

**The Interagency Committee on Disability Research  
Interagency Subcommittee on Medical Rehabilitation**



**A Research Agenda for Getting Beyond the Plateau:  
Promoting Recovery through the Chronic Phase**

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Promoting Recovery through the Chronic Phase  
Interagency Committee on Disability Research  
Interagency Subcommittee on Medical Rehabilitation  
March 6–7, 2007  
Executive Summary**

The National Center for Medical Rehabilitation Research (NCMRR) and the Interagency Committee on Disability Research (ICDR) Subcommittee on Medical Rehabilitation (ISMR) jointly sponsored a two-day workshop bringing together 11 distinguished experts in the field of rehabilitation medicine to develop a strategy and a possible research agenda for moving beyond the plateau after the acute phase of recovery from a traumatic injury or stroke to promote recovery in the months and years that follow.

Currently, biomedical research and health services are largely focused on promoting recovery in the early stage of injury. There is increasing evidence, however, that significant functional recovery and treatment opportunities can occur in the months or years that follow, provided that appropriate strategies are used to promote activity, adaptation, and participation. There also appears to be increased potential for functional recovery in developmental or degenerative conditions.

This workshop evaluated physiological, behavioral and psychosocial approaches to promote functional recovery and participation in the chronic phase. The idea that a “plateau” exists may well be a fallacy, according to researchers, as recovery is not a linear process, but rather a continuous effort to manage an uneven trajectory, which is complicated and challenged by episodes of disability, secondary conditions, and relapse. The participants, who included officials from the Centers for Medicare and Medicaid Services (CMS), discussed therapeutic strategies, appropriate outcome measures, environmental supports/barriers, health service constraints, and possible changes in reimbursement criteria to support extended rehabilitation services.

Formal presentations on the first day addressed the physiological, behavioral, and psychosocial substrates that may interact with therapeutic strategies, environmental factors, outcome measures and health service contracts to promote functional recovery. The specific topics are listed below:

- Understanding the Neurological and Musculoskeletal Substrates of Recovery
- Clinical Issues of Therapy in the Acute Phase
- Promoting Cognitive and Behavioral Rehabilitation
- Assessing Outcomes
- Cardiovascular Fitness and Health
- Environmental Factors and Trajectories of Recovery
- Community Support and Health Promotion
- Community Neurorehabilitation: Developing a social-ecological approach

- Preventing Secondary Conditions
- Health Policy Perspective
- The CMS Perspectives

The presentations on the first day and the subsequent discussion on the second day supported recovery in a community environment after discharge from an acute-care rehabilitative setting. This phase of recovery requires breaking new ground in research and developing collaborative efforts to demonstrate cost effectiveness that will promote long-term reform of the payment system so that reimbursement for rehabilitation can be made in the later stages of recovery.

Highlights of the discussion included cultivating a cooperative effort between CMS and government organizations, such as the National Institutes of Health (NIH), to work in partnership to develop a national restructuring of the Medicare payment system that would include post-acute and chronic care maintenance reimbursement. CMS currently reimburses different amounts based on the setting (e.g., nursing homes, in-patient rehab, outpatient programs) and not on the services rendered. While this CMS five-year plan is in the development stages, feedback and outcomes data from researchers relevant to payment restructuring should be considered for incremental changes to make current programs more responsive.

One's ability to recover is not only affected by the severity of the injury, but also by the external environment and available resources. The workshop explored cognitive and behavioral deficits, which can impact the delivery of therapeutic interventions and the individual's participation; the lack of provision for cardiovascular fitness and health in conventional care, which does not exploit the time window or capacity for plasticity; and secondary conditions and functional limitations, which can be brought on by inactivity post-stroke.

A goal of the workshop was to develop a community-based research model to better evaluate the potential for the person with a disability returning to the community to live in a social context. The community has the responsibility to transition that person after acute rehabilitation to become an asset rather than a liability. A roadmap or conceptual model would help to determine the research needed to help people re-enter their environment. While recovery and rehabilitation will be ongoing in the sub-acute or chronic phases, there are huge gaps in evidence-based findings indicating how effective therapeutic interventions are across settings. A health care model must also consider secondary conditions and the impact of the aging process. International models that have been executed in Italy and Scandinavia may guide this process.

Given Medicare's focus on maximizing a person's potential, measurements must consider functional independence and quality of life (QoL). With reimbursement presently front-loaded, there are not payment systems in place to enhance health and decrease other co-morbidities. A standard of practice with rules as to what is considered therapeutic exercise and how that should be reimbursed in particular settings is crucial. In addition, there is a need to understand the psychosocial, physical and community barriers as well as the behavioral factors that influence aging with a disability. This will influence practical implementation.

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**Introduction**

The National Center for Medical Rehabilitation Research (NCMRR) and the Interagency Committee on Disability Research (ICDR) Subcommittee on Medical Rehabilitation (ISMR) jointly sponsored a two-day workshop bringing together 11 distinguished experts in the field of rehabilitation medicine to develop a strategy and a possible research agenda for moving beyond the plateau after the acute phase of recovery from a traumatic injury or stroke to promote recovery in the months and years that follow.

The meeting was inspired by Ralph Nitkin, Program Director for Biological Sciences and Career Development at NCMRR. Currently, biomedical research and health services are largely focused on promoting recovery in the early stage of injury. There is increasing evidence, however, that significant functional recovery and treatment opportunities can occur in the months or years that follow, provided that appropriate strategies are used to promote activity, adaptation, and participation. There also appears to be increased potential for functional recovery in developmental or degenerative conditions.

This workshop evaluated physiological, behavioral and psychosocial approaches to promote functional recovery and participation in the chronic phase. The idea that a “plateau” exists may well be a fallacy, according to researchers, as recovery is not a linear process, but rather a continuous effort to manage an uneven trajectory, which is complicated and challenged by episodes of disability, secondary conditions, and relapse. The participants, who included officials from the Centers for Medicare and Medicaid Services (CMS), discussed therapeutic strategies, appropriate outcome measures, environmental supports/barriers, health service constraints and possible changes in reimbursement criteria to support extended rehabilitation services.

