

### Rehabilitation medicine summit: Building research capacity—Executive Summary

The Summit was organized by the Foundation for Physical Medicine and Rehabilitation, the American Academy of Physical Medicine and Rehabilitation, the American Congress of Rehabilitation Medicine, and the Association of Academic Physiatrists.

No commercial party having a direct financial interest in the results of the research supporting this article has or will confer a benefit upon the authors or upon any organization with which the authors are associated.

#### Editor's Note

This article will be published almost simultaneously in the following journals: American Journal of Occupational Therapy; American Journal of Physical Medicine and Rehabilitation; American Journal of Speech-Language Pathology; Archives of Physical Medicine and Rehabilitation; Assistive Technology; Burn Care and Rehabilitation; Disability and Rehabilitation; Journal of Musculoskeletal Pain; Journal of NeuroEngineering and Rehabilitation (online); Journal of Rehabilitation Research and Development; Journal of Spinal Cord Medicine; Neurorehabilitation and Neural Repair; OTJR: Occupation, Participation, and Health; Physical Therapy; The Journal of Head Trauma and Rehabilitation; and Topics in Stroke Rehabilitation.

**Abstract**—The general objective of the “Rehabilitation Medicine Summit: Building Research Capacity” was to advance and promote research in medical rehabilitation by making recommendations to expand research capacity. The five elements of research capacity that guided the discussions were (1) researchers; (2) research culture, environment, and infrastructure; (3) funding; (4) partnerships; and (5) metrics. The 100 participants included representatives of professional organizations, consumer groups, academic departments, researchers, governmental funding agencies, and the private sector. The small group discussions and plenary sessions generated an array of problems, possible solutions, and recommended actions. A post-Summit, multi-organizational initiative is called to pursue the agendas outlined in this report.

#### INTRODUCTION

The advancement of medical science depends on the production, availability, and utilization of new information generated by research. A successful research enterprise depends on not only a carefully designed agenda that responds to clinical and societal needs but also the research capacity necessary to perform the work. Research that is likely to enhance clinical practice presupposes the existence of a critical mass of investigators working as teams in supportive environments. Unfortunately, far too little research capacity of that kind exists in rehabilitation medicine to ensure a robust future for the field. The “Rehabilitation Medicine Summit: Building Research Capacity” was conceptualized as a way of fashioning a long-term plan to foster the required developments.

#### OBJECTIVES

The general objective of the summit was to advance and promote research in medical rehabilitation by making recommendations to expand research capacity.

More specific objectives were to (1) bring together leaders in medical rehabilitation research to characterize current research capacity in the field and identify obstacles to expanding that capacity, (2) propose specific actions and mechanisms to enhance research and the development of capacity, (3) formulate an action agenda for use by stakeholders in medical rehabilitation to enhance existing research and training programs or to create new ones, and (4) stimulate federal agencies and foundations to support the needed elements of rehabilitation research and training. Although the purpose of the summit was not to discuss a specific research agenda, the above objectives were considered in the context of five research categories: (1) basic science, (2) clinical research (including clinical trials), (3) outcomes research, (4) health services research, and (5) engineering and technology development.

## RESEARCH CAPACITY: OPERATIONAL DEFINITION AND ELEMENTS

For the purpose of the discussions, building research capacity was defined as “a process of individual and institutional development which leads to higher levels of skills and greater ability to perform useful research” [1]. Five elements of research capacity were identified and used to guide the pre-Summit work and the Summit discussions. These included (1) researchers (their training, mentoring, recruitment, and retention; the value of a career in research and incentives for research); (2) research culture, environment, and infrastructure (academic institutions, the creation and maintenance of core facilities, the role of chairpersons and deans, collaborations, institutional research administration and social culture, and policies governing incentives and job security); (3) funding (sources, advocacy for changing policies, peer-review procedures, funding mechanisms, grantsmanship and fund-raising, timing of funding requests, and conflicts of interest); (4) partnerships with other disciplines and disability consumer groups (the purposes of these partnerships; choices of research topics, disciplines, and consumer groups; modes of participation; and potential conflicts of interest when partnering with industry); and (5) the metrics of research capacity (quality and quantity of the pool of available researchers, the productivity of their research and its impacts).

## METHODOLOGY

Several important activities took place before the Summit convened. The Program Committee had extensive discussions about existing research capacity. Key bibliographic references were identified on the topic of building research capacity and made available to all participants. A special article on the history of rehabilitation research was commissioned. Recognized experts were invited to write articles on each of the five elements of research capacity to serve as a basis for discussion during the Summit. These articles were peer-reviewed and five additional experts wrote detailed responses to them. The

Research Committee of the American Academy of Physical Medicine and Rehabilitation (AAPM&R) conducted a survey of researchers in the field to identify problems of research capacity and their potential solutions. Several funding agencies submitted reports of their efforts to build research capacity. Finally, participants were given access to a Web site where all key information was posted, including the articles mentioned previously.

