Blue Ribbon Panel on Rehabilitation Research at the NIH

A Preliminary Report to NICHD Council

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Charge

Assess rehabilitation research across the NIH

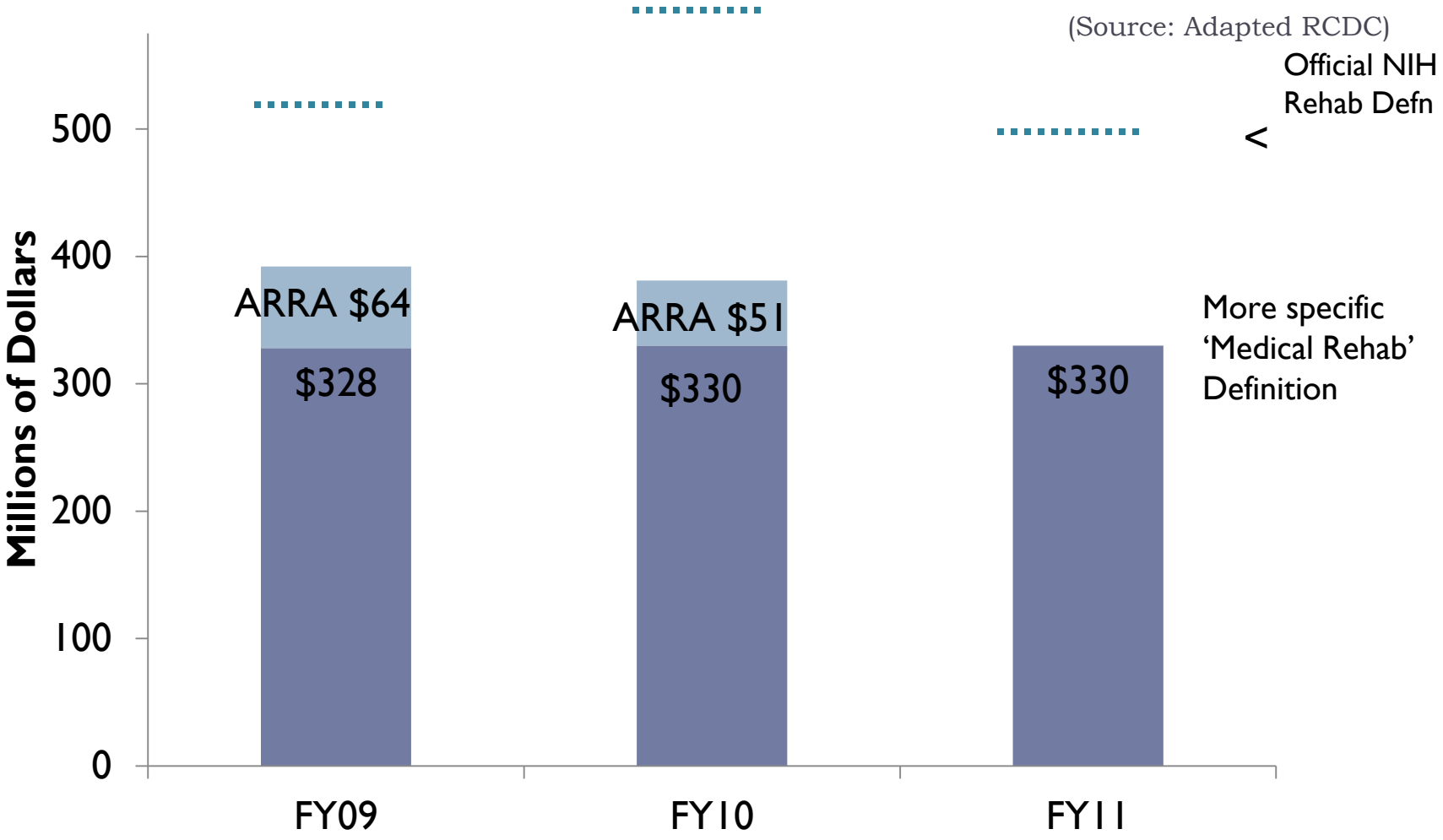
- How do we define rehabilitation research?
- What is the scope of rehabilitation research within NIH?
- Is NCMRR doing what it is supposed to be doing?
- Can or should there be coordination of all rehabilitation research within NIH?
- What are the scientific opportunities?
- What barriers prevent rehabilitation science to progress?

Rehabilitation Research Definition?

The study of mechanisms and interventions that prevent, improve, restore or replace lost, underdeveloped or deteriorating function. "Function" is defined at the level of impairment, activity and participation according to the World Health Organization International Classification on Function, Disability and Health (WHO-ICF) Model.

