Program
 - Topic II-Medical Rehabilitation Research
- TOPIC I-STRENGTHENING THE SCIENTIFIC REVIEW PROCEDURES
OF THE NIH INTRAMURAL RESEARCH PROGRAM**
- 8:45-9:00 Overview and Background Dr. Raub
- 9:00-9:15 Statement of the Issue Dr. Shapiro
- 9:15-9:45 Summary of Considerations and
 Recommendations of the Ad Hoc Consultant
 Panel Dr. Hill
- 9:45-10:00 Coffee Break

10:00-11:45	Discussion and Recommendations of the Advisory Committee to the Director, NIH	Members, Advisory Committee to the Director, NIH, and ICD Council Representatives
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11:45-1:00	Lunch
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TOPIC II-MEDICAL REHABILITATION RESEARCH

1:00-1:15	Overview and Background	Dr. Raub
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1:15-1:45	Summary of November 20-21 Meeting and Recommendations of the Panel and Rationale Leading to Conclusions	Dr. Brandt
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1:45-2:35	Statements by Panel Members
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2:35-2:50	Coffee Break
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2:50-5:00	Discussion and Recommendations of the Advisory Committee to the Director, NIH	Members, Advisory Committee to the Director, NIH, and ICD Council Representatives
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5:00	Adjourn
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Appendix B

Meeting Participants

- Advisory Committee to the Director, NIH
- Advisory Council Representatives/
Board Members
- Panel on Physical Medicine and
Rehabilitation Research

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Appendix C

Recommendations of the
Panel on Physical Medicine
and Rehabilitation Research
from the December 1989
Report of the Panel

PANEL RECOMMENDATIONS

During the course of the January 26 meeting of the Advisory Committee to the Director, NIH, the Advisory Committee reviewed the Report of the Panel on Physical Medicine and Rehabilitation Research and discussed the following recommendations contained in the Panel's December 1989 report.

Recommendation 1

That the Director, NIH, appoint a panel consisting of experts in rehabilitation research and persons with disabilities to define a research agenda with priorities, time lines to complete research, and dollars needed. Such a research agenda should include short- and long-term elements and a plan for developing a larger number of experts in rehabilitation research relative to the NIH mission.

Recommendation 2

That the mission of any rehabilitation research administrative entity should be to foster research and research training in rehabilitation sciences and to promote all aspects of rehabilitation research within the mission of the NIH.

Recommendation 3

That the Director, NIH, work through appropriate channels to create a high-level transgovernmental entity to monitor and coordinate rehabilitation research in all Federal agencies, to identify unserved rehabilitation research needs and opportunities, and to stimulate programs in appropriate agencies to address these needs and opportunities.

Recommendation 4

That the NIH establish a National Institute of Rehabilitation Sciences reporting to the Director, NIH, to accomplish the mission defined [to foster research and research training in rehabilitation sciences and to promote all aspects of rehabilitation research within the mission of the NIH].

Recommendation 5

That a Center of Rehabilitation Sciences be created, either freestanding or integrated into an existing institute, to contain the following elements:

- training grant authority,
- gap-filling and cross-cutting award authority,
- a long-range plan for rehabilitation research that can be implemented,
- a central focus for rehabilitation,
- an advisory body (to include people with disabilities), and
- a way to coordinate and promote rehabilitation research throughout the NIH.

Recommendation 6

That the Director, NIH, as an interim step, create an entity that includes the following elements:

- a long-range plan for rehabilitation research that can be implemented,
- a central focus for rehabilitation,
- an advisory body (to include people with disabilities), and
- a way to coordinate and promote rehabilitation research throughout the NIH.

All recommendations were accepted with the exception of recommendation 4.

Appendix D

**Presentations by Individual Members of the
Panel on Physical Medicine and
Rehabilitation Research**

January 26, 1990

*Statement of Edward N. Brandt, Jr., M.D., Ph.D.
Chairman of the Panel on Physical Medicine
and Rehabilitation Research*

to the

*Advisory Committee to the Director
National Institutes of Health
January 26, 1990*

Thank you very much, Dr. Raub. I appreciate the opportunity to be here and the opportunity to present our report. I want to thank you also for the opportunity to be able to participate in this panel. We've dealt with an important topic, and I am delighted to have been invited.