The summit consisted of keynote lectures, paper presentations, and small-group working sessions that took place in Washington, DC, on April 28 and 29, 2005. Invited participants included leaders in the field, senior and junior researchers, department chairs, deans, research directors, professional organizations (12), government agencies (10), disability consumer groups (6), and multiple medical specialties (7). For the group discussions, the participants were divided into 10 small groups, 10 participants per group, making sure that different points of view were represented in each group. Each element of research capacity was discussed independently by two different groups that were charged with identifying problems, solutions, and recommended actions. Their reports were integrated prior to the Summit’s final session that was devoted to presenting the reports to the larger group and to discussing additional recommendations. The following sections summarize the groups’ conclusions with respect to each of the five elements of research capacity. A more detailed summary of the problems, solutions, and recommended actions identified by the five integrated groups is included in the **Table**.

## PROBLEM IDENTIFICATION

### Researchers

Capacity building requires the development of a pool of well-qualified researchers. To accomplish this task, issues such as training, mentoring, and placing new investigators must be addressed, as should other issues concerning the recruitment and retention of established investigators. The ideal trainee must have a strong commitment to inquiry and the desire and skill to collaborate with others.

**Rehabilitation Medicine Summit: Building Research Capacity**  
**April 28–29, 2005, Washington, DC**  
**Final Action Plan**

Research Capacity Element Group Leaders	Researchers	
Problem	Solution	Recommended Action
<p><b>1. Lack of definition of the domains of rehabilitation science.</b></p>	<p>1. Develop/evaluate proposed models of rehabilitation science (multidisciplinary, IOM, others).</p>	<p>1. Convene a group of “conceptualizers” with inclusion from various stakeholders to examine different models and relate the outcomes to research training models.</p> <p>2. Develop a white paper or report that lists potential successful models of rehabilitation science based on the outcomes of this meeting.</p> <p>3. Participate in a rehabilitation consortium that would address the definition of rehabilitation science, including research training issues and implications for the field.</p>
<p>2. Lack of exposure to rehabilitation and rehabilitation research and need to create a research environment aligning recruitment practices to address <b>insufficient number and quality of researchers.</b></p>	<p>1. Short-term undergraduate and graduate funding options such as summer programs for exposing nonrehabilitation researchers to rehabilitation research and rehabilitation scientists to new research trends.</p> <p>2. Extend research training duration under current training programs available by our current funding agencies.</p>	<p>1. Ask organizations to problem solve how to more effectively highlight research through plenary sessions and invitations to cutting-edge speakers.</p> <p>2. Encourage joint meetings on common scientific themes.</p> <p>3. Foster relationships with Schools of Public Health to expand training opportunities.</p> <p>4. Develop a “suite” of mechanisms for precandidates with potential to be trained in rehabilitation research to incorporate clinicians into research activities.</p>
<p><b>3. Lack of training funds.</b></p>	<p>1. Expand financial support for research training.</p>	<p>1. Advocate for funds for research training—this might be best achieved through a joint coalition with special attention to career development avenues.</p> <p>2. Expand the rehabilitation research networks approach for specific research training in specific scientific domains including specific laboratories and research environments.</p> <p>3. Explore private donor relationships to support trainees’ stipends.</p>
<p>4. Lack of available program <b>models fostering interdisciplinary collaboration.</b></p>	<p>1. Create venues for interdisciplinary collaborations across departments and universities.</p>	<p>1. Require that existing training grants (such as the NIH T32 and K12s) include a multidisciplinary training focus for research.</p>
<p><b>5. Lack of appropriate mentoring.</b></p>	<p>1. Create and develop guidance materials.</p> <p>2. Teach mentees how to select and use mentors.</p>	<p>1. Emphasize the scope of mentorship and develop guidance materials (career advisement, scientific, and professional).</p> <p>2. Identify models of mentoring from other specialties and organizations (Psychiatry, Geriatrics, Pediatrics, National Science Foundation Advance programs).</p>
<p>6. Lack of a standard <b>scientific training curriculum.</b></p>	<p>1. Develop standard protocols for research and a related curriculum for training in rehabilitation research.</p>	<p>1. Review current research training curriculum and ensure that it includes clinical trials training.</p> <p>2. Utilize the consortium mechanism to review curriculum approaches to ensure the scientific mission of our disciplines.</p>
<p>7. Lack of strategies for <b>retention</b> of vulnerable groups (women, minorities, consumers).</p>	<p>1. Gain a greater awareness of problems that impede retention (i.e., rules for promotion).</p>	<p>1. Establish a multidisciplinary task force to review these problems.</p>

**Table. (cont'd)**

8. Preparation of individual for her/his <b>role</b> (how to get researchers to be competitive).	1. Develop an adequate career path for retention of rehabilitation scientists.	1. Establish special interest groups (SIGs) related to developing materials and communicating strategies. 2. Develop joint appointments that promote career development.
9. Lack of <b>critical mass</b> of researchers.	1. Develop strategies for bringing together a critical mass of researchers in our field.	1. Support efforts to modify the way agencies list departmental and institutional funding so it will create incentives for collaborative research.