Nitkin’s charge to the group was to collect ideas and themes from the formal presentations, then return on the second day with ideas for supporting recovery in a community environment after discharge from a rehabilitative setting. This phase of recovery requires breaking new ground in research and developing collaborative efforts to demonstrate cost-effectiveness. Nitkin specified that goals for the meeting included assisting NCMRR (and other NIH Institutes) in developing new initiatives for rehabilitation research and to help other agencies in establishing significant and beneficial policies in rehabilitation.

The formal presentations on the first day brought forth some of the physiological, behavioral, and psychosocial substrates that may interact with therapeutic strategies, environmental factors, outcome measures, and health service contracts to promote functional recovery. (Note: The PowerPoint presentations are included in an addendum to this summary.)

## **Understanding the Neurological and Musculoskeletal Substrates of Recovery**

### **William Zev Rymer**

An important point Rymer raised during his presentation was that many mechanisms in the acute phase of recovery, especially in reference to stroke, carry potential secrets for long-term recovery.

#### **What is meant by plateau?**

According to Kreisel et al. in “Pathophysiology of Stroke Rehabilitation,” a plateau is a pattern that is often seen independent of initial severity. A severe impairment improves over time showing a plateau around the 4–6 week mark. Many believe that some continuous improvement may happen spontaneously, though it will most certainly occur with interventions. For someone with a severe impairment, improvement is substantially greater relative to a person with a mild or moderate impairment.

Understanding the neuron is crucial to the issue of long-term recovery. In neurological conditions such as stroke, data indicate that the cellular environment is far from one of just death and destruction, but rather involves an evolving process of neuronal regeneration characterized by waves of cellular and molecular events. Manipulating these waves of regeneration may provide for novel therapies that will encourage long-term intervention and improve recovery after stroke. (Ann Neurol 2006; Carmichael et al. 59:735–742). The genetics of recovery and the chain of cellular and molecular events triggering cell sequences are crucial in developing therapies for recovery and a time course for long-term interventions.

## **Clinical Issues of Therapy in the Acute Phase**

### **John Chae**

#### **Levels of Care, Goals, Focus**

The goal of the acute phase of care is to preserve life and achieve medical stability to enter a rehabilitation facility. Long-term acute care (25 days or more) achieves medical stability for discharge to acute/skilled nursing rehabilitation or home. The goal for these two levels of care is to stabilize and mitigate pathophysiology and medical sequelae, with a focus on basic activities for daily living (ADLS). The goal for short-term outpatient care is functional recovery for community re-integration with a focus on instrumental ADLS. The goal for long-term outpatient care is vocational re-integration with a focus on societal participation.

Recovery is not only influenced by the injury itself, but also by the external environment and available resources. Therapeutic options face the reality of medical economics, which has implications for the acute and chronic phases of recovery. The care and reimbursement available after the 3–6 month acute care window must be further assessed.

## **Promoting Cognitive and Behavioral Rehabilitation**

**John Whyte**

Cognitive and behavioral deficits can impact the delivery of therapeutic interventions and the individual's participation in the therapeutic process. Therefore it is necessary for the treatment to allow for alternative means of accomplishing tasks. In considering how rehabilitation occurs, it is necessary to consider whether there is a time window constraint for the reestablishment of synaptic connections; whether plasticity might be greater earlier than later; and whether it is practical to use an alternative cognitive process or compensatory strategy.

One problem that rehabilitation medicine specialists face is a weak understanding of treatment mechanisms they are advocating and not knowing whether these mechanisms promote skill acquisition or other positive outcomes. The post-acute patient environment is not necessarily conducive to conducting treatment research due to numerous practical considerations.

## **Assessing Outcomes**

**Steve Wolf**

Assessing progress and functional recovery from a stroke or other neurological event involves evaluating statistical versus clinical meaningfulness; measuring the impact of progress as viewed by patients, clinicians, and third-party payers; and understanding confounding variables.

This presentation addresses the concept of patient-oriented outcomes by relating functional changes to patient-centered outcomes in a predictive mode. Consideration also must also be given to the cost of treatments.

In determining future outcomes and weighing the numbers, the following must be considered: (1) *cost numbers*: cost to produce a percent change in a patient; (2) *number needed to treat*: How many need to be treated for one patient to "benefit" (100/absolute risk reduction) where absolute risk reduction = difference in event rates; and (3) *Absolute Benefit Increase (ABI)*: Proportion of participants who experience: Beneficial "Favorable" Outcome in Control (Alternative Treatment) Group, minus Beneficial "Favorable" Outcome in Intervention Group.

Additional questions to determine future outcomes:

- Can/should this concept be employed in chronic stage rehabilitation studies?
- Can/should there be **uniform** "codes of conduct" (expectations from applications)?
- Can there be uniformity based upon the nature of the outcome measure (e.g., impairment, activity, or participatory) – are levels of magnitude of minimally clinical important differences (MCIDs) domain specific?

The mission is to determine ways to provide a knowledge base for future applications and the notion of impairment in future research designs.

## **Cardiovascular Fitness and Health**

### **Rich Macko**

Two reasons for a plateau in mobility recovery after stroke are: (1) poor cardiovascular fitness and metabolic health limit recovery post-stroke; and (2) conventional care, which does not fully exploit the time window or capacity for plasticity.

Two questions that must be answered in determining the feasibility of cardiovascular (CV) fitness training are: (1) Is task-repetition adequate to stimulate locomotor learning? (2) Do provisions exist for community outreach of exercise programs across the phases of stroke recovery?

#### I. Biological rationale – Exercise in chronic stroke

MODEL = MOTOR LEARNING + EXERCISE

#### II. RCT Maryland: Treadmill aerobic exercise

- Improves fitness & metabolic health
- Improves walking function – brain plasticity

#### III. Controlled Community-Based Study: Adaptive Physical Activity (APA) in Tuscany

- Improves walking, balance, basic ADL function
- Reverses declines that accompany aging with stroke

Treadmill aerobic exercise training can progressively control exercise training. The study indicated that when walking on the ground versus walking on a treadmill, there is a 5% improvement in stance, stride to stride, and gait pattern.