We spent two rather intense days examining this issue. The first day was devoted largely to testimony from a whole variety of interested groups, including various institutes at the NIH that are involved in active research on the subject.

I must admit that during the course of my career I have been involved in a large number of public meetings of government advisory groups, and I found that there was a minimal amount of the posturing, game playing, etc., by this panel, that tends to characterize many of these meetings, especially if the press is there.

At the end of our deliberations, or toward the end of our deliberations, we considered a series of recommendations and chose to make five to you, which are listed beginning on page 31 of the report. It is important to recognize, I think, that we are dealing with an important area of medicine and the health sciences, but we are also dealing with a subject that, to my knowledge, is not well handled by almost any multipurpose research organization, including one that cuts across numerous disciplines. It's not unique to the NIH that they have had difficulty dealing with multidisciplinary problems through the years. Every academic institution that I have ever been around has had the same kinds of problems. It's also important to recognize that we are not dealing with a single discipline in terms of the research programs, but with a whole variety.

I'd like to go through the five recommendations with you briefly, just to be sure that they are clear. The first recommendation was that the Director of the NIH appoint a panel that would define a research agenda with priorities, time lines, dollars, etc., that is within the mission of the NIH. Implicit in that, of course, is that it would

be a definition forthcoming, in some sense, of what rehabilitation research is going to be at the NIH.

Second, we recommend a mission statement. Nothing too different there, except to point out the importance of fostering research training. Most of the people actively involved in rehabilitation testified to the need to develop a larger cadre of people in this country who are trained in rehabilitation research and all of its activities.

Recommendation 3 deals with the entire Federal government. The Panel believed that, in spite of the fact that it was an NIH advisory committee, it might just as well take on the world, and it did. It turns out that many Federal agencies are actively involved in some aspect of rehabilitation and rehabilitation research. The Veterans Administration, the Department of Defense, and the National Institute on Disability Rehabilitation and Research in the Department of Education are probably the three big ones. However, in my experience with the Federal government, when you start turning over rocks in a Federal agency looking for things, you will find a large number of organizations involved.

Certainly, even within the Public Health Service, one component that didn't receive a lot of attention—but which I subsequently learned has a great deal—is the National Institute of Mental Health, in the Alcohol, Drug Abuse, and Mental Health Administration.

Consequently, the panel felt that there needed to be a real coordinating body—a high-level, transgovernmental entity. Translate that into some kind of coordinating body that can make sure that the Federal government as a whole has a total agenda that is meaningful, that does not permit wide gaps in subjects, and that can make true assignments of direction and so forth. That's easier said than done, of course; but nevertheless, it's important.

Recommendation 5: that a Center of Rehabilitation Sciences be created, either freestanding or integrated into an existing institute, to contain the elements that we have listed there for you in the report. Again, we have emphasized the central focus: long-range planning, coordination, and promotion of rehabilitation research, including an advisory group. By advisory group, again we're talking about essentially an outside, i.e., extra-NIH-type advisory group.

Recommendation 6 deals with a sense of immediacy and urgency expressed by the Panel, that the initiative be taken as soon as possible to establish the appropriate agenda setting mechanisms, begin the planning, identify the advisory body, and begin the coordination effort within the NIH to define a way in which the institutes can continue to work together.

I want to stress that one of the things that we say very clearly in the report is that the attempt was not to try to create some new body that pulls all of the rehabilitation research currently underway within the institutes out of those institutes into a central group; but rather, that current efforts continue and be enhanced in appropriate areas, once we know what the agenda really is and ought to be for that.

With those comments, I look forward to the discussion, sir.