**Research Capacity Element Group Leaders**     **Research Environment, Infrastructure, and Culture**  
**Kenneth Ottenbacher, PhD, and Elliot Roth, MD**

<b>Problem</b>	<b>Solution</b>	<b>Recommended Action</b>
1. Lack of explicit <b>prioritization of research in mission statements.</b>	1. Incorporate research into mission statements of rehabilitation entities and revisit relative position of research as a component of the mission.	1. National organizations to revisit the position of research in their mission statements. 2. National organizations to develop sample mission statements for use by organizations and institutions.
2. Lack of <b>strategic planning</b> that supports collaborative and interdisciplinary research and is consistent with the resources and institutional culture.	1. Develop strategic plans for targeted research themes.	1. Professional organizations and individual institutions to develop strategic plans for targeted research areas and building coalitions. 2. Identify and disseminate examples of successful strategic plans.
3. <b>Beliefs, attitudes, and values</b> that do not support research.	1. Establish cross-discipline successful models.	1. Identify, utilize, and disseminate database of "research evangelists." 2. Develop database of successful researcher-clinician role models and successful research institutions. 3. Publicly recognize research success in organizations. 4. Develop cross-discipline articles and workshops on the topic of research culture to include in specialty journals and conferences.
4. Inadequate <b>incentives and rewards</b> for research.	1. Develop incentive and reward programs that incorporate research.	1. Develop and disseminate models for providing monetary and nonmonetary incentives. 2. Recognize institutions and organizations that have adopted successful models. 3. Establish research incentive consultation teams.
5. Lack of scientific <b>training, grantsmanship, and senior faculty</b> to serve as <b>role models.</b>	1. Increase training opportunities and number of senior investigators with successful research programs.	1. Increase career and faculty development programs (such as the NIH's K12, K30, K02, K05, and K07 type awards). Develop partnerships with other entities to fund such programs. Encourage development and expansion of fellowship programs for senior faculty (such as NIDRRs). 2. Encourage institutions to recognize mentoring as a faculty responsibility; provide credit and incentives in faculty evaluation process for successful mentoring. 3. Create task force to identify needs and existing research courses and workshops in the field. Identify most successful courses and sponsors. List courses and workshops on a Web site. Develop list of faculty willing to serve as mentors within their area of expertise. 4. Develop funding (internal and external) to provide extended research experiences in high priority (hot-topic) areas for students, residents, and fellows or for senior faculty who want to retool.

**Table. (cont'd)**

<p>6. Lack of <b>infrastructure</b> that supports collaborative and interdisciplinary research and is consistent with the resources and <b>institutional culture</b>.</p>	<p>1. Develop strategic plans to enhance local and national infrastructure.</p>	<p>1. Professional organizations and/or foundations to establish a consultation model/service to help new or small departments develop research programs. PM&amp;R Foundation to consider subsidizing consultation program. 2. Identify, develop and disseminate a database of successful models of organizational infrastructure including resources such as “toolkit” and Web-based resources.</p>
<p>7. Chairs and faculty leaders often lack <b>experience and skills in developing and maintaining successful research programs</b>.</p>	<p>1. Create and/or expand training programs for faculty leaders.</p>	<p>1. Professional organizations and foundations in rehabilitation should expand existing training programs for chairs and faculty to include more emphasis on research. 2. Identify and publicize existing training programs for chairs offered by research intensive universities (e.g., program at Harvard) and organizations (e.g., AAMC). 3. PM&amp;R Foundation develop program to subsidize faculty chairs attending leadership training programs. 4. Identify and disseminate existing and potential models of leadership that promote rehabilitation research. 5. Establish mentorship and coaching models to develop research leaders. 6. Create a research development consultation team.</p>
<p>8. Lack of <b>visibility and identity</b> limits opportunities for collaboration with potential academic and industry partners.</p>	<p>1. Enhance visibility and recognition in targeted arenas: academic, general public, industry, etc.</p>	<p>1. Expand existing marketing plans and efforts to highlight research as well as clinical contributions to society. 2. Invest in development of public relations program using professional consultants focused on current and potential future contributions of rehabilitation researchers in specific hot-topic targeted areas.</p>

<p><b>Research Capacity Element Group Leaders</b></p>	<p><b>Funding Leighton Chan, MD, MPH, and Pam Duncan, PhD</b></p>	
<p><b>Problem</b></p>	<p><b>Solution</b></p>	<p><b>Recommended Action</b></p>
<p>1. Lack of <b>advocacy</b> for research support.</p>	<p>1. Mobilize population(s) to advocate for rehabilitation research including people with disabilities.</p>	<p>1. Organize a summit for constituency organizations (for example, NMSS, AARP, and others) to join efforts and support rehabilitation research. 2. Form “Friends of Rehabilitation Research” campaign to highlight voters with disabilities living in your community. 3. Emphasize demographics of disability.</p>
<p>2. Lack of <b>rehabilitation penetration</b> in federal issues.</p>	<p>1. Implement scientific review panels with expertise and interest in rehabilitation. 2. Develop more research centers of excellence. 3. Become more influential and engage NIH networks. 4. Consider a non-NIH Federal Agency to consolidate federal disability organizations in the DHHS (including more support for rehabilitation research).</p>	<p>1. Request NIH-dedicated rehabilitation permanent scientific review panel. 2. Issue a request for applications (RFA) for additional “Interdisciplinary Research Centers of Excellence.” 3. Organize meetings of leaders of rehabilitation organizations (a coalition) with the Directors of NIH and other funding agencies. 4. Ask NIH to send out RFAs related to rehabilitation research across Institutes as a development tool for capacity of less experienced researchers. 5. Given disparity in federal funding agencies for disability, consider legal opinion to pursue Federal Government for Discrimination against People with Disabilities. 6. Develop a group of accomplished researchers (Speaker’s Bureau) who would be willing to speak to funding agencies as needed to discuss research funding, training, and over-riding issues.</p>