### **Summary**

1. Treadmill exercise improves CV metabolic health and walking function for individuals with chronic hypertensive stroke.
2. A community APA improves function and reduces disability, reversing declines that accompany aging with stroke.

#### Future – Getting beyond the Plateau

- Mechanisms – Multiple physiologic systems
- Fitness/Muscle/Metabolism/Central Nervous System
- Define optimal dose-intensity
- Community translation – barriers, behavioral, social network

## **Community Support and Health Promotion**

### **Jim Rimmer**

Physical inactivity leads to an onset of secondary conditions and functional limitations creating a vicious cycle. Post-rehabilitation physical activity has been shown to reverse this cycle. The social component of community exercise is an important part of a person's day; it reduces social isolation and increases social ties. At the population level, epidemiological studies have shown that social isolation is a major risk factor for morbidity and mortality from widely varying causes (Seeman et al. 1993).

While there are barriers to community participation, including transportation issues and lack of an accessible facility, the challenge ahead is addressing these barriers and closing the gap between acute rehabilitation and community exercise. Further obstacles include a population whose physical activity is significantly lower than in the past partly due to technology and "convenience" items that reduce energy expenditure in instrumental activities of daily living (IADL) and activities of daily living (ADL).

### **Future research directions**

1. Access
  - Computerized Adaptive Testing (CAT)-based assessment instruments
  - Online assessment applications and reports
2. Participation
  - Continued development of immersive, engaging, interactive virtual exercise environments (VEEs)
  - User-specific auto-configuration of cardiovascular exercise equipment
  - Continued development of tele-exercise
3. Adherence
  - Virtual social support systems including co-location and exercise "buddies"
  - Virtual online competition
  - Intrinsic activity gaming and massively multiplayer online games (MMOG)
4. Physiological and psychological benefit
  - Activity monitor(s) for people with disabilities
  - Energy expenditure equivalency tables for functional levels

### **Future questions**

1. Can we extend the recovery phase through targeted community-based exercise interventions?
2. What are the dose-response effects of exercise?
3. How can we become more consumer-focused in the transition from rehabilitation to community participation?
4. What are the mediating/moderating effects of personal ties on mental and physical recovery?
5. How can we build stronger social relationships in acute rehabilitation that transition into the community?
6. Should reimbursement include incentives for successful transition into community exercise programs?

## **Community Neurorehabilitation: Developing a social-ecological approach**

### **Sarah Chard**

The key theme of this presentation was social support through a **social-ecological approach** to health (social, political, economic). This model for community neurorehabilitation includes interpersonal/intrapersonal variables.

Community neurorehabilitation is defined as specialized, multidisciplinary, neurological rehabilitation with individuals living in their home community and not individuals in acute care or rehabilitation institutions. This program is a mechanism for systematic rehabilitation post-discharge or for those not requiring hospitalization; allows for earlier, coordinated inpatient discharge; and/or provides maintenance rehabilitation for individuals with chronic, progressive disorders.

Social-ecology of Neurorehabilitation Program:

- Intrapersonal variables: Self-efficacy beliefs, which are associated with higher levels of physical activity
- Interpersonal factors: Social support – associated with mental and physical health outcomes
  - ICF-participation variables (Jette 2005)
  - Physical activity among older adults and individuals with chronic illness
- Institutional factors: Neurorehabilitation structure and process
- Community factors: Relationship between primary care and rehabilitation intervention
- Public policy: Insurance, state, and federal policies

The ecological perspective helps establish the multiple variables influencing rehabilitation participation. Further research is needed on the relationships between rehabilitation and interpersonal (self-efficacy) and intrapersonal (social support) variables. Qualitative research methods may provide additional insight into the factors influencing participation and the impact of interventions.

## **Preventing Secondary Conditions**

### **Alan Jette**

A secondary condition is “any additional physical or mental health condition that occurs as a result of having a primary disabling condition” (Pope & Tarlov, 1991).

Common key factors:

- Has a causal relationship to the primary condition;
- May be preventable;
- May vary in its expression and timing of its expression;
- May be modified; and
- May increase the severity of the primary condition

(Turk, IOM Workshop, 2005).

Examples of secondary conditions are pain, edema, pressure ulcers, obesity, and depression.

Associated conditions are aspects or features of the primary condition itself and are expected elements of the primary pathology, although their expression may be variable (e.g., limited skin sensation associated with spinal cord injury).

Promoting the recovery process through the chronic phase means the prevention of disability on three levels:

- **Primary:** Avert onset of disease
- **Secondary:** Early disease detection and management
- **Tertiary:** Avert secondary conditions, avert death, restore and maintain function

Telemedicine is now being used to prevent secondary conditions and for chronic ongoing management of people with disabling conditions. Based on randomized clinical trials, Telephone-Linked Communication systems (TLC) improve outcomes of patients with chronic disease, may reduce preventable hospitalizations and avoidable health care expenditures, and are widely accepted by patients from diverse racial and socio-economic backgrounds.

If found to be efficacious, TLC:

- Has promise as an innovative approach to reducing the incidence and severity of secondary conditions;
- Is low risk, feasible, and inexpensive to use;
- Could be widely disseminated; and
- Facilitates long-term monitoring and promotes patient self-management.

## **Health Policy Perspective**

### **Mary Stuart**

In the next 20-plus years, the elderly population is projected to double, with 80% of seniors having at least one chronic disease, and 50% having at least two. It is estimated that 78% of health expenditures are devoted to chronic conditions. Will the policy perspective reduce costs and improve outcomes? If so, in what timeframe will it occur and for which population?

Stewart's perspective as the Director of Medicare/Medicaid Policy for the State of Maryland is that we need to move beyond the medical model to prevent and manage chronic disease. Presently, 10% of Medicaid patients account for 75% of costs. With a grant from the Robert Wood Johnson Foundation, Stewart has been reviewing medical records to look at best practices for systems of care.

International models:

- Denmark—Home and Community Services – Skaevinge – exercise and social support – sophisticated support in rural area

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- France—Regional systems for congestive obstructive pulmonary disease (COPD) – Lyon
- Italy—Adaptive Physical Activity (APA) Program – Empoli – new evolving model, possible to observe process of social and organizational change
  - Chronic disease management system, home care, social integration, chronic rehabilitation/exercise.
  - Designed for specific alterations of health status for the secondary or tertiary prevention of disability.
  - Program is a public/private partnership with linkages to the medical community. Gyms have been signing on steadily to offer APA classes for back pain, stroke, Parkinson's, and lower limb disabilities. Instructors are trained by physical therapists.