Statement of Henry B. Betts, M.D.

to the

*Advisory Committee to the Director
National Institutes of Health
January 26, 1990*

I appreciate very much being able to be here. I'm Henry Betts. I'm Professor and Chairman of the Department of Rehabilitation Medicine at Northwestern, and the head of the Rehabilitation Institute of Chicago. I've been head of the American Congress of Rehabilitation Medicine, and I'm right now on a task force at the Institute of Medicine for the CDC, looking at an initiative for the prevention of disability.

We are, of course, interested in advocacy for the disabled. I don't think that it's particularly new to any of you that the considerations for disabled people have been sparse in this country and ironically so—ironically because, after all, most of us will be disabled at some time. Ironically enough, it has received short shrift over the years in medical schools; in most medical schools rehabilitation is not taught. Relatively little care of the disabled is taught, research has been slow in coming about, and the attitudes of society toward the disabled continue to be rather negative.

I think that in hearing the figures that are spent on research relative to the disabled in the NIH, we must all be reassured that there has been a movement in the proper direction, and I certainly attest to that. I think that for the disabled we should all be grateful for that.

There is a tendency to feel that rehabilitation is everybody's business now. It does cross a lot of lines, it is true. It does touch a lot of agencies in the government. The fact that disability is a relative thing makes this particularly susceptible.

In other words, one is disabled in a relative sense—a disability is the impairment of somebody relative to society. That gives you a large, large spectrum to consider in dealing with disability.

There is a basic pathology of the functional loss and then the relationship of that to societal interests. That means, in researching these issues, you can deal with the basic pathology, the functional loss, the influence of society, of vocation, of psychodynamics, and so on. A lot of areas can touch upon these needs.

Indeed, we would like all agencies and all organizations to give consideration to disability. I think, for those of you on a committee like this, it must seem somewhat ponderous, because you must feel that you're sort of dealing with a disease of the month club. I know that everyone comes to you with a particular disease and says, "This is the main disease; here are my figures that prove that this is the main disease in the country. All of you will be stricken with it, all of your children will be affected by it, and, therefore, you must build a building around it and fund it." And here I am, and here we are, which must seem like the same thing.

I would simply point out: we're not dealing with a disease. We're dealing with a variety of diseases and impairments that cross a lot of lines, and we do know that. It is a lot of people. You've heard the figures for every other disease. Ours is 43 million, except it's not a disease. It's a disability and, as I say, almost every American will at some time be disabled.

The main thing I would like to simply point out is that we did have, I think, wonderful meetings, extremely interesting and productive, highly challenging. There are the considerations of coordination, crossing the lines, and so on. I would simply point out that, to my way of thinking, this is the moment for disabled people.

There is the American Disabilities Act. The consumers are being heard. There is the initiative at the CDC and the Institute of Medicine. There is the independent living movement. The National Institute on Disability Rehabilitation and Research is proceeding, and in many ways the disabled are rising to the forefront.

In research, I think that it would be reasonable to do as well. I think that, as nearly as I can tell, here in Washington--and elsewhere, too--in order to get something done, you need an advocate, a powerful advocate. That advocate should have the title and have the power and have the money. In those ways you move things along.

I think that in research in this very important area, that would be the way to move this along, to have that person in this place moved to the highest realm of scientific endeavor that we can have in the country. I think that that would be the thing that would get it done.

The field is ready for that. The disabled are ready for it. People in rehabilitation--there are bright people going into rehabilitation who can be trained in research, and others as well.

So my point of view is that this identity, this advocacy, would get the job done. Thank you.

Statement of Cheryl M. Chanaud, Ph.D.

to the

*Advisory Committee to the Director
National Institutes of Health
January 26, 1990*

As a neuroscientist, as the director of a research foundation, and as an advocate for a subgroup of the disability community, it was an honor to have served on the Physical Medicine and Rehabilitation Research Panel.

My formal statement is as follows:

In order to establish an explicit commitment to rehabilitation research by the NIH and to create a means whereby rehabilitation research is legitimized and supported through a variety of programs (including research, training, education, and information), I, as a representative of individuals with spinal cord injury, recommend the creation of a National Center of Rehabilitation Sciences.