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<p>3. <b>Fragmentation</b> of rehabilitation organizations and <b>lack of coordination</b> among organizations (PM&amp;R, PT, OT, Neuroscience).</p>	<p>1. Consolidation of rehabilitation organizations to create a focused voice on rehabilitation research.</p>	<p>7. Move beyond NIH to develop a Disability Agency in DHHS (incorporates medical, social, transportation, and other issues).</p> <p>1. Get the AAPM&amp;R, AAP, and ACRM to develop a plan to coordinate the efforts of rehabilitation organizations.</p> <p>2. Create a united voice with participation of all organizations (PM&amp;R, Neuroscience, Allied Health Professions).</p>
<p>4. Lack of departmental <b>resources for infrastructure in local institutions and medical schools.</b> Recognition of financial resources rather than science.</p>	<p>1. Center grants for institutional infrastructure supporting rehabilitation research are needed.</p> <p>2. Obtain the support of the leadership, including Deans of professional schools.</p>	<p>1. Meet with AAMC representatives and leadership to advocate for encouragement, visibility, and funding in medical schools for rehabilitation research infrastructure.</p> <p>2. Consider new branding (hire professional consultants) of rehabilitation efforts to be more visible, consistent, and inclusive, and to emphasize research.</p>
<p>5. Quality of research and <b>competitiveness</b> of individual researcher. (Do we walk the walk to get funding?)</p>	<p>1. Local institution must value individual researcher to be competitive.</p> <p>2. Make resources available to develop quality grants.</p>	<p>1. Look within ourselves and accept responsibility to be more competitive researchers and seek collaboration across disciplines.</p> <p>2. Teach the art of networking outside of our own department and grantsmanship.</p> <p>3. Conduct mock study section reviews “in house” to refine grants.</p>
<p>6. We can <b>better identify other funding sources.</b></p>	<p>1. Identify other funding sources.</p>	<p>1. Foundation for PM&amp;R, AAP, AAPM&amp;R, ACRM, and other professional organizations to develop Web page listing of all possible resources (e.g., Paralyzed Veterans of America, National Stroke Association, foundations, and others).</p> <p>2. Develop case studies of rehabilitation researchers who have been successful in obtaining funding.</p> <p>3. Develop a portfolio of funding options.</p>

**Research Capacity Element Group Leaders Partnerships**  
**Rory Cooper, PhD, and John Kemp, JD**

Problem	Solution	Recommended Action
<p>1. <b>There are diverse stakeholders and a lack of a common framework.</b></p> <p>Lack of unified research vision among rehabilitation research partners. There needs to be a national agenda from “the field” on disability and rehabilitation policy. How do length of stay and rehabilitation outcomes affect the cost to the family, community, and society?</p>	<p>1. Try to bring together the federal agencies, state agencies, professional societies, consumer organizations, foundations, and research institutions. Develop effective partnerships with and among these organizations.</p> <p>2. Try to bring together the diverse professional societies to agree upon key issues and strategies for areas of common interest. (For example, those professional societies participating in this summit.)</p> <p>3. Form partnerships with different departments and professions. Incorporate industry as part of the partnership where sensible. Work with state organizations.</p>	<p>1. Form a “Rehabilitation Coalition” to speak with a common voice. This would likely have to be issue or project focused—for example, to promote research and capacity building. The American Institute of Medical and Biological Engineering (AIMBE) or ITEM Coalition may be models to consider.</p> <p>2. Create educational programs to inform the various stakeholders—professional organizations and consumers—and to seek their support for rehabilitation research and research policy.</p> <p>3. Create educational programs for consumers and nonrehabilitation professional groups about the benefits and positive outcomes of rehabilitation research. For example, increased risk of cardiovascular disease among people with spinal cord injury.</p> <p>4. Establish an annual forum.</p>