Preliminary results show improvements for stroke APA in function, walking, and depression. For back pain, APA programs reduce the pain and improve bone mineral density and health status. It appears to be feasible and safe as implemented in Empoli. This includes:

- Referral by general practitioners (GP)
- Coordination by a health authority
- Instructors who are trained and monitored
- Follow-up survey

#### **Lessons learned:**

- GP is key
- Access/short travel
- Gyms are willing to offer APA classes in off hours
- Politically popular program with the elderly
- Tensions over professional roles
- Pilot data is promising
- Quasi-experimental design
- Action research generates political support
- How to translate to US

The challenge is to now look at chronic diseases and the potential for therapeutic exercise to improve health models in a number of domains. Factors that contribute to initiating and continuing exercise are: self-efficacy, social support, stigma, satisfaction, and access (financial, geographic, transportation, and handicap access).

#### **CMS Perspectives**

##### **Sheila Lambowitz**

CMS is struggling with the issue of placement after the acute setting. They are asking whether placement and different treatment settings produce differential outcomes. They are presently working on a reform initiative that will track sites to help determine the placement necessary to get the best outcomes.

The present Medicare benefit structure was created at a time when there wasn't much need for rehabilitation since the mortality rate was high. After the acute and chronic phase of rehabilitation, reimbursement becomes a private insurer model.

In 1983, the average length of a hospital stay was based on certain conditions that ensured maintaining profitability. They identified 13 conditions with the cost reimbursed under a cap and it remained small. In the 1990s, a payment system was developed that paid substantially more than Diagnosis-Related Groups (DRGs) paid for in-hospitalization.

In the new payment system, expenditure levels are significantly increasing, with a lot of facilities moving toward a restorative model – pain management, cardiac rehabilitation, improved conditioning – regardless of the diagnosis. The 13 criteria from 1983 are now obsolete.

CMS currently reimburses different amounts for nursing homes, in-patient rehabilitation, and outpatient programs. They are now at a crossroads in reference to providing the needed care, but paying on the basis of the setting and not the service needed. They are hopeful that research can help in providing accurate placement.

The Integrated Post-acute Project is an instrument for functional assessment including long-term care. They are hopeful that it will answer the question about whether benefit dollars can be used more effectively if focused on need and not on location. In-patient rehabilitation providers believe the program should be extended well beyond the original implications. CMS must go beyond the acute care medical model – they just don't know how to get there.

### **Group Discussion – Summary Highlights**

The purpose of this document and subsequent published reports are to stimulate further discussion that might generate needed resources and collaborations among researchers with an interest in better understanding neuro-rehabilitation in the later stages of recovery.

It was determined that further information-sharing and a published paper should focus on this expert group's strengths in the area of neuro-geriatrics, which may have general applications to other areas of the field as well. Nitkin emphasized that applications for treating other diseases may well apply to this milieu and lessons can be learned from testing hypotheses on the basis of treating other populations, e.g., the impact of chemotherapy on the quality of life of cancer patients. Proceedings in a prominent journal would further assist in reaching and attracting the attention of junior colleagues, who will have an impact on a future research agenda.

The topic headings below represent key areas which the meeting participants believe need further attention.

### **Redesigning the payment system**

The difference between the present Medicare payment structure and research directions is that the former focuses on the early phases of the rehabilitation process while most research work centers on the plateau and later phases of rehabilitation. Lambowitz questioned whether aspects

of the short-term payment structure are hindering present research and how present findings might better influence policy.

Medicare is seeking feedback relevant to revisions to its payment/financing structure. This forum created a unique opportunity for ideas raised and research executed to influence that change. It also provides a unique opportunity for key organizations, such as the NIH, to work in partnership with CMS, which is looking at long-term reform of the payment system. They need help to structure this new national plan, which will include post-acute and chronic maintenance care reimbursement. While looking at overall reform, incremental changes can make the current programs more responsive.

Lambowitz indicated that when they're in the process of making decisions, if they don't have evidence-based data, they react to industry data, which is slanted from a different perspective than policy. They are trying to establish a baseline, or evidence that they can evaluate and compare to something. They did a scope of work for the demonstration that will give an idea of the data they are trying to collect to develop a system. There is nothing that tells them how outcomes differ by setting. How do they make policy? They must look at patient characteristics if the decision making is not done based on policy implications. While it is unlikely that CMS will achieve optimal reform at the first pass, Weinrich suggested that the research community partner with CMS to develop reforms to the payment system that would yield ongoing data. Reforms should also include a data gathering capacity that will move toward a system that is empirically based and that can gradually move toward optimization.

Since the research studies to answer priority questions take 3–5 years, it was suggested that data structures ought to be in place throughout the transformation to consider the sequence of changes to develop uniform outcome measures across sites and analyzable timeframes of those outcomes.

Jette believes that Clinical and Translational Science Awards (CTSAs), which differ from the NIH R01, can be a model for organizing the research to get beyond the plateau, putting money into coalitions of researchers and communities interested in long-term research agendas. Two issues of great concern in clinical trials were raised. First, denying someone something that is better for them becomes an ethical issue. Second, sample sizes have to be much larger to have a measurable effect. To demonstrate the impact to Congress requires large contracts. The extent that one can track outcomes with existing research would be a big step forward and wouldn't cost \$35 million for additional research. There is a big transition when research involves service delivery. Duncan pointed to SSA's ability to partner with Medicare and Medicaid to look at clinically relevant outcomes by doing a random sample to understand the characteristics of the patients through merging of clinical data. That doesn't have to be done under informed consent; represents analysis based on data that is currently available; and wouldn't cost millions of dollars.

SSA has a legal agreement in place with CMS, the Department of Education, and Vocational Rehabilitation that allows them to merge data. They are in the beginning stages of using administrative data and have funded small grants. Medicare Demonstration Projects can also help to inform researchers in setting an agenda to address issues from a policy perspective.