Furthermore, because rehabilitation research benefits ill or disabled people directly, often for their entire lives, and can critically affect their quality of life, it seems imperative that input from the disability community be given a high priority in this particular NIH entity. For example, many individuals with spinal cord injury are eager to explain medical problems they have that *no* research is currently addressing. In fact, it may be essential to include any extensive cross-section of the disability community, because each group may have unique medical and quality of life problems.

Statement of John F. Ditunno, Jr., M.D.

to the

*Advisory Committee to the Director
National Institutes of Health
January 26, 1990*

I wish to express my appreciation to the Chairman and staff of the Panel for all their effort in the preparation and publication of this report. It has been a pleasure and privilege to serve in such an important deliberation.

I believe we have an unusual opportunity today and—as was stated in another national forum recently—we face an historic moment in Rehabilitation Medicinal Science: *never* has the *recognition of the public* for improving the lot of the disabled been *higher*. Clinicians and investigators from the biomedical and social sciences are aware of the mounting numbers of disabled people due to trauma in our youth and degenerative diseases in our aged. Awareness by the professional community has never been higher, along with *recognition* of the need for expanded scientific effort and leadership. The field of rehabilitation has never been stronger, with a surplus of bright young people applying to our field with promise to fill the shortage of academic faculty, provided the mature programs are enabled to assume this scientific initiative.

Therefore, *the time is right* for launching a major rehabilitation research mission within the National Institutes of Health to achieve success at a pace demanded by society and responsive to the professional and scientific community. The Panel is unanimous in recognizing the need to define the rehabilitation research mission and the majority, at 2:1, favor a center, but some recommend an office and planning effort. An office and an increased awareness in each institute is insufficient *by itself* at this time. We need a much stronger initiative and focus. We believe the public and Congress will support such an initiative. We do not feel such an initiative threatens the survival of rehabilitation research in the other institutes. A principal focus and authority should increase awareness in each institute and we believe our concept of the evolution of pathology to impairment to disability, which may be impeded and partially reversed and function restored, is a scientific perspective we can bring, which will advance this awareness across all institutes.

NIH has the *blueprint* for training basic and clinical scientists. It has a proven system for the development of young scientists into career investigators. It has a superb peer review system for the awarding of grants. We desire to embrace this system as a

medical discipline and as a group of disciplines committed to excellence in rehabilitation research. The surest and most direct route to this goal is the establishment of a center, with its own authority for training and research grant awards. I support recommendation 5.

Statement of George Dohrmann, M.D., Ph.D.

to the

*Advisory Committee to the Director
National Institutes of Health
January 26, 1990*

Ladies and gentlemen, first let me say that it was a great pleasure to participate on this Panel under the chairmanship of Dr. Brandt. He summarized the views of the Panel quite well earlier this afternoon.

My reason for speaking with you today is to offer a neurosurgical perspective on all of this. I'm a neurosurgeon at the University of Chicago Medical Center, involved in practice, involved in research, and involved in teaching.

I represent the United States on two international committees. One is that of neuro-traumatology, and other is that of neuro-oncology. I see a number of patients in my service at our medical center with head injuries and spinal cord injuries, as well as many patients with tumors of the brain and tumors of the spinal cord.

What we do for these patients as neurosurgeons is only half of what these people need. The other half is rehabilitation. We work very closely with and depend very much upon specialists in rehabilitation, and they in turn depend very much upon rehabilitation scientists and rehabilitation science research to further their efforts.

I strongly support the development of a Center of Rehabilitation Sciences, with the goal of that center to foster rehabilitation research and research training in rehabilitation sciences and to promote all aspects of rehabilitation research within the mission of the National Institutes of Health.

I hope you will recommend that such a center be created. Thank you very much.

Statement of Douglas Fenderson, Ph.D.

to the

*Advisory Committee to the Director
National Institutes of Health
January 26, 1990*

Dr. Raub, members of the Committee, I am pleased to be here today as a member of the Panel and as a former director of the National Institute for Disability and Rehabilitation Research, to bring that particular perspective to my statement in favor of the recommendations as presented to you in the report.