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	<p>4. Much larger group needs to demand funding. Only through partnering with consumers (disability organizations, individuals with disabilities, advocacy organizations) can there be a large and effective enough group to increase funding. Organizations of people with disabilities need to be brought together.</p> <p>5. Educate foundations and other organizations about disability and medical rehabilitation research.</p> <p>6. We need to form partnerships to educate the public and public officials to remove social stigma of disability and to understand the value of research.</p>	<p>5. Establish a national partnership body, composed of—</p> <ul style="list-style-type: none"> <li>• Government <ul style="list-style-type: none"> <li>– ICDR</li> <li>– Research regulation and reimbursement</li> </ul> </li> <li>• For-profit sector <ul style="list-style-type: none"> <li>– Venture capital</li> <li>– Pharma</li> <li>– Insurance</li> </ul> </li> <li>• Voluntary consumer organizations <ul style="list-style-type: none"> <li>– Health</li> <li>– Rehabilitation</li> </ul> </li> <li>• Professional organizations</li> <li>• Legislative organizations</li> <li>• Academic community</li> </ul>
<p><b>2. Inadequate full participation of consumers in research and development.</b></p>	<p>1. Include “Relevance to the Consumer Population” and “Significance to the Consumer” as part of the grant process in every funding agency.</p> <p>2. Include educated consumers in the peer-review process.</p> <p>3. Provide incentives to investigators to include people with disabilities.</p> <p>4. Greater communication with consumers needs to be established. We need to institutionalize consumer-driven research priorities, and we need to regularly and effectively communicate R&amp;D results to consumers.</p> <p>5. Partnering with groups that can provide necessary funds.</p> <p>6. Education of general public about the potential to ameliorate or live with a disability.</p>	<p>1. Develop training programs for people with disabilities (including family members) in order to promote meaningful participation in rehabilitation research.</p> <p>2. Expand scholarship opportunities within federal agencies and private foundations for people with disabilities.</p> <p>3. Create an awareness campaign so that consumers become knowledgeable about opportunities to contribute to research and development.</p> <p>4. Partner with consumer groups (AAPD, NCIL, etc.) and other health advocacy groups.</p> <p>5. Conduct research in public policy.</p> <p>6. Seek dedicated funding to enhance partnerships.</p> <p>7. Support a disability leadership summit on research.</p> <p>8. Train researchers and proposal writers how to tap into priorities and consumer expertise.</p> <p>9. Encourage PIs to implement participatory action research.</p>
<p><b>3. Lack of relationships with payers results in discrimination toward people with disabilities.</b></p>	<p>1. Partnerships with reimbursement organizations. (For example, to show that the 75% rule is flawed—there are cost implications and community participation issues. This dialog needs to be inclusive of more groups of people with disabilities.)</p>	<p>1. Have discussions with payers prior to the research projects.</p> <p>2. Request the IOM to look into the 75% rule and the “In the Home” rule again to prevent people from being shuffled off to nursing homes.</p>

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	2. Dialog with CMS and other healthcare providers about provisions of specific services for people with specific disabilities (“In the Home” rule).	3. Promote a “call for research” to determine the best “rehabilitation processes and structures” and the possible impacts of proposed policy changes. For example, what are the best combinations of rehabilitation services and settings to achieve optimal (acceptable) outcomes for people with various impairments?
<b>4. Lack of rehabilitation research capacity and rigor.</b>	<ol style="list-style-type: none"> <li>Partnering with other relevant disciplines (medical specialties, allied health professionals).</li> <li>Funded networks with adequate resources to conduct collaborative, rigorous research.</li> <li>Partnership with patients to create cohorts for long-term follow-up.</li> <li>Increasing rehabilitation exposure to medical students.</li> </ol>	<ol style="list-style-type: none"> <li>Leadership training for department chairs.</li> <li>Partner with institution to develop an infrastructure for rehabilitation research.</li> <li>Conduct research in the mechanisms by which treatments work—basic science.</li> <li>Special incentives for new investigators.</li> <li>Partnership with patients to create cohorts for long-term follow-up.</li> <li>Mentoring, developing a presentation to give to medical students to encourage rehabilitation research.</li> </ol>

**Research Capacity Element**    **Metrics**  
**Group Leaders**                **Marcus Fuhrer, PhD, and Alan Jette, PhD**

<b>Problem</b>	<b>Solution</b>	<b>Recommended Action</b>
1. Lack of a <b>consensual definition</b> of “research capacity.”	1. Define the construct by delineating its essential components, some attractive candidates being funding, qualified researchers, institutions, research training, research methods, an applicable knowledge base, an encompassing research agenda (including topics, their relative priority, and funding levels), knowledge translation activities, defined consumer demand and need, and political advocacy.	1. Submit the array of domains to an intensive review to ensure that it is reasonably comprehensive and free of redundancies.
2. Lack of <b>conventions for deciding on metrics and measures for many of the domains.</b>	1. Attain consensus on feasible ways to (a) quantify each domain and (b) characterize each domain’s quality of achievement. Then establish the psychometric properties of the key indicators, e.g., their validity, reliability, and sensitivity.	1. Devote the post-Summit, multiorganizational strategic planning effort in part to deciding how to implement the necessary empirical work, both the psychometric development of indicators and their application in a data gathering effort to characterize baseline research capacity.
3. Lack of a database describing <b>current research capacity as a baseline</b> for assessing future gains.	1. Create a database describing current research capacity as a baseline for assessing future gains.	1. Develop the database, drawing on the AAPM&R/RAAC Survey on Academic Leadership & Research Development, on behalf of either (a) a possible effort to coordinate federal agencies supporting rehabilitation research or (b) a consortium of rehabilitation-related voluntary organizations such as those represented at the summit.