Models of systems of care can better predict the appropriate levels of care for the initial recovery and plateau periods.

### **Develop a community research model**

A person with a disability wants to return to the community, according to Rimmer, and wants to live in a social context. That community has the responsibility to get that person reengaged – whether it is back to work, involved in leisure activity, or involved in a spiritual pursuit. The goal is to transition people after rehabilitation back into the community so that they become an asset rather than a liability. SSA wants to hear the most effective way to transition someone back into activities of daily living, working a few hours a day and engaging in community life.

Reimbursement only goes so far; people discharged from rehabilitation can achieve greater improvements from the community with a model to help people re-enter their environment. These models should include everything from the social-environmental context to a molecular/genetic basis. A roadmap or conceptual model would help to place studies or ideas into categories. Nitkin thought the model could be a conduit for creative improvement. Weinrich suggested laying out the research questions the group most wants answered, and then outlining the study to answer those questions – indicating the barriers to getting it done.

### **Success of interventions across settings**

At Macko's institution it is unclear how interventions work across settings, or how to triage people. Many of the presentations discussed stages of recovery. He no longer refers to a chronic phase – instead he terms phases acute, sub-acute, and maintenance or long-term. There are huge gaps as to where interventions are executed across settings. These gaps are of particular concern when evidence-based findings show that therapeutic interventions can affect co-morbidities and change long-term health outcomes. Nitkin believes that the strengths and weaknesses of skilled nursing facilities, for instance, versus other environments, are valid research questions. Macko agreed that we don't know how rehabilitation will work in the sub-acute or chronic phases; it needs to be formally tested across settings.

### **Two broad concepts – systems of care and local intervention**

Nitkin noted that in rehabilitation they are forced to look at the bigger picture. Whyte and Chae agreed that there is a potpourri of health services involving the organization of care. Mitigating the cycles and the blips in the trajectory, they do not apply equally across all problem areas and age groups. They need to determine health care models appropriate for different problem areas and age groups. Is there any evidence that a focused intervention for a cognitive impairment works? It is not at a health services level right now; the nature of rehabilitation, however, creates a focus on these issues.

Duncan believes that a systems approach is the best way to accomplish the goals. Could this be translated into a model of community practice and health care delivery? There are a number of good conceptual translational models. Start with an intervention – what really does affect the uptake in practice? What are the structural factors, patient factors, and socio-economic factors? In trying to be innovative, one has to understand the system, even while testing other potential

systems. What is the trajectory of recovery that inherently affects the intervention and the viability of translating that intervention into practice?

### **How to build a research community**

When looking at the delivery to intervention interface, the very nature of the issue mandates an inter-disciplinary approach. It was recommended that the work drive the collaborations and that applicants must have the requisite expertise on their teams.

In order to answer questions about site, timing, and dose intensity, they need to move away from their small grants and form partnerships. One of the models mandates a link with the community, such as Skilled Nursing Facilities (SNF) and medical corporations that offer assisted living. In Italy, in a zone of 230,000 people, they can form this type of intervention. Socialized medicine, which helps outreach, is necessary to form partnerships in the U.S. economy as well. It was agreed to take a research organizational approach that would pursue coalitions to organize funding and support.

### **Obstacles to organizational approach**

- (1) SNFs do not have the research infrastructure and don't have the incentives to engage in the inefficiencies of research that cost them time and aggravation.
- (2) They must be cognizant of issues in operationalizing research as they move forward.
- (3) CTSAs may not address, embrace, or acknowledge the existence of rehabilitative issues unless the field decides it is the route to take to develop a research infrastructure.
- (4) CTSAs need to know that one out of seven Americans have disabilities and that number will rise dramatically by 2030.
- (5) The community partnerships were often with biotechnology companies or community medicine clinics.

### **Opportune time to inform health care policy**

Weinrich mentioned that every political candidate for 2008 is talking about health care reform and many newspaper articles are referring to projected increased health care costs. The American public wants freedom of choice about health care, but they are also concerned about what they are paying for it. While this cadre of researchers cannot make political recommendations, they can suggest topics for research that will help to inform political decisions. Properly timed research results can have profound effects on policy. The opportunity exists to promote and perhaps fund research that can inform policy.

### **Examining the data**

Whyte asked what data are needed to determine that people get the services that they require, and also asked that service providers alter behavior in response to contingencies. Once the payment reimburses for the intensive level of care, he doesn't believe that payment reform will work to pay for contingencies. However, if everyone with the same problem gets the same service and as funding constraints eliminate variability in the system, there is no way to determine that they received the right service since there is no basis of comparison.

On the international level, according to Stewart, they are providing different services, even in the same jurisdiction. Services are dependent on the funding source. It might be possible to learn from these programs by looking at the reimbursement system. In reference to the kind of research, a lot of success is based on asking the right questions. Getting feedback from people is a great first step.

Lambowitz mentioned that there are two, possibly three types of acute rehabilitation facilities whose acuity patterns are different. When they initiated their present payment system in 2002, they were seeing a changing patient population with decreasing numbers of stroke patients and an increased number of knee replacements. This is not acuity-based, it is monetarily-based. They have started to look at the data and they don't see different characteristics in persons who are being placed in different facilities. Their outcomes have been based only on information from providers. Duncan disagreed, indicating that they do have outcomes. They have outcomes on whether the patient lives or dies; whether they were re-hospitalized; and whether they fractured their hip. Clinicians get overwhelmed because they want every little detail. Global outcomes are important. They need to be aware that if they provide a bolus of rehabilitation and there is not a sustainable benefit, it's not worth the cost. Researchers must show that they have impacted a large population across multiple data sets.

### **Quality of Life measurement**

Stewart brought attention to considering measures of functional independence and quality of life (QoL). If there is no QoL measurement, then there is no justification for spending the money. Functional independence makes a big difference with caregiver burden. People are always talking about the patient dying, but the caregiver dying is a significant problem for Medicare/Medicaid. Functional independence is important if it translates into cost. It is necessary to develop an important (and perhaps small) set of measures that everyone can agree on. Stewart knows that the FIM and the Barthel have floor and ceiling effects and are not measuring the elements that clinicians all over the world think are important.