In the report that you have you will notice a letter transmitted by Mary Lasker pointing out that this discussion has been going on for 25 years. She said that at the beginning of the discussion she was much in favor of having the home for the scientific study of disability and rehabilitation at NIH, and at that time hers was not the prevailing opinion; but she was pleased to see that the question was back and at this particular stage of development.

The 1978 legislation that authorized the National Institute for Disability and Rehabilitation Research (NIDRR), formerly known as the National Institute for Handicapped Research, is a model of comprehensiveness, coordination, and interagency communication with regard to rehabilitation research. However, medical rehabilitation is only one of five major themes to be found within the programs of NIDRR; and, in truth, the scientific study of disability and rehabilitation has not taken root well within that agency in relation to its administration within the U.S. Department of Education.

That agency has, of course, been influential in the development of rehabilitation research in this country, supporting in 1984 some 38 long-term rehabilitation research and training centers, 20 of them in some aspect of medicine, and 16 rehabilitation engineering centers.

These are basically \$500,000 a year grants, generally for 5 years. Some of these centers have been supported for much longer periods of time—10 to 20 years. However, until 1984 there was no program for investigator-initiated research and since that time about half of the investigator-initiated proposals to NIDRR have been on some medically related topic.

The NIDRR legislation required an interagency committee for the coordination of rehabilitation research activities within the Federal government. At the time that I was director, we were able to identify some 32 Federal agencies that had a program or activity that was relevant to rehabilitation research.

Within the aegis of that committee, we developed working groups on disability data, disability technology, research in physical disabilities, and in mental illnesses. A great deal was accomplished.

At least we were able to understand what other agencies were interested in and funding, and what their particular talents and commitments were. In a number of instances, we were able to bring about the conjoint funding of projects of interest to several agencies.

During my tenure as the director of that rehabilitation research agency, I came to a number of conclusions:

1. There is an exemplary piece of legislation in the Department of Education in support of rehabilitation research.
2. The scientific study of disability and rehabilitation has not fared well under that agency.
3. There has been a serious problem of continuity of leadership, there having been a director of NIDRR for less than one-half of the 12 years of its existence, and certainly there has been a lack of medical and scientific leadership in the development of its rehabilitation programs.

Finally, the legislation requires the development and updating of a comprehensive rehabilitation research plan every 3 years. In the 12 years of its existence, only one such plan has been prepared and submitted as required.

In my tenure in 1984, when such a plan was due, it was submitted and it was embargoed by one of the assistant secretaries in the Department of Education. It has languished there ever since.

Dr. Betts mentioned that the Institute of Medicine is currently undertaking a study with regard to the prevention of disabilities. That study is helping to focus attention on the importance of the topic under discussion here. Basically, that committee's deliberations have identified risks for disabilities and the secondary disabling consequences and conditions associated with them. Based on an understanding of those

risks, the committee has considered strategies for intervention, to reduce the burden of disability on society. The report, due out this spring, will emphasize the need for the scientific study of disability, its consequences, and rehabilitation.

So I support the recommendations that have been made to this group and to Dr. Raub.

Statement of Dorothy L. Gordon, D.N.Sc., R.N.

to the

*Advisory Committee to the Director
National Institutes of Health
January 26, 1990*

It has been my pleasure to serve and deliberate with distinguished colleagues from across the country under the skilled leadership of Dr. Brandt on the Medical Rehabilitation Panel. It was also my pleasure, last November, to have been elected president of the American Congress of Rehabilitation Medicine (ACRM), the multidisciplinary organization that represents all of the disciplines and professions engaged in medical rehabilitation services, educational efforts, and research. An expressed mission of the ACRM is to foster medical rehabilitation research.