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4. There may be <b>too many specific domains</b> , making it potentially unrealistic to capture them all in a database.	1. Organize the domains by identifying a subset of underlying ones.	1. We developed a Venn diagram comprised of three “super-domains” that relate directly to the four other focus-group topics (cf. PowerPoint slide).
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**Indicators of Research Capacity Building**

<b>1. Rehabilitation research trainees.</b>	<ol style="list-style-type: none"> <li>1. Number of funded postdoctoral positions available in rehabilitation (NIH, NIDRR, VA, CDC, AHRQ, and other national funding agencies) and the distribution of fellows across rehabilitation disciplines.</li> <li>2. Proportion of trainees who come through research training programs who become researchers: full, part-time, none.</li> <li>3. Average research products by research trainees in rehabilitation including citation of research products and extramural and intramural levels of funding.</li> </ol>	<ol style="list-style-type: none"> <li>1. Define who is considered a core rehabilitation professional.</li> <li>2. Explore and use, where possible, existing methodology.</li> <li>3. Enlist cooperation of funding agencies to collect and share this information.</li> </ol>
<b>2. Size of rehabilitation research cadre.</b>	<ol style="list-style-type: none"> <li>1. Track size of academic departments of PM&amp;R and beyond: number of fellows, openings, number filled.</li> <li>2. Measure amount of time rehabilitation professionals, broadly defined, spend in research: 50%+, part-time, none.</li> </ol>	<ol style="list-style-type: none"> <li>1. Enlist professional organizations to collect this information on a regular and standardized basis.</li> <li>2. Secure data from the AAP Annual Survey.</li> </ol>
<b>3. Productivity.</b>	<ol style="list-style-type: none"> <li>1. Measuring publications by rehabilitation professionals, broadly defined, and citations of published articles; extramural and intramural levels of research funding.</li> <li>2. Track levels of research designs published in rehabilitation literature.</li> </ol>	<ol style="list-style-type: none"> <li>1. Define the articles and journals relevant to include.</li> <li>2. Could search by professional organization membership, institutions, discipline, and country.</li> <li>3. Enlist professional organizations to collect this information on a regular and standardized basis.</li> <li>4. Explore and use, where possible, existing methodology.</li> </ol>
<b>4. Funding.</b>	<ol style="list-style-type: none"> <li>1. Track federal agency expenditures on rehabilitation research by specific content areas.</li> </ol>	<ol style="list-style-type: none"> <li>1. Enlist friends of rehabilitation to identify agency contact points to secure these data on an annual basis.</li> </ol>

Note: IOM = Institute of Medicine, NIH = National Institutes of Health, NIDRR = National Institute on Disability and Rehabilitation Research, PM&R = Physical Medicine and Rehabilitation, AAMC = Association of American Medical Colleges, NMSS = National Multiple Sclerosis Society, AARP = American Association of Retired Persons, AAPM&R = American Academy of Physical Medicine and Rehabilitation, AAP = Association of Academic Physiatrists, ACRM = American Congress of Rehabilitation Medicine, ICDR = Interagency Committee on Disability Research, AAPD = American Association of People with Disabilities, NCIL = National Council on Independent Living, DHHS = Department of Health and Human Services, PIs = Principal Investigators, CMS = Centers for Medicare and Medicaid Services, RAAC = Research Advisory and Advocacy Committee, VA = Department of Veterans Affairs, CDC = Centers for Disease Control and Prevention, AHRQ = Agency for Health Care Research and Quality.

Defining the domain of medical rehabilitation research was singled out as being a paramount requirement for expanding research capacity. The field is inclusive by nature because it receives contributions from the physical, biological, psychological, engineering, and social sciences; hence, the difficulty in delineating it. This predicament is reflected in the different conceptual models that are frequently invoked in discussing the field, including the Institute of Medicine's Enabling-Disabling [2] model and the World Health Organization's International Classification of Functioning, Disability and Health [3].

Difficulties in developing, promoting, and retaining greater numbers of skilled rehabilitation researchers were highlighted as well. Far too few programs exist that provide optimal training in medical rehabilitation research. Reasons for the dearth of training opportunities include a lack of training funds from government agencies and private institutions, a paucity of program models for fostering interdisciplinary collaboration, a lack of appropriate mentoring coupled with standardized training curricula for preparing individuals to be competitive as researchers, and inadequate attention to promoting the retention of minorities, women, and individuals with disabilities.

### **Research Environment, Infrastructure, and Culture**

Research environment, infrastructure, and culture represent a matrix of complex factors essential for excellence in generating medical rehabilitation research, training, recruiting researchers, and conducting research involving people with disabilities.

A major problem is the lack of recognition of research and scientific discovery as an institutional, organizational, and professional core value. In too many instances, scientific discovery is not an explicit priority in the vision and mission statements of clinical and professional organizations with national memberships. Consequently, the strategic plans of these organizations do not promote collaborative or interdisciplinary research, and they are not expressly supportive of the necessary investments in scientific training, the development of grant-writing skills, and the mentoring of promising

research faculty. The human and physical resources to accomplish these tasks are unavailable in many academic rehabilitation environments. Mechanisms to recognize research productivity in formal and informal evaluation and reward systems are frequently lacking as well.

### **Funding**

Significant funding must be specifically assigned to building research capacity. However, the current economic environment is likely to result in flat or even reduced funding for medical rehabilitation research, at least in the near future. This unfortunate financial picture exists at a time of increasing need associated with the growing number of individuals with disabilities, and of unparalleled opportunities to improve their lives by means of new knowledge generated by research.