In response to a question from Rimmer as to what Medicare is looking for and how to shift a patient from a liability to an asset, Lambowitz responded that Medicare is looking to maximize potential – to help people reach the highest level that they are capable of. For some people that standard might be lower than for others, as they have issues that would prevent them from going back to work. In a nursing home setting, the emphasis is on getting people back into the community and improving the quality of life, though this may only represent 5–10% of the industry. They try to combine the health quality and QoL to get the best mixture. They have the ability to merge the data into an episode of care and are starting to ask better questions. The idea of episode of care and having one payer has been around for 20 years. A lot of ideas are starting to take focus, but they don't have the research to support them yet.

Whyte maintained that without an episode of care model it would be hard to give payment for a brief hospital stay followed by community support. The payment is front-loaded and they are constrained to look beyond the existing models and minor variations. Whyte and Chae are not convinced that this group can address the global systems of care issues. They are capable of developing policy and evaluating it prospectively. Chae wants to address the biggest barriers –

standards of care fixations that can challenge him as a physician. If all the money is put in the front end, how will CMS pay for reasonable data?

### **Changes to the SSA payment system**

SSA has narrow silos of interest, which define disability within the confines of their legislative requirements. It is based on someone's ability to work. Their other narrow interest is returning people to work. Their beneficiary group is severely impaired and many on the rolls will not be able to return to work. They are not set up for a support service system that is required for an initial accident or impairment transition. Payment and support only occurs after someone has had impairment for a long period of time. Research demonstrates that if they intervened much earlier and faster, they could save money across the lifespan. These needed changes to the system would reduce overall cost.

Wolf believes it would be helpful for a randomized clinical trial (RCT) to show the value of early intervention. His strategy is to provide a statement to CMS before May when they review CPD codes. Whyte added that the more the data speaks to cost savings or macro outcomes such as employment, the more compelling it is for policy purposes. The sample size needed to demonstrate an impact on arm movement, however, is different from the sample size needed to demonstrate changes in return-to-work data. If you take a more sequential approach and if it does improve arm movement, no one wants to be in the RCT where you don't get the benefit anymore. With a pharmaceutical trial they had to do a 4–6 week trial since no one wants to be on a placebo for a long period of time. They can't show that the placebo won't make a difference in the long term – no one will continue to take the placebo after the study shows a positive outcome. Because of the nature of rehabilitation, demonstrating the impact on the whole from the beginning is difficult, but it becomes more difficult as time goes on.

### **Macro outcomes/demo projects**

Weinrich questioned Lambowitz as to how to reorganize recovery such as walking therapy. For instance, if patients were able to receive a half hour of walking therapy in different facilities instead of more traditional therapy, how could it be paid under the Medicare benefit? Whyte asked if it couldn't just be called PT. She responded that they don't ask for the modality – they simply ask for the amount of PT service time. There are no rules as to what is counted as therapy. In nursing homes, it would be called restorative nursing, rather than a therapy service. Duncan disagreed, saying that walking recovery in this model does require therapeutic intervention early on, leading to greater intensity and aerobic training.

Lambowitz indicated that they do have rules as to what is counted as therapy. As long as it's a therapeutic problem within a standard of practice, they would not have a problem with reimbursement. Macko added that in 2005 the Director of the APTA for Policy was working on redesigning the rules as to how therapists provide services, get reimbursed, and oversee and supervise therapeutic exercise to improve fitness, which is related to function and is now built into their bylaws. This shows that you don't need a one-on-one physical therapist if you have an exercise model.

Membership in a community-based exercise center while someone is in rehabilitation is not a Medicare reimbursable service, although under managed care, the Medicare HMO offers a fitness club membership as part of the HMO. Fitness programs are of more interest to state Medicaid and county governments programs at the present time.

There is a disconnect between the policy and the rehabilitation research worlds. If both groups are truly interested in progressing beyond the plateau, the organizational mechanism for encouraging this kind of research must bring together these two worlds to test promising interventions and pay for services in the Medicare/Medicaid Programs.

**Research considerations that may influence CMS guidelines for reimbursements:**

- Rimmer emphasized that there are no reimbursement systems in place to reintegrate people into the community to enhance health and decrease other co-morbidities that occur in the interim. When concentrating solely on stroke, all the other systems fall apart. Look at models that provide exercise and health promotion in these settings and put the burden of proof on communities to get people re-integrated.
- It takes 2–3 months after trauma to be at a place where a person can begin training to reach aerobic capacity. Issues to be taken into consideration include motor and cognitive functioning. In individuals exercising with stroke, there appears to be a high incidence of sudden death. It would be beneficial to hold a demonstration project to determine adverse events, which may also determine extreme benefits.
- The possibility of secondary complications and the need to address them sufficiently should be considered. There are potential issues for the acute rehabilitation period that look at pay for performance with specific guidelines. For instance, are there changes that can be made in the outpatient setting for those patients who didn't have enough tolerance in the inpatient program and needed a more supervised setting? When the person no longer needs close supervision, can an incentive be created for both the provider and person to move into the community?
- Understanding the psychosocial, physical and community barriers as well as the impact of behavioral factors that influence aging with a disability. These will all influence the practical implementation.
- The community of health care providers must have a standard assessment for a stroke patient. A mandate of standardized assessments should include a template of risk factors, age, prior functional status, and key indicators of function that becomes part of their assessment. This could link to outcomes. Guidelines based on an interdisciplinary approach have never been endorsed or adopted.
- A uniformity of assessments is necessary for people to get a macro picture of health services across phases.