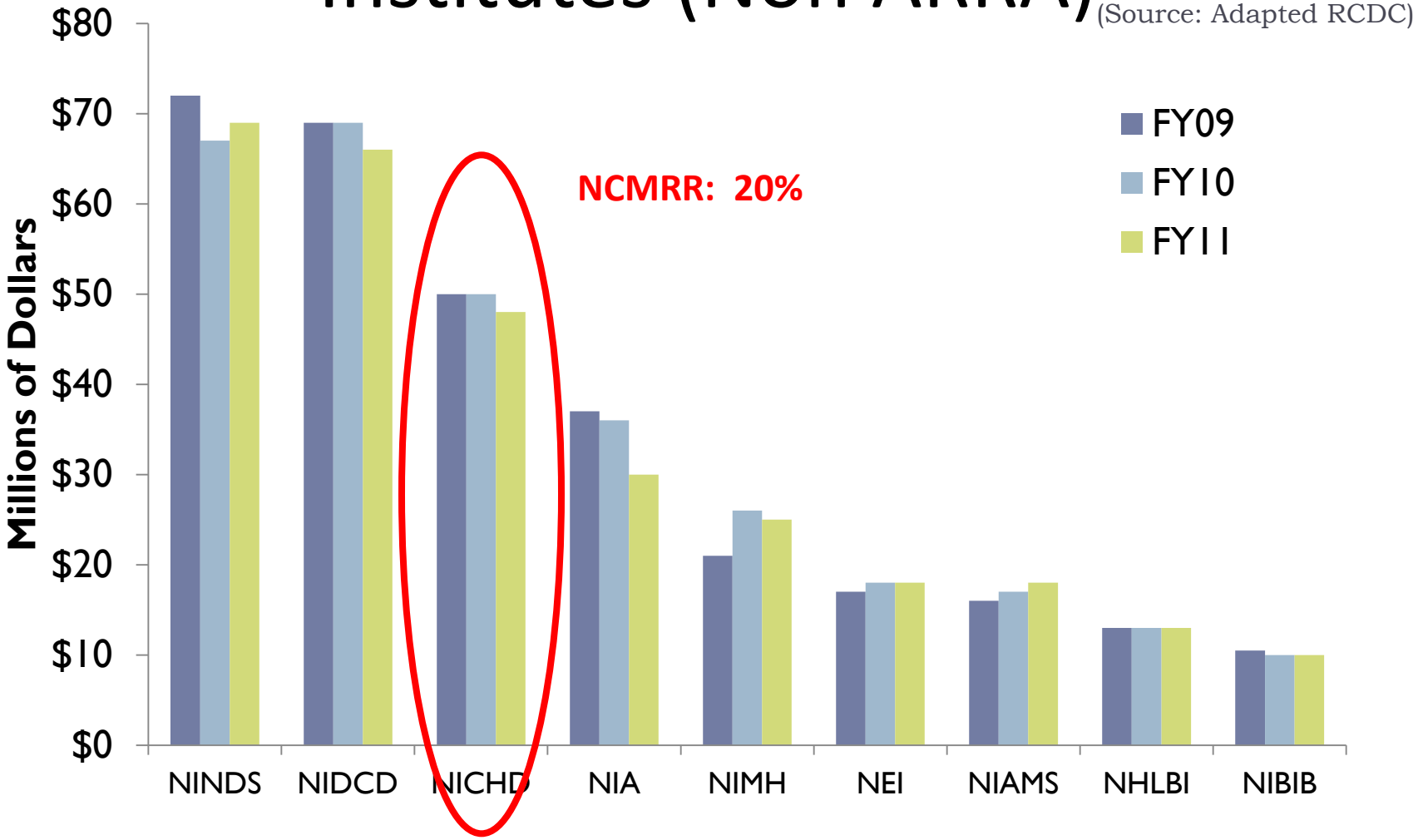
http://www.who.int/classifications/icf/training/icfbeginnersguide.pdf

Scope of Rehabilitation Research within NIH?



Rehabilitation Research Across Institutes (Non ARRA)

(Source: Adapted RCDC)



UNOFFICIAL NUMBERS

Is NCMRR Doing What it is Supposed to be Doing?

- Minimum criteria:
  - Is NCMRR compliant with the letter of the Law?
  - Public Law 101-613
  - November 16, 1990

NCMRR: “Shall”

- **Develop a comprehensive Research Plan YES**
  - Identify current research activities, opportunities and needs for additional research, & priorities
  - Make recommendation for coordination of rehabilitation research across NIH & federal government

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  - Written in 1993
- **Periodically revise and update the Research Plan NO**
  - No official periodic updates

NCMRR: “Shall”

- **Establish the Medical Rehabilitation Coordinating Committee Yes, but**
  - Make recommendations to the Institute Director and Center Director regarding content of the Research Plan and the activities of the Center that are carried out in conjunction within NIH and other federal agencies.

  - 80% of rehab research occurs outside of NCMRR
  - A Coordination Committee exists, but meets inconsistently
  - Coordination and joint funding with NINDS & NIBIB, but rarely with other ICs
  - No actionable recommendations
  - No resources allocated to coordination: personnel, workshops, “topping off,” etc.

Coordination Resources

Estimated Number of Personnel* and Overall Budget of Selected Coordinating Bodies

(As *reported during BRP teleconferences with coordinating body representatives*)

Body	Staff	Budget
Office of Behavioral and Social Sciences Research	16	30 M
Office of Autism Research Coordination/ Interagency Autism Coordinating Committee	8	1.9 M
Office of AIDS Research	40-45	3 B/63.8 M+
Office of Research on Women's Health	17	40-42 M
National Center for Medical Rehabilitation Research	7	0

*Estimated staff figures include a wide range of personnel categories--scientific and administrative. In the case of the Office of AIDS Research, the figure also includes staff funded by OAR but working in other NIH offices (budget, contracts, legislative affairs, etc.) and assisting with AIDS-related research activities.

+The total AIDS appropriation for NIH is ~$3B each year, most of which OAR distributes to the ICs. OAR retains ~$63.8M for its own operating expenses, research coordination activities, and co-sponsorship of initiatives and programs.

NCMRR: “Shall”

- **Establish a National Advisory Board on Medical Rehabilitation Research** **Yes, but**
  - Review and assess Federal research priorities, activities and finding regarding medical research
  - Advise the Director of the Center and the Institute on the provisions of the Research Plan