Mr. Chairman, I believe the acid test of our Panel's usefulness will occur in a year or so when we see whether the NIH is supporting more research of greater relevance to improving medical rehabilitation practices and to improving the functioning, productivity, and quality of life of persons with disabilities. While the Panel's recommendations regarding the planning and monitoring of such research are relevant to that objective, my belief is that the critical recommendation is the one concerned with establishing a Center of Rehabilitation Sciences, with authority for making training and research grants that are characterized as "gap-filling and cross-cutting." In the present context, gap-filling and cross-cutting have specific meaning. The terms allude to research and research training that may touch upon the priorities of the individual institutes, but that are not central to the priorities of any particular institute. In a word, the allusion is to distinctive research and research training that would go unsupported unless funded by the Center of Rehabilitation Sciences.

In relation to that, a point I wish to make, Mr. Chairman, is that the budget implications of our recommendations need to be faced directly and considered thoughtfully today. For the desired result of more research to improve the life of persons with disabilities, a timely response is important to organizing and staffing the proposed Center, planning for congressional relations bearing on the needed authorizations and appropriations, and developing constituency relations required to support those actions.

I hope that you will support the Panel's recommendations, particularly that related to the Center. They are intended to foster the continuing development of the NIH in its efforts to be responsive to the needs of medical rehabilitation researchers, service providers, and, above all, the estimated 35 million persons in this country who have disabilities.

Statement of Oscar M. Reinmuth, M.D.

to the

*Advisory Committee to the Director
National Institutes of Health
January 26, 1990*

In offering a brief summary statement of my own views of the informative discussions that led to the *Report of the Panel on Physical Medicine and Rehabilitation Research*, I would like to emphasize a feature that I believe must be kept in mind in attempting to come to recommendations for the best steps to follow. Several Panel members developed ideas that emphasize the diversity of program and research efforts that bear on improving the field of rehabilitation medicine. Among these important distinctions it seems to me that the broad area of what may be called rehabilitation medicine must be distinguished from the more focused efforts of programs in physical medicine and rehabilitation. The basic investigations that study the neurobiology of bone regeneration related to orthopaedic rehabilitation or immunological mechanisms operative in multiple sclerosis are vitally important to research in rehabilitation medicine, but in the near future are not likely to be undertaken by the cadre of physicians trained in programs of physical medicine. This is in contrast to the situation that exists in many of the more traditional clinical sciences, where there is a continuum of investigative work that crosses into the basic sciences. Such fertile relationships are obviously desirable but also require time and evolution to develop to become highly productive in quality research. At the present time the very important clinical disciplines of physical medicine are not likely to move rapidly into this model but, appropriately, will direct into areas of more clinical and applied research. In some of the discussion of the Panel it was not always clear that a separation of this kind was kept in mind as the different recommendations were considered.

My own bias is that the model provided by most of the institutes of the National Institutes of Health has been the coexistence of pertinent bodies of information encompassed in one of the basic sciences as they relate to one or more of the traditional and long-experienced clinical sciences. While there is every reason to encourage inquisitive beginners in the field of rehabilitation medicine to focus on investigative curiosity in the diversity of areas pertinent to their discipline and their own interest, it seems to me unlikely that attempting to train individuals capable of research of unspecified type will lead to the spectrum of widely diverse proposals that provide the important material that existing institutions now can assess and support.

As a result it seems to me that however worthwhile the need for rapidly improving rehabilitation services, the most healthy growth will be provided by moving with some degree of conservatism, with a dedication to continue to broaden both the amount and the nature of the support in furthering progress in rehabilitation medicine.

It seems to me that one positive step, one that was approved by the Panel in its deliberations, would be to focus on recommendation 6 to develop a long-range plan, to seek the advice and input of a wide variety of scientists and disabled persons, and to move with circumspection in ensuring the future strength of rehabilitation science.

Statement of Marilyn Price Spivack

to the

*Advisory Committee to the Director
National Institutes of Health
January 26, 1990*

It has been an honor to serve on the Physical Medicine and Rehabilitation Research Panel for the National Institutes of Health (NIH). I want to thank you and the Advisory Board for this opportunity to represent consumers who face the realities and challenges after disability.