The biggest problem is lack of a coherent strategy for advocating the needed research support. Stakeholders in medical rehabilitation research are fractionated in their efforts to obtain larger expenditures. The austerity of the current funding environment underscores the importance of organizations bringing their advocacy efforts together under common goals.

The problem of generating adequate funding for medical rehabilitation research exists at three levels. At the federal level, the field lacks visibility as being a worthy object of support when strategic funding decisions are made. At the local level, only a handful of academic programs have the research infrastructure required to produce successful research, and very few new programs have been developed in the past decade. This partially reflects the fact that many academic medical centers invest most of their resources in expanding the ability of their extant programs to generate research funds, rather than in developing promising new programs such as ones in medical rehabilitation. Finally, at the level of individual researchers, proposed research too frequently lacks the quality to merit being funded. Additionally, some researchers fail to take advantage of existing opportunities for funding, simply because they do not know of their existence.

## Partnerships

Partnerships with scientists in other disciplines, academic departments, and institutions, and with consumers with disabilities, among others, are vital to enhancing the capacity for conducting high-quality, meaningful research. Several factors have limited the development of those partnerships. Because of the diversity of stakeholders and stakeholder objectives, a common framework has been lacking upon which to build funding, policy, programmatic, and marketing messages regarding research. Nor have consistent efforts been made to ensure the meaningful participation of individuals with disabilities in the research process.

## Metrics

Concerted efforts to enlarge the capacity of medical rehabilitation research must be complemented by an ability to assess that capacity over time in order to gauge progress. No constitutive definition of research capacity appears to have won broad endorsement in the health sciences literature, and little guidance exists for deciding on the metrics and measures for its principal domains. Notwithstanding the lack of precedence, the meaning of medical rehabilitation research capacity must be understood with precision if that capacity is to be rigorously and comprehensively assessed.

## SOLUTIONS AND RECOMMENDED ACTIONS

Although each group worked independently on its assigned problems, many of the solutions and recommended actions they identified were quite similar. This section integrates the solutions and recommended actions.

### Coalition

Several discussion groups suggested the formation of a coalition of professional groups and consumer organizations. This coalition would create a national agenda addressing the issues of funding, capacity-building needs, and public education and

awareness. It would develop specific objectives and action plans regarding (1) funding targets for research and research training, (2) needed changes in funding agencies' policies and practices, and (3) initiatives to educate the public about the importance and societal benefits of rehabilitation research, and it would coordinate efforts to address those issues.

### Training

A high-priority area is the training of new investigators. To accomplish this goal, training curricula need to be created, and funding needs to be expanded for rehabilitation research training programs across disciplines and at multiple levels, including undergraduate students, students in professional training program, faculty, and department chairs. Special efforts should be made to recruit and train women, students with disabilities, and minorities.

### Career Paths

Researchers need support at different stages in their careers. Current funding sources fail to provide the needed continuity of support as their careers evolve. To foster researchers' development and their retention in the field, funding opportunities must be increased for predoctoral students, postdoctoral fellows, junior faculty, and established faculty transitioning into new investigative areas.

### Partnerships to Conduct Research

To assure its scientific importance and clinical relevance, rehabilitation research requires both interdisciplinary and multistakeholder partnerships. Collaborations among researchers of different scientific and professional disciplines need to be promoted and cultivated. The required initiatives must come from individual researchers as well as from professional organizations that encourage joint scientific meetings and discussions of interdisciplinary research issues. Partnerships are vital, too, to assure that rehabilitation research is informed by the perspectives of its intended beneficiaries—individuals with disabilities, their family members, and rehabilitation practitioners. Principal investigators should implement Participatory Action Research, making it

an integral part of medical rehabilitation and disability research. Greater emphasis should be placed as well on providing people with disabilities with the training and support necessary for them to assume leadership roles in rehabilitation research.

### **Infrastructure**

Currently, only a handful of departments or centers have the research personnel, equipment, space, and support staff that constitute a strong infrastructure for medical rehabilitation research. Many more such programs must be established before the aggregate research capacity is commensurate with existing knowledge needs. Inevitably, that will require host institutions to invest in establishing new rehabilitation research programs or in strengthening ongoing ones. A growth strategy should be pursued concurrently with building intrainstitutional partnerships that facilitate access to the infrastructure available to colleagues in other scientific and professional disciplines.

### **Message to Funding Agencies**

Funding agencies do not assign sufficiently high priority to medical rehabilitation research. Within the National Institutes of Health, this can be rectified by establishing an independent institute dedicated to rehabilitation research. Actions are needed as well to expand the participation of rehabilitation scientists in scientific review panels, and to generate more requests for applications that focus on interdisciplinary rehabilitation research. A farther-reaching possibility is creation of an independent agency for disability issues within the Department of Health and Human Services. Advocacy directed at federal agencies must be complemented by initiatives aimed at increasing support from private-sector sources such as third-party payers.

### **Rehabilitation Science Model**

It is generally accepted that the field lacks a unified scientific model. A consortium of experienced researchers should be created to develop this model and to define the domains and boundaries of rehabilitation research.