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  - Role and impact unclear

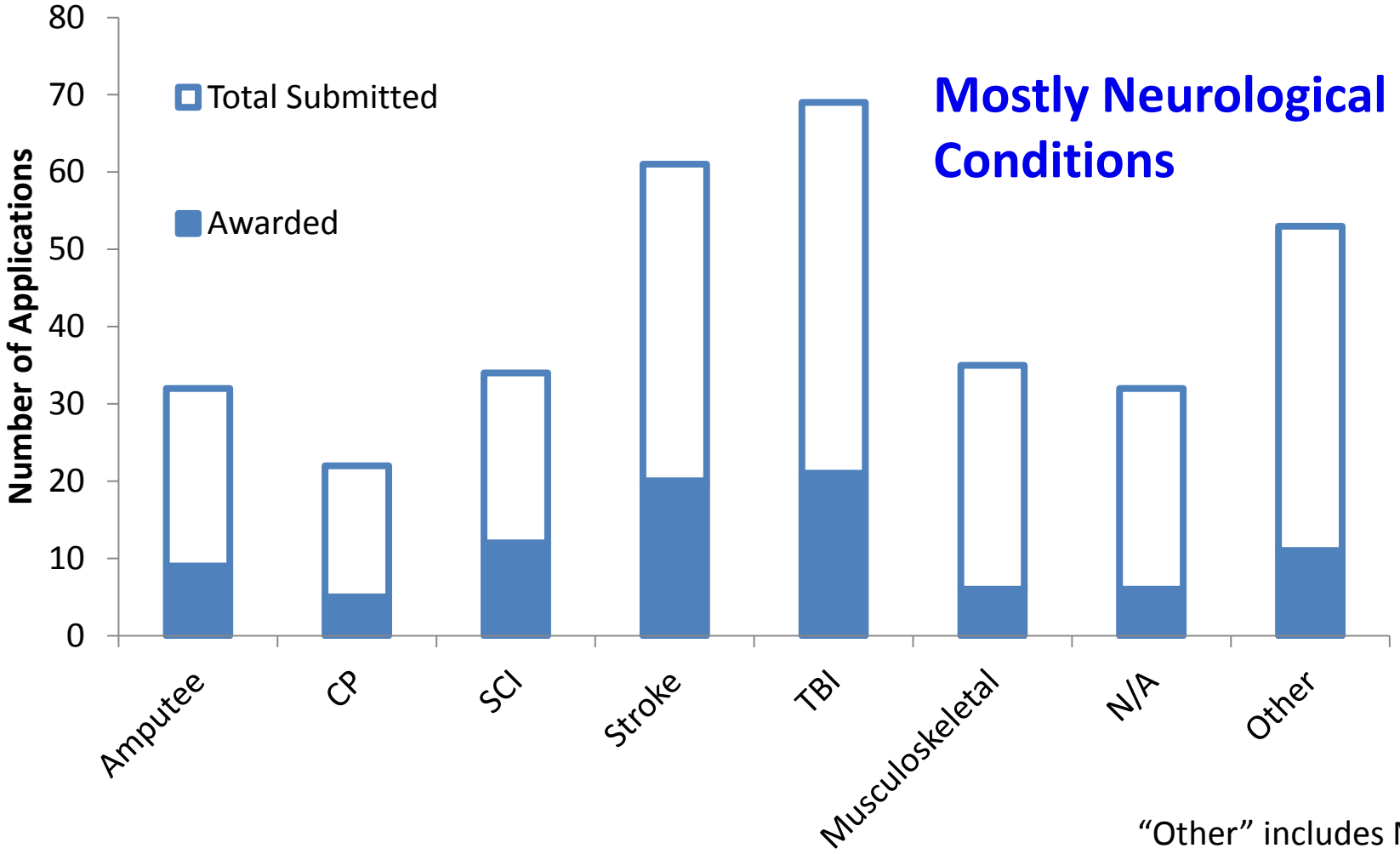
NCMRR Performance

- **Disease Domains**
  - "…rehabilitation of individuals with physical disabilities resulting from diseases or disorders of the neurological, musculoskeletal, cardiovascular, pulmonary, or any other physiological system…"

  - NCMRR and NIH portfolios are heavy focused on neurological diseases
- **Relative to other Centers in NICHD:**
  - Declining budget
  - Far fewer FOA proposals and declining number of published FOAs
  - Far fewer staff