- RTI is developing an integrated assessment tool for CMS that will be utilized at various demonstration sites. This new instrument can be evaluated in reference to the FIM, which is used for Medicare rehabilitation. This instrument may be used at hospital discharge to determine post-acute patient needs and help determine where the patient should be treated. According to a Congressional mandate, it is supposed to be operational January 2008 and they are only in the design phase. Under the demonstration they are continuing the present payment system and won't change until 1–2 years post-demonstration evaluation. They are collecting data prior to a change in payment and have not made firm decisions as to when the form will be required during the demonstration.
- There might be the possibility of an episode of care follow-up. It might be the key for getting out of the narrow silo and stretching it into real life. This might lay the groundwork for a reimbursement methodology and payment process that would introduce technology to enable someone to go back to work.
- NIMH developed a mechanism to require researchers to partner with persons in the community. Most of the money the first few years went to the community to set up the research infrastructure. Developing a center and advanced center mechanisms follows that and continues to pay for infrastructure. To do good science and get it implemented means bringing people to the table who have never been there before. That includes consumers. Mental health policy that didn't take into account what consumers wanted gave them deinstitutionalization and dumped people on the street. Within the disability movement a central phrase states – “Nothing about us, without us.” CMS will do their thing and researchers will have input.
- The challenge in a fragmented system is that the payer changes depending on the length of time of disability. There is a window of opportunity in reference to the reimbursement methodology. Three years is enough time to come up with evidence around specific questions that will be circulated through specific documents. NIH is looking at the mechanism and then getting the science to underpin it.

**Focal issues:**

This part of the discussion centered on more traditional research questions or research initiatives that should result in publishable results. This discussion included consideration of two suggestions for funding opportunity announcements:

- NCMRR could follow the model of NIMH and issue a request for R24 grant applications for infrastructure development, specifically to develop a community network capable of doing effective studies of rehabilitation interventions.
- There might be a trans-NIH effort to implement a version of CTSAs that would be more appropriate for rehabilitation. While it would be the same as the R24s, it would engage

rehabilitation more broadly to include the efforts by other Institutes such as the Cancer Institute and NHLBI, who are concerned with rehabilitation issues that this community hasn't dealt with before.

- There is a value in getting players together to agree to collect a basic data set in common and communicate. It would be a platform for R01 type studies layered on top.

### **Research design tactics:**

- There is a need to test the hypothesis that when patients are discharged from the hospital they still have an enormous amount of recovery that can be obtained in the community setting. Can they do this in a safe and effective way in a particular period of time? Trials are necessary to determine this.
- Show in the chronic phase that it is still worth investing in rehabilitation – the Wolf study helps demonstrate this.
- There are two different ways to think about research in the post-acute setting. One is with no efficacy data, but treatment would take place in the post-acute setting – in the community. How can it be done without the infrastructure? Another component has to do with intervention in the post-acute setting or translational research. With evidence that something works, how do you move it into practice? How do you make it cost effective and get people to adopt it? It must have acceptability to the community, translation into the community – consider effectiveness and then move into implementation.
- Infusion of innovation – shown to be efficacious, then put it into practice; doesn't just happen.
- If we are going to affect rehabilitation practice, inherent in design we should be dealing with intensity and dosing.
- Social support is more or less relevant depending on the situation at hand. Good measurement tools are needed for characterizing the types of family structures that matter.
- Social support and social-behavioral factors are major determinants of sustaining rehabilitative progress. These are factors that the aging field has shown influence longitudinal exercise and health promoting behavior. There will be health disparities across cities, suburban areas, and socio-economic situations. The environment has a big impact on the translation of research.

## **Injury response:**

When the brain is responding to an injury – to what extent is that a positive or negative response?

- Populations can show better or worse prospects in terms of brain injury or cerebral palsy (CP). How far out can you go before you can induce useful recovery? The only good example of a sick neuron that can be followed is Amyotrophic Lateral Sclerosis (ALS). It is very fundamental and may best be done as partnerships.
- Amplify what the sick neuron represents. The genomics/rehabilitation interface is a very contemporary issue. There are a slew of novel interventions that include robotics and virtual environments, as well as direct cortical stimulation – these will have profound effects upon neuro-plasticity and function. Allocated resources must now be geared toward these types of initiatives.
- When referring to a plateau, it may be a decline in people who are aging, some of which may be related to disability and risk factors. Risk factors predict how much white sensory brain matter you lose. You can't carry on in life if you don't have the neuro-cognitive function. Look at neuro-cognitive function and computer-adapted testing protocols and sophisticated imaging. Understand the predictors of response and whether these represent factors of brain health.
- Most research and rehabilitation tends to be insular. When thinking about exercise drugs, don't prescribe one drug – prescribe a bunch of drugs. Try to find agents that promote synaptic plasticity, which we think is the substrate of learning. How do we combine pharmacology and exercise in a therapeutic and rational way? Part of the value of convening a group like this is to get ideas of relative importance. What should we do first? What ideas are most important and feasible?
- Work with pharmaceutical companies on treating the sick neuron in the sub-acute phase. If moving trials to phases 2 and 3, how do you control what the rehabilitation intervention is? They need a level of standardized approach. We need to think about cocktails of therapies. Partner with drug companies to determine what standards of rehabilitation interventions should be. Look at it from an integrated approach – we need intervention with drug therapy.

## **How do we conceptualize the chronic phase plateau?**

- We transition from acute to sub-acute. It isn't the same as plateau. We need to be careful with the word plateau as there are too many secondary conditions that influence it. When dealing with Parkinson's and multiple sclerosis (MS) there is a complex course in those diseases that can influence the natural history of those diseases over time.

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- Plateau has profound policy implications. To what extent is it inherent to physiology or to ceiling issues? The Medicare program is mandated as an acute care insurance program.
- “Recovery curve” has more appeal than talking about a plateau. It encompasses disability-related diseases that have an insidious onset as opposed to acute onset.
- If plasticity speaks to an absence of a plateau state, it implies the direction of overcoming the disability in the chronic state. Express this as dynamically as one can.
- If taking these recovery curves further down, will we see this decline and is that part of the initial event or is that age-adjusted?
- To what degree are plateaus caused by the allocation of funding? Incidence of depression rises and stays. But if you treat depression it gets better. Depression is a plateau, because if you don’t have money to treat it, it doesn’t get better.

**Next steps:**

- Share authorship and seek an appropriate venue for a published journal article.
- Educate colleagues on how to approach the aforementioned issues.
- Progress review groups – review what research has been done in the past.
- Editorial Board of Archives – possibility of special issue of peer-reviewed articles is an option. Initial draft is important to decide on the direction.
- Target audience and a list of authors. Need it in publishable format.
- Maybe an extended editorial piece without substantiated articles.
- Something short of a special issue may be a better approach, with common denominators and review of existing obstacles. Not necessary to lay out psycho-social issues, just to say that these issues exist.