As the parent of a daughter significantly disabled after a severe closed head injury, I and my family have become too familiar with the world of trauma, medical care, and rehabilitation services. It has been, and continues to be, a frustrating, difficult, and oftentimes lonely road. Surely there have been stretches of hope, but the miles of obstacles are more common, created by specific lack of knowledge and expertise and poor attempts at prognosis, since outcome data—particularly in neurotrauma rehabilitation—are sparse. Add to the above, a lack of access, resources, and funding. The rehabilitation process must improve if the ultimate goal of the maximum retention of function is to be achieved.

The end result of medical recovery oftentimes is a patient disabled. The excitement and interest of biomedical and neuroscience has not been infused into the field of rehabilitation science; therefore, even though "disability" has gained recognition, it has not gained "respect" by scientists and academicians.

As I stand here, I am curious about my observation that there are no individuals here with a visible disability. That is too bad, as they could add a great deal to the discussion and argument for the value of the establishment of a Rehabilitation Research Center.

These observations and experiences are as a parent and consumer.

As the founder, president, and CEO of the National Head Injury Foundation for the past 10 years, I have another dimension of experience and observation, through close association with hundreds of professionals in physical medicine and all disciplines and phases of rehabilitation. They suffer as we do from the lack of focus and resources committed to this field. It is not a perception, but a reality that rehabilitation has been

a stepchild of academic medicine. Certainly major advances have been accomplished by outstanding individuals and institutions over the past 15 years. Even rehabilitation environments have changed—out of the basement to brightly lit upper floors of acute-care hospitals and to freestanding rehabilitation hospitals—but significant barriers remain. The major change in removing those barriers can happen today! This advisory board, all of you, can change the future for those you ultimately save by cure or the prolonging of life. If this major step forward is rejected, and if a center for rehabilitation research and training does not receive substantive funding and recognition, there will continue to be minimal credibility and ability to attract the best and brightest to this field.

As long as there are minimal avenues to test and weigh rehabilitation methodology and techniques, validation of services will be at risk. Therefore, patients are at risk and society suffers. Rehabilitation science and training needs a central, secure home out of which research can be coordinated and funded. Such a home could stabilize training programs of excellence, well-structured and monitored clinical trials can be developed and therapies perfected to establish state-of-the-art standards.

None of this will become a reality as long as the pursuit of rehabilitation is fragmented among the centers, institutes, Federal agencies, and private agencies. The past is proof. I do not advocate decreasing or minimizing any existing effort or focus now in place. A rehabilitation research center will enhance, strengthen, and coordinate current and future efforts.

This morning Dr. Hill used the phrase "a strong connection with the best." The future center would begin to build that connection. As the president of the National Head Injury Foundation and as a leader of the disability movement, I support the fifth and sixth recommendations of the Panel's report, and I underscore the need for people with disabilities to take an active role within a future entity and on advisory boards. I certainly support the statements made by the distinguished panelists before me.

To summarize my statement, I would like to close by recognizing the superb work done at the National Institutes of Health in saving and extending life and holding out hope for the future for all people, but every success has created challenge and opportunity. There are an estimated 43 million Americans with disabilities. Most do not have what is known as "quality of life." Most do not have access or opportunity. That is not your issue, but hopefully it is your concern as a caring physician and scientist. Two-thirds of this population are young. Most are under the age of 60. Most still want to feel productive and involved. This creation of a center for rehabilitation science research can be the hope for the future of millions of people with disabilities in the decades to follow.

This is the decade devoted to the brain, to injury prevention, to disease prevention and health promotion, to the family, and to education. In essence, to improve the future all Americans—well, ill, and disabled. You have an important contribution to make for all our futures. We hope you will support our recommendation to carry out the ultimate goals of your work and the work of the NIH.

Thank you Dr. Raub, Dr. Brandt, Dr. Moskowitz, and the members of the Panel for this opportunity.