NCMRR Portfolio

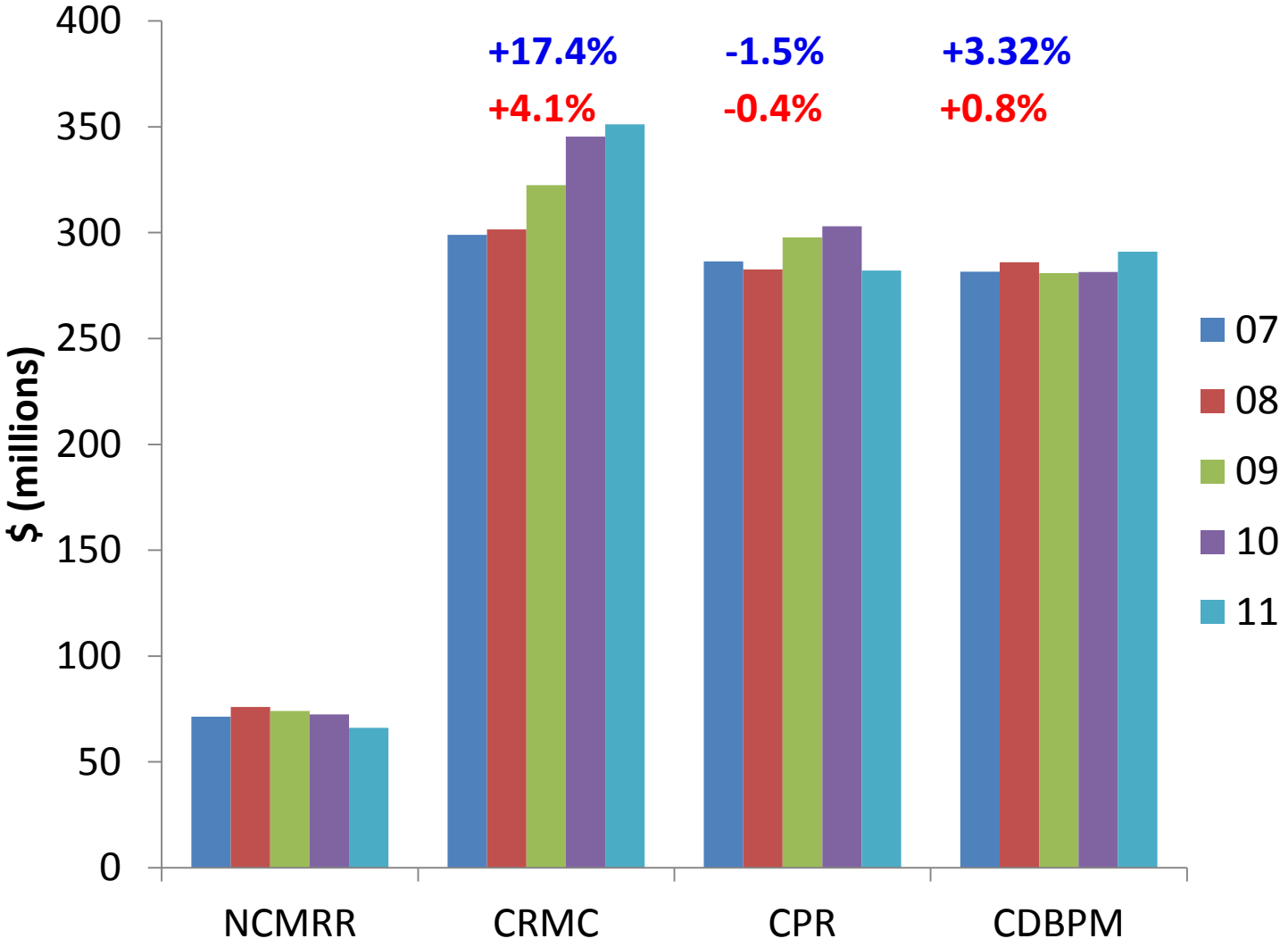
Spectrum of Diseases



*Excludes PCC

"Other" includes MS, PD, paralysis, neurological disorders

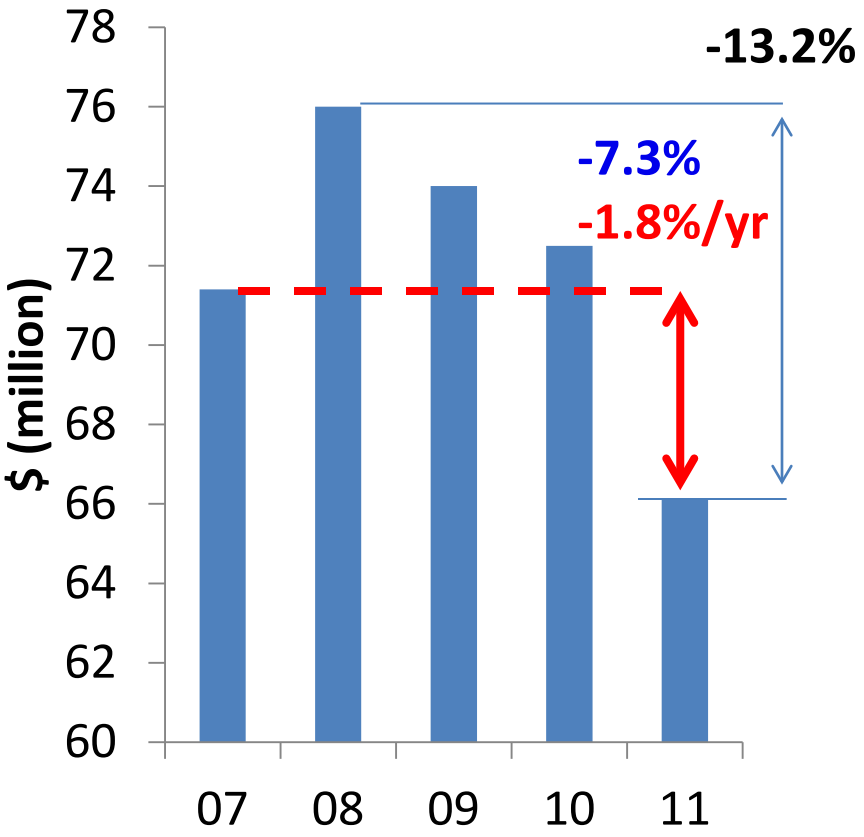
Budget (NICHD Centers)



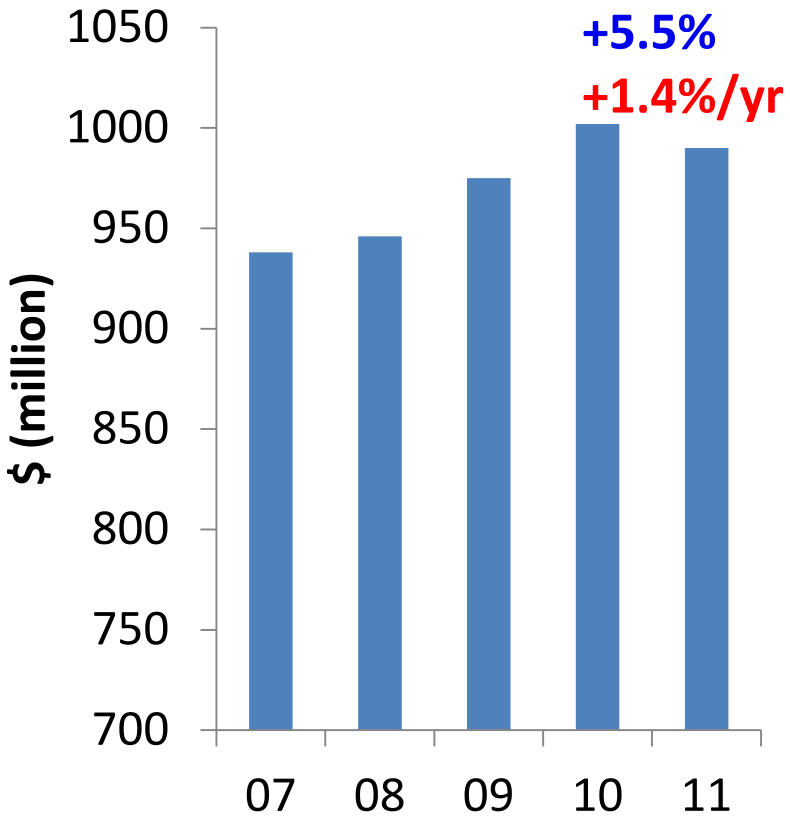
CRMC = Center for Research for Mothers & Children**; CPR =** Center for Population Research**; CDBPM =** Center for Developmental Biology and Perinatal Medicine