### **Mission Statements and Strategic Plans**

Scientific discovery is not always recognized as an institutional or organizational core value. Professional organizations should include research as an important component of their mission statements. This should be reflected in their strategic plans and used as a means to promote interdisciplinary and collaborative research.

### **METRICS**

Both long-term and short-term perspectives are called for to meet the challenges of assessing medical rehabilitation research capacity. The long-term perspective highlights the definitional and operational challenges that must be addressed eventually if that capacity is to be rigorously conceptualized and comprehensively assessed. The short-term outlook emphasizes that some information gathering can and should begin immediately in the following four areas.

#### **Rehabilitation Research Trainees**

Information to be tracked includes the number of funded postdoctoral positions available in rehabilitation and the distribution of fellows across rehabilitation disciplines; the proportion of trainees who come through research training programs and who become researchers—full, part-time, or none; and the research products that the trainees generate, as well as their extramural and intramural levels of funding. Possible action steps include defining who is considered as a core rehabilitation professional, exploring and using existing methodology where possible, and enlisting the cooperation of funding agencies to collect and share this information.

#### **Size of the Rehabilitation Research Cadre**

Information to be tracked includes the size of academic departments relevant to medical rehabilitation (e.g., number of research fellows, filled and unfilled faculty positions), and the amount of time rehabilitation professionals, broadly defined, spend in research (e.g., half-time or more, part-time, or

none). Professional organizations should be enlisted to collect this information on a regular and standardized basis.

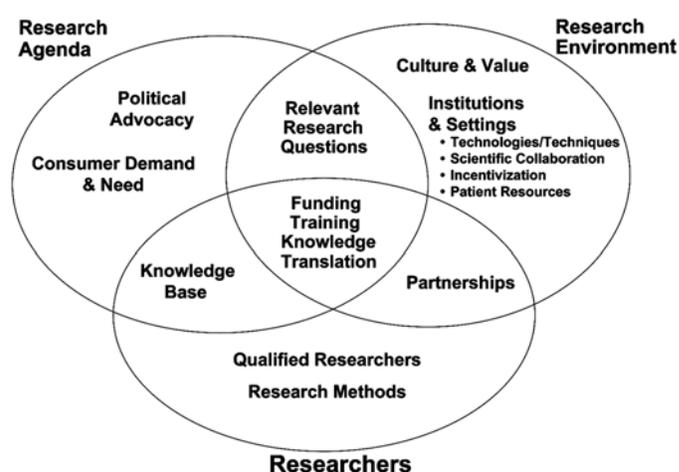
## Productivity

The information to be monitored includes citations of published articles, extramural and intramural levels of research funding, and the types of research designs appearing in the rehabilitation literature. Action steps include specifying the kinds of articles and the journals to include and searching by professional organization memberships, institutions, or disciplines or countries. Professional organizations should be enlisted to collect this information on a regular and standardized basis, using existing methodology where possible.

## Federal Agency Expenditures on Rehabilitation Research

Expenditures allocated to rehabilitation research in specific content areas should be monitored. A recommended action step is to identify agency contact points to secure these data on an annual basis.

The longer-term challenge is to develop a consensually acceptable definition of medical rehabilitation capacity and then to operationalize each of its key components. Domains that are likely to be encompassed in that definition include *funding*, *qualified researchers*, *institutions*, *research training*, *research methods*, *an applicable knowledge base*, *an encompassing research agenda* (including topics, their relative priority, and funding levels), *knowledge translation activities*, *defined consumer demand and need*, and *political advocacy*. The **Figure** is an attempt to organize those domains within a coherent framework. Each domain is assigned to one of three categories—the Research Agenda, Research Environment, or Researchers—or to the conjunction of two of these groups. Steps should be taken to refine that schematization, along with the separate domains comprising it. Additionally, feasible means must be identified to (1) quantify each domain and (2) characterize its quality of achievement (against some standard or norm). It will be necessary, then, to



**Figure.**

Taxonomy of research capacity as a guide for knowing what to measure.

establish the psychometric properties of the key indicators, e.g., their validity, reliability, and sensitivity.

A post-Summit, multiorganizational initiative is called for to pursue the agendas outlined above. Data-gathering efforts should be launched as soon as possible to characterize current research capacity as a baseline for assessing possible future gains. Those efforts should draw on findings of the Survey on Academic Leadership and Research Development conducted by the Research Advisory and Advocacy Committee of the AAPM&R, and be implemented by either (1) an ensemble of federal agencies supporting rehabilitation research or (2) a consortium of rehabilitation-related voluntary organizations such as those represented at the Summit.

## REFERENCES

1. Trostle J. Research capacity building in international health: Definitions, evaluations, and strategies for success. *Soc Sci Med*. 1992;35(11):1321–24.
2. Brandt E, Pope A. *Enabling America: Assessing the role of rehabilitation science and engineering*. Washington (DC): National Academy Press; 1997.
3. World Health Organization. *International classification of functioning, disability and health: ICF*. Geneva (Switzerland): World Health Organization; 2001.

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DOI: 10.1682/JRRD.2005.12.0179