## **Appendix A: Program Proposal**

### **ICDR Subcommittee Annual State-of-the-Art Conference Program Proposal**

**All requests to conduct subcommittee conferences, summits, or State-of-the-Science meetings must be submitted to the ICDR Executive Director by Subcommittee Co-chairs and reviewed and approved by the full ICDR.**

**Subcommittee Name:** Medical Subcommittee

**Proposed Conference Topic:** The Rehabilitation Plateau

**Conference Objective:** Discuss issues and create a research agenda around the apparent limitations of recovery from injuries such as stroke and traumatic brain injury.

**Describe relevance of the proposed event to the Subcommittee and ICDR mission and goals (50 words or less):** The existence of a plateau for recovery drives clinical and reimbursement decisions, but may be an artifact of service delivery and measurement tools.

**Expected Outcome and Contribution to the Field:** Research agenda, education of policy makers.

**Dissemination and Knowledge Translation Plan or Utilization Plan:** Summary article in journal, invitation of regulatory and policy staff to the meeting.

**Target Date:** Spring 2007

**Number of Days:** 2

**Target Audience:** Regulatory and policy staff, funding agency staff, and investigators.

**Number of Participants:** 10 experts, 20 federal staff

**Anticipated Meeting Format:** Workshop

## **Appendix B: Meeting Agenda**

### **A Research Agenda for Getting Beyond the Plateau: Promoting Recovery through the Chronic Phase**

March 6–7, 2007  
Neuroscience Center (NIH)  
6001 Executive Blvd, Rockville, MD 20852

Currently, biomedical research and health services are largely focused on promoting recovery in the acute phase of traumatic injury or stroke. But there is increasing evidence that significant functional recovery can occur in the months or years that follow, provided that appropriate strategies are used to promote activity, adaptation, and participation. There also appears to be increased potential for functional recovery in developmental or degenerative conditions. This workshop will evaluate physiological, behavioral, and psychosocial approaches to promote functional recovery and participation in the chronic phase. The group will discuss therapeutic strategies, appropriate outcome measures, environmental supports/barriers, and health service constraints.

**Organizer:** Dr. Ralph Nitkin,  
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First day

9:00-9:20	Introductions and charge to the group
9:20-9:50	Neurological/musculoskeletal substrate/Rymer
9:50-10:20	Clinical issues of the acute phase/Chae
10:20-10:50	Cognitive/Behavioral rehab/Whyte
<b>10:50-11:20</b>	<b>Break</b>
11:20-11:50	Assessing Outcomes/Wolf
11:50-12:20	Environmental factors and trajectories of recovery/Duncan
12:20-12:50	Cardiovascular fitness and health/Macko
<b>12:50-2:00</b>	<b>Lunch</b>
2:00-2:30	Community support and health promotion/Rimmer
2:30-3:00	Community-based rehab/Chard
3:00-3:30	Secondary conditions/Jette
<b>3:30-3:45</b>	<b>Break</b>
3:45-4:15	Health Policy/Stuart
4:15-4:45	CMS perspectives
4:45-5:15	Conclusions and homework <b>[working dinner]</b>

Second day

Recurrent themes and strategies

Needed resources, tools, collaborations, and projects

Challenges to the research community

Collaborations

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Written product(s) and next steps

## Details of sessions

Understanding the neurological and musculoskeletal substrate – William Zev Rymer  
Overlapping processes: Pathology, recovery, plasticity, and adaptation  
Activity too early may be detrimental  
Windows of opportunity  
Activity-driven effects on the substrate  
Do acute interventions limit/enhance potential for advancement in chronic phase?

Clinical issues of therapy in the acute phase – John Chae  
Clinical hierarchy for support of traumatic injuries and stroke  
Communications and goals among patient, clinician, therapist, family  
Taking advantage of neuroplasticity  
Integrated therapy: Activity, electrical stimulation, drugs, and other approaches

Promoting cognitive and behavioral rehabilitation – John Whyte  
Vocational rehab and milieu-oriented approaches  
Practice and learning strategies for cognitive/behavioral rehab  
Macro-impact – Getting beyond the FIM  
How cognitive and behavioral deficits impact therapy and participation

Assessing outcomes – Steven Wolf  
How do we assess progress and functional recovery?  
What do we mean by a functional “plateau”?  
Are ‘functional’ tests an appropriate measure of rehabilitation?  
Adaptive strategies to cope with chronic disabilities

Accounting for environmental factors and trajectories of recovery – Pamela Duncan  
Functional improvement and real-world considerations  
Trajectories of recovery and selection of outcome measures.  
Functional goals and sustainable plateaus  
Strategies for supporting and maintaining functional improvements

Cardiovascular Fitness, Function, and Physical Activity after Stroke – Richard Macko  
Negative and positive spirals in cardiovascular function  
Fatigue, deconditioning, and insulin resistance  
Exercise for people with chronic disabilities  
Exercise and brain plasticity of Ambulation

Community support of exercise and health promotion – James Rimmer  
Psychosocial aspects of health promotion and participation  
Strategies for supporting and promoting exercise  
Community activism and patient empowerment

Community-based rehabilitation – Sarah Chard

- Micro to macro: Individual and environmental factors to promote participation
- Building on social networks and community support
- School-based approaches
- Using the socio-ecology model to promote participation

Secondary conditions – Alan Jette

- Primary conditions and secondary risks
- Health care support for tertiary prevention
- Understanding the balance between acute care and out-patient follow-up

Health policy – Mary Stuart

- Understanding health care utilization and prioritization
- Health care organization and management for chronic disease
- Models from other countries
- Implications for future research

CMS perspective – Sheila Lambowitz

- Access to assistive devices and health care services
- How research and evidence shapes reimbursement policy

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**Appendix C: PowerPoint presentations  
to follow this page**

## **Appendix D: Participant List**

### **A Research Agenda for Getting Beyond the Plateau: Promoting Recovery through the Chronic Phase March 6–7, 2007      Neuroscience Center (NIH)**

#### ROSTER

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