BUDGET

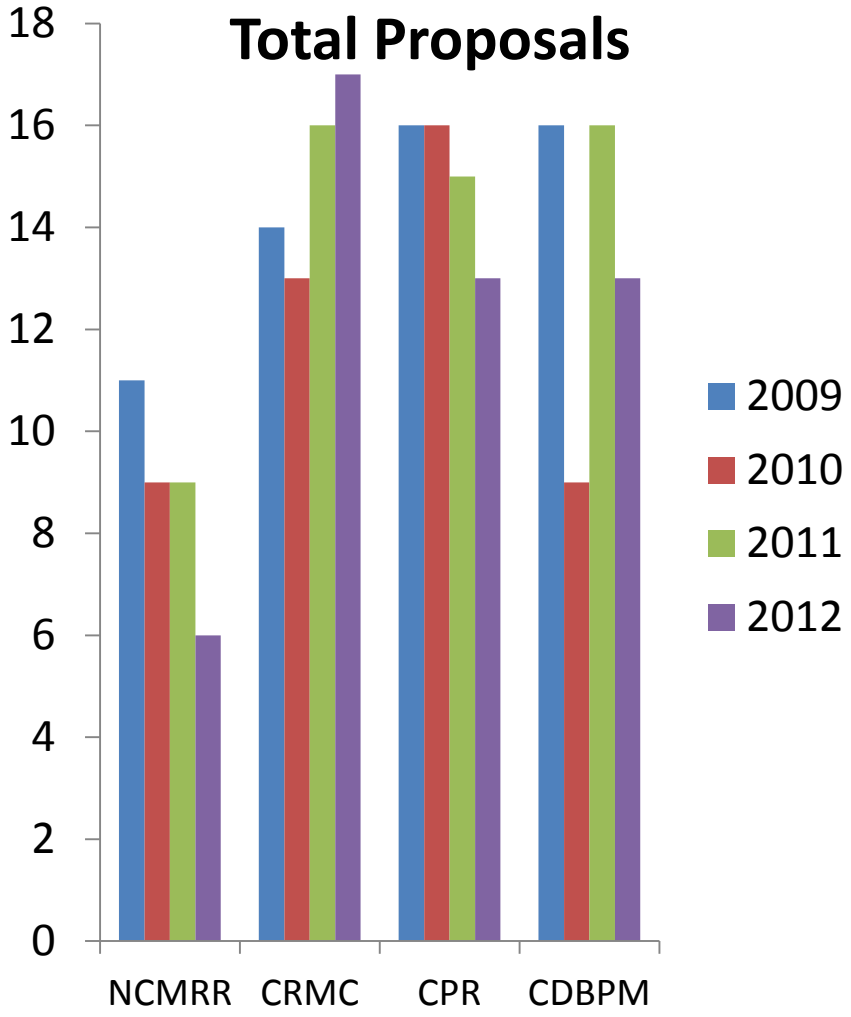
NCMRR



NICHD



Funding Opportunity Announcements



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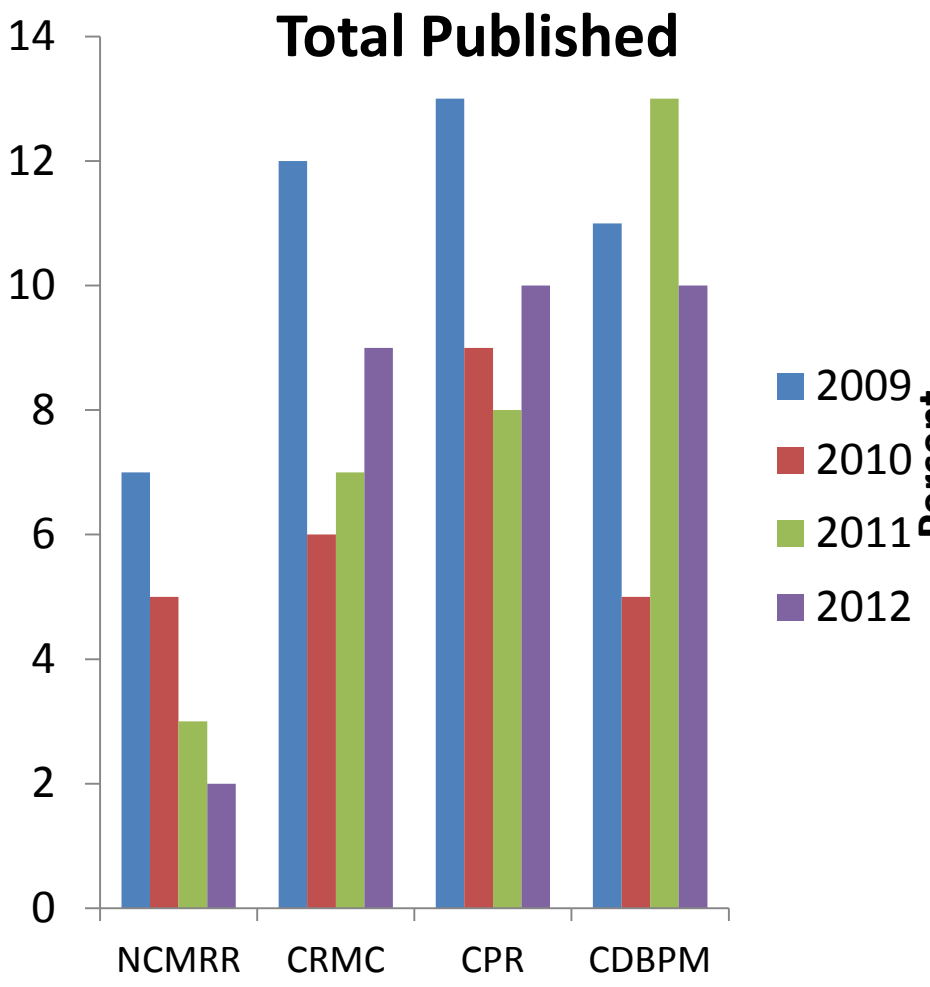
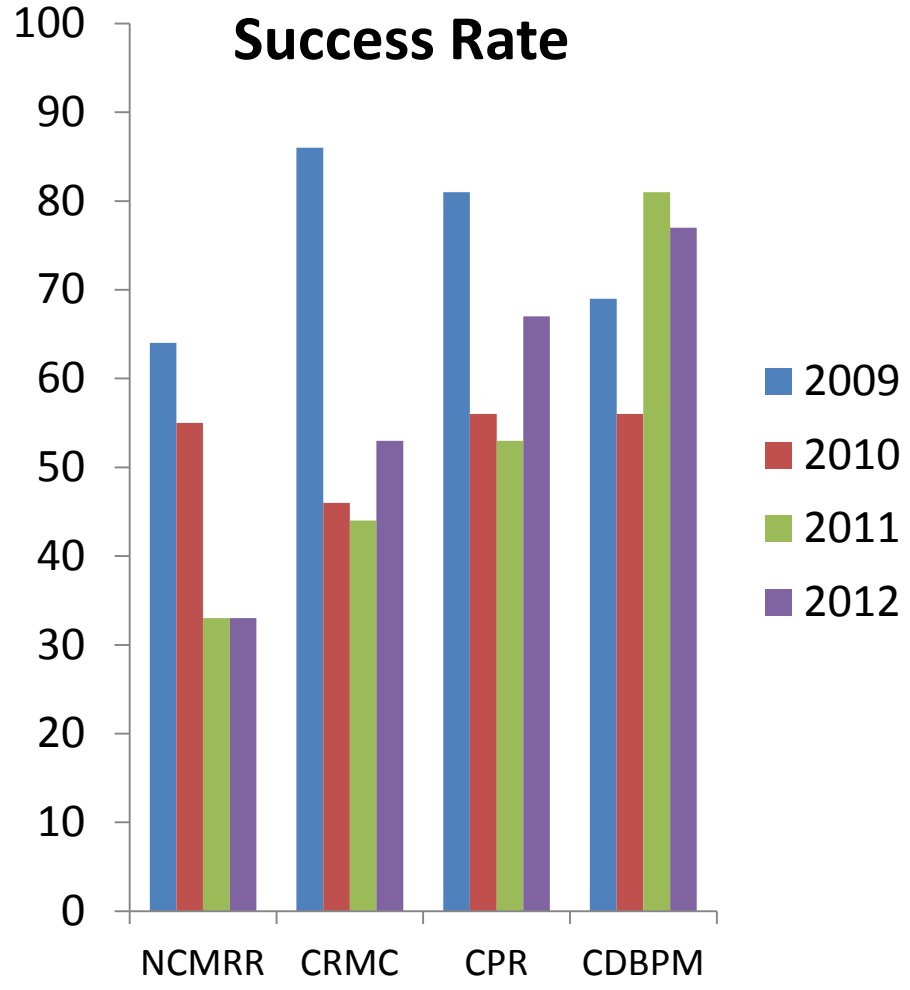