Appendix E

Statement by Dr. T. Franklin Williams
on the Report of the Panel on Physical
Medicine and Rehabilitation Research

*Statement of T. Franklin Williams, M.D.
Director, National Institute on Aging*

to the

*Advisory Committee to the Director
National Institutes of Health
January 26, 1990*

Thank you very much, Dr. Raub. I regretted that I couldn't be at the meeting of the Panel, but our institute was well represented there by Dr. Hadley, and summarizing comments are in the Panel's supporting material about the National Institute of Aging.

I really did want to have a moment to speak to the members of the Panel who are here to thank them for their efforts, and also to the Advisory Committee to the Director, just to give my own views about this issue.

I bring some credentials. I'm the editor of one of the two books that deal with rehabilitation and aging. I was a medical director of the facility in Monroe County, New York, which served all chronically ill people of all ages and was a large resource in rehabilitation for all ages.

So I have some background in relation to this field, as well as having been honored with the Coulter Lecture of the American Congress of Rehabilitation Medicine a few years ago. There is no question that rehabilitation is the core of geriatric medicine; it's at the heart of it. The whole goal of care of older people is restoration and maintenance of function and independence. It should infuse, and I hope does infuse, every aspect of our institute's research, from the basic biology and its ultimate contribution on through to the very practical applications.

Now with this kind of perspective, I hope you would appreciate that rehabilitation research is important in our institute. We do support it, as our records show. Along with the National Center of Nursing Research, we recently issued a request for applications for studies on frailty and correction in older people. We had 42 applications. We'll be able to fund about eight of those, if we're lucky, out of some twenty or so that were highly rated in the review process.

We also have a program announcement on rehabilitation in aging. We've co-funded with the National Institute on Disability and Rehabilitation Research one of the two centers on aging and rehabilitation that they support.

We need to do a lot more, and I'm sure this applies to my sister and brother institutes here at the NIH. I think you would find that any of a majority of institute directors here would point out the important role that rehabilitation does play and should play in each of their missions.

So I really would like to underscore, in my judgment, the importance of seeing that the recommendations of this Panel are carried forward in a way that reinforces and strengthens what we can and should do in our individual institutes.

Now this bring me to a comment about the center. I think the concept of some focus within the NIH as a whole is called for, to help focus the interest in the whole area of rehabilitation and the multiple cross-relations that can and should exist and be coordinated across all of our institutes and centers.

I think the concept of a center or an office is called for. I think there are questions to raise about how it might best function. I would like to specifically suggest that such a center have, first of all, a coordinating function and, second, would receive funds for which it would establish priorities, and would challenge the various institutes and centers of our NIH to show how they would use these funds to meet the goals called for, to meet the gap areas.

In other words, rather than setting up an entirely new system of funding, I would favor a center that had some authority and money, that could impact on all the rest of us in very competitive and incentive-producing ways. That's a slight modification of the way the center is proposed in the Panel's report.

I wanted to bring that out as an alternative way to try to encourage and help all of the institutes that now have a stake in this area to do more, rather than setting up an entirely new and separate funding mechanism.

I want to end my remarks with a brief reference to the issue of training. I think, as several have said and the report certainly says, we desperately need more researchers trained in disciplines across the board to press forward in rehabilitation-related research.

I was just at the University of Texas Health Sciences Center in San Antonio, and I made some inquiries there about what they are doing in this area. I learned, for example, of a--to my mind--very imaginative approach in which the Department of Physiology and the School of Physical Therapy are working together to give a joint Ph.D. This program is based in physiology and has the strengths of physiology, but it also brings in the perspectives and goals of physical therapy.

I think there could be other examples, and that's implied in some of the material in the Panel report where there could be this joint work. It has been mentioned by one or two of the Panel speakers that there could be joint development of research training programs that would involve neurosciences and physical medicine or other aspects of rehabilitation medicine, involve physiology, involve other fields in which there would be the joint undergirding of research training.

It seems to me that we need to give some imaginative thought to how we can really move to get good research training, coupled with the goals of rehabilitation, into pre-doctoral and post-doctoral programs.

I hope that, in whatever ways we proceed with the overall results of this report, we can give some real emphasis to ways to promote the research training.

Thank you.