NCMRR: “May”

- **Provide for clinical trials** **Yes**
- **Provide for research regarding model systems of medical rehabilitation** **No**
- **Coordinate the activities of the center with similar activities at the NIH and other agencies of the Federal Government** **No**
- **Support multidisciplinary research conducted or supported by more than one agency** **Yes**
- **Establish peer review groups and appoint members** **Yes**
- **Support research and training centers** **Yes**

NCMRR Performance

- With one exception (revision of the Research Plan), NCMRR meets the “minimum” letter of the Law criteria
- Given the limited number of staff and resources allocated to the Center, **NCMRR should be commended** for what it has accomplished

NCMRR is Functioning, but not Thriving

“Failure to Thrive”

NCMRR Performance

- **There are significant opportunities to help NCMRR meet the broader criteria of:**
  - Spirit or intent of the Law
  - How do we best advance rehabilitation science?
  - What is best for Americans with disabilities?

Can There be Coordination of all Rehabilitation Research within NIH?

- Track record exists in the NIH for successful coordination activities
- Barriers
  - The incumbent IC silo mentality and individualism
  - Collaboration inadequately rewarded or recognized during performance review
  - Funding allocation determines behavior
- Facilitators
  - Public advocacy, congressional influence and high level NIH buy-in
  - Negotiations, diplomacy and social interaction
  - Dedicated $ for coordination, including “Topping off” opportunities and co-funding
- **YES**

Should there be coordination of all rehabilitation research within NIH?

- 80% of rehabilitation research at the NIH occurs outside NCMRR
  - High redundancy within NIH (and other federal agencies)
  - Outside of WHO-ICF framework
  - Most did not coordinate with NCMRR
  - Some weren't aware that NCMRR existed
- **Yes**

Coordination Example

- **Office of AIDS Research**

"Most of the earliest AIDS research was conducted by NCI and NIAID, which, by 1985 was the lead Institute conducting and sponsoring AIDS research."

"…the challenges posed by AIDS exceeded the mission of any individual Institute. AIDS is a multi-system and multi-organ disease, involving malignancies, opportunistic infections, and cardiovascular, neurological, gynecological, ocular, oral, dermatological, and gastrointestinal complications. It affects people across the life span from infancy to old age. Both behavioral and biomedical interventions are required to prevent new infections. Consequently, virtually every NIH Institute and Center (IC) became involved in conducting or supporting AIDS research. This burgeoning effort required coordination.

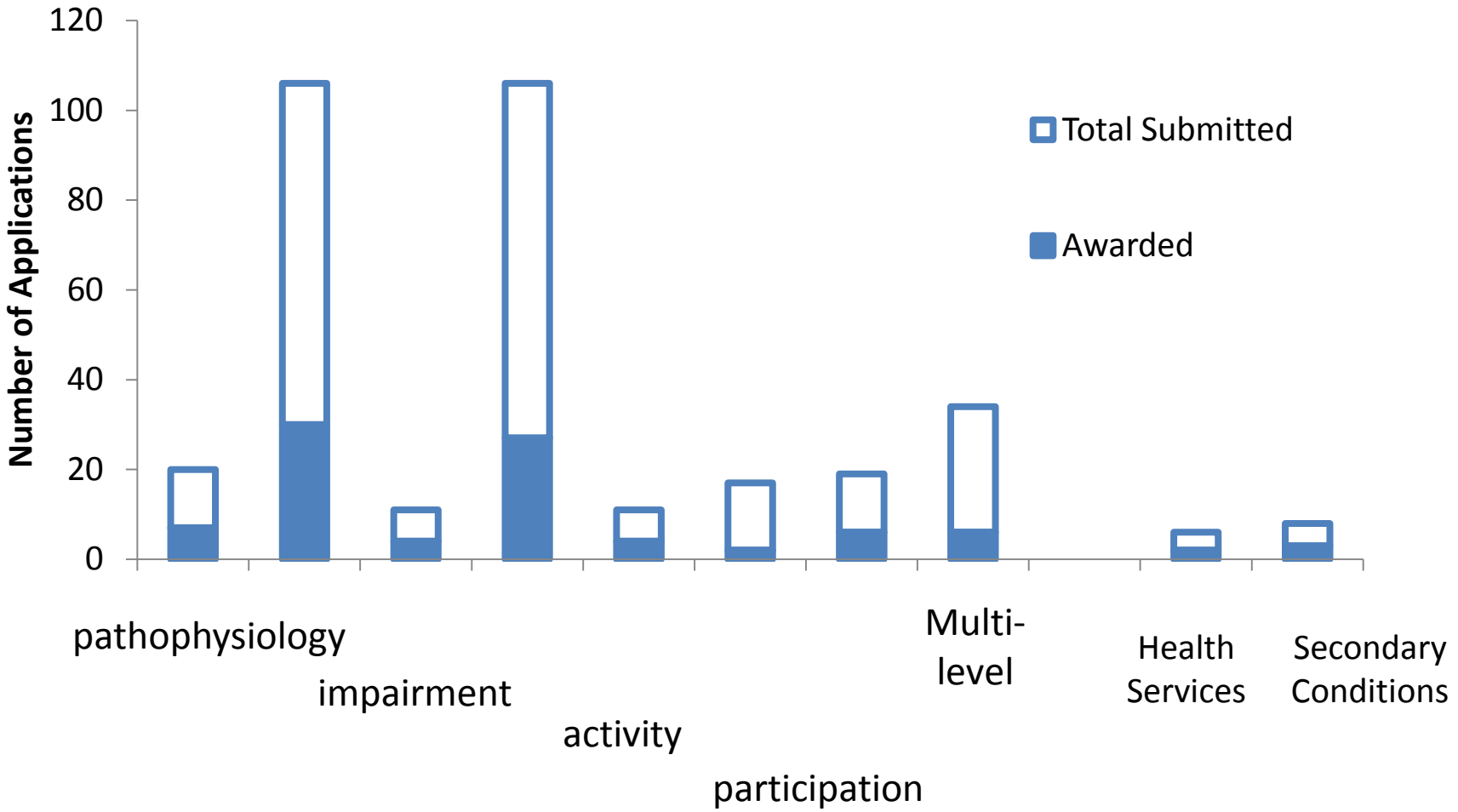
What are the Scientific Opportunities?

Scientific opportunities in rehabilitation research were assessed in the context of:

1) Stages of translational research
2) Framework of the World Health Organization (WHO) International Classification of Function (ICF)
3) The spectrum of diseases
4) Prevalence of disability

NCMRR Portfolio

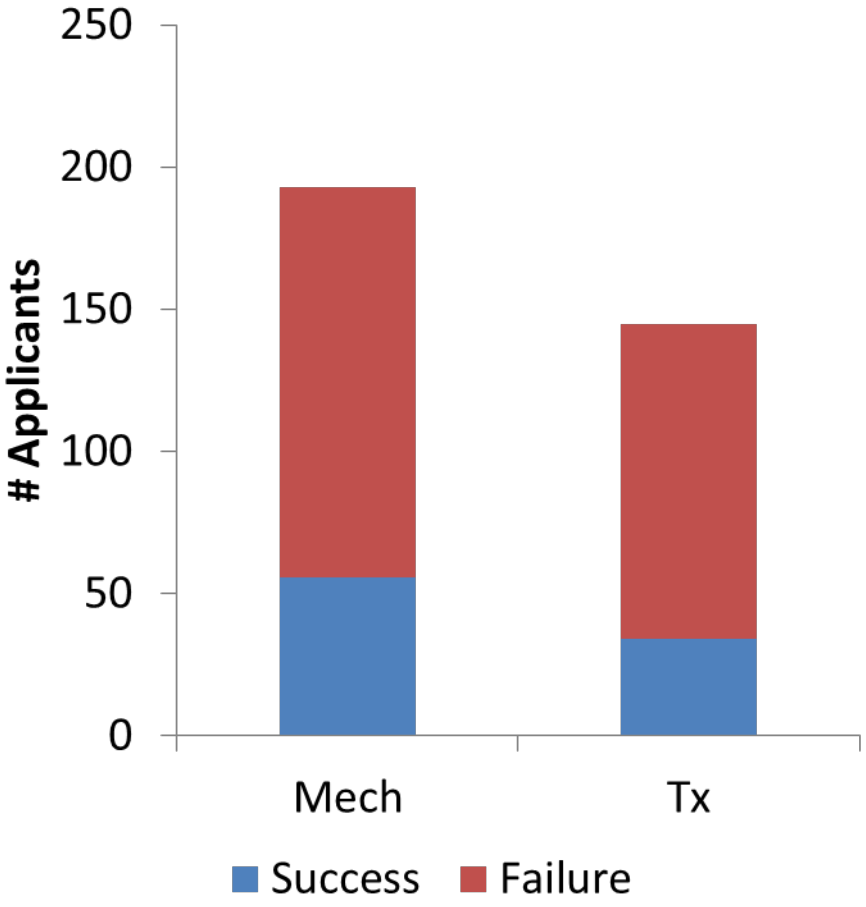
Analysis by "ICF" Level



*Excludes PCC, which is largely pathophysiology

NCMRR Portfolio

Analysis by Mechanism vs. Treatment



- Applications focus is on mechanisms: 57 vs. 43%
- Mechanistic studies have slightly higher success rates: 29 vs. 23%

Scientific Opportunities

Translation and WHO-ICF

Participation restriction					
Activity limitation					
Impairment					
Disease					
	T0	T1	T2	T3	T4
	Basic Science	Feasibility, Phase I and II trials	Phase III trials	Clinical Practice	Policy

- Activity Limitations and Participation Restriction: Capacity > Performance
- Environmental Factors: Physical > Societal, Attitudinal

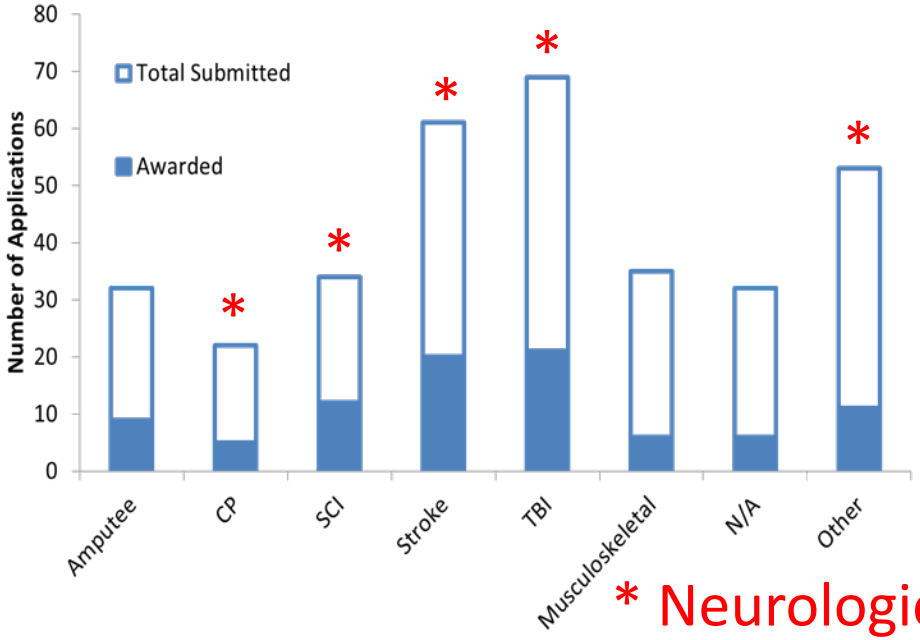
Higher activity Lower activity Minimal to no activity

There are tremendous opportunities to increase the clinical and societal relevance of rehabilitation research throughout the NIH by addressing the gaps in the continuum of translational research and the WHO-ICF framework.

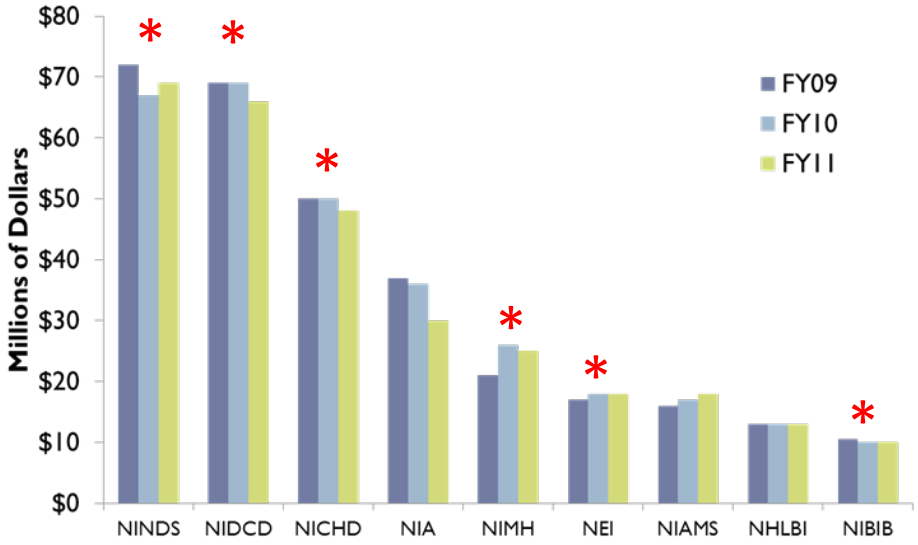
Scientific Opportunities

Spectrum of Diseases

NCMRR



NIH



* Neurological Conditions

There is opportunity to substantially expand rehabilitation research to non-neurological conditions.

Scientific Opportunities

Prevalence and Expenditure

- Disability Prevalence
  - US: ~10-12% (IOM, 2007)
  - World: 16% (WHO)
- NIH Expenditure on Rehabilitation Research: 1.2%
- Incongruity
  - Focus on “relative gaps” misleading
  - All aspects of rehabilitation research at the NIH must increase, including basic science and efficacy trials
- **There is a critical need to substantially increase ALL aspects of rehabilitation research across the continuum of translational research and the WHO-ICF framework to meet the growing rehabilitation needs of the American people.**

What barriers prevent rehabilitation science to progress?

- **Self focus, limited advocacy**
  - Rehabilitation scientists are too self-focused
  - Not enough discussion about the consumer.
- **Lack of understanding of rehabilitation by resource holders**
  - At the NIH, funding tends to be centered on organs or diseases.
  - Rehabilitation is on restoration or maintenance of *function or prevention of disability*, which is not part of the NIH culture.
- **Inadequate research tools**
  - Great need for better outcome measures for use in rehabilitation research.

Barriers

- **Lack of Coordination of Rehabilitation Research**
  - Rehabilitation research within and outside (VA, DOD, NIDRR, NSF) the NIH is fragmented.
  - Since the vast majority of rehabilitation research at NIH occurs outside NCMRR, coordination is critical to maximize the impact of available resources.
- **Difficulty in maintaining funding of newly funded investigators**
  - Due to its relatively small size, minor changes in funding have a major impact, especially on younger scientists.
  - Considerable progress has been achieved over the past 20 years, but research capacity and sustained funding remain a problem

Recommendations

1. Define Rehabilitation Research as:

   "The study of mechanisms and interventions that prevent*, improve, restore or replace lost, underdeveloped or deteriorating function. "Function" is defined at the level of impairment, activity and participation according to the WHO-ICF Model.*
2. Develop and implement a Research Plan that includes a trans-NIH strategic plan to tackle rehabilitation problems that span the life-span across a myriad of conditions (beyond neurological conditions) in a transdisciplinary manner.
3. Periodically review, revise and update the Research Plan.
4. Strategically network with (1) staff of other institutes and (2) selected members of the rehabilitation research community to broadly and comprehensively identify rehabilitation research needs and opportunities worth pursuing, and to facilitate prioritizing rehabilitation research within each relevant institute and center.

Recommendations

5. Increase the clinical and societal relevance of rehabilitation research throughout the NIH by addressing the gaps in the continuum of translational research and the WHO-ICF framework.
6. Substantially increase funding for ALL aspects of rehabilitation research across the continuum of translational research and the WHO-ICF framework, including basic science and early phase clinical trials.
7. Continue to build research capacity.
8. Increase participation of persons with disability and public advocates in the development and implementation of the Research Plan.
9. Change name of the Center to National Center for Rehabilitation Research.
10. Functional recommendations
11. Structural recommendations

10. Functional Recommendations

In order to implement the 9 recommendations, and satisfy the broader performance criteria, NCMRR, as an entity, must satisfy the following functions:

- Granting – with independent control
- Coordination – within NIH, across federal agencies
- Budgetary control and stability for granting and coordination function
- Reporting mechanism – opportunity for negotiation for budgetary control and stability
- Capacity building
- Advocacy (persons with disability centered, not “us”)
- Single-entity

11. Structural Recommendations

- **In order to satisfy the specified functional requirements, structural changes are recommended**
- **NICHD and NCMRR**
  - Good home for incubation
  - Maturing through the “teenage” years
- **It is time for NCMRR to spread its wings**
- **Structural change recommendations**
  - Independent Institute /Center OR
  - Office in the Director’s Office

Independent Institute/Center

- **Doesn't this just create another silo at the NIH?**
- Coordination is a major objective and thus a significant portion of the budget is dedicated to this:
  - Co-funding and "topping off" grants with other institutes and federal agencies
  - Maintain a distributed approach to rehabilitation research as a "cross-cutting" element of all NIH Institutes
  - Centrally coordinated by the new I/C
- Performance criteria and budget allocation based on:
  - Grants that are co-funded with **other** institutes
  - Number of "Topping off" grants with **other** institutes
  - Growth of rehabilitation research in **other** institutes
  - New investigators in rehabilitation research in **other** institutes

A New Office in the Office of the Director

- Office of AIDS Research as the model, but not necessarily in the same magnitude (although, there won't be any objections)
- Develops an annual trans-NIH strategic plan with input from:
  - IC program staff and senior leadership
  - trans-NIH coordinating committees
  - advisory council
  - representatives from other federal agencies
  - outside organizations and advocates
  - community stakeholders.
- ICs submit funding proposals to the new Office, and the Office distributes money to ICs based on scientific priorities as outlined in the strategic plan.
- The Office has grant-making authority and helps coordinate research across NIH. Every IC has a designated Rehabilitation Research Coordinator (with access to the IC director) to work with the Office.

Thank You!
Questions?