

Sustaining Rehabilitation Outcomes: Helping People Flourish

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Objectives

- ◆ Discuss selected key challenges facing rehabilitation and chronic disease care
- ◆ Outline possible strategies to address these challenges
- ◆ Provide some examples of patient centered care and self-management initiatives that can improve and maintain rehabilitation outcomes



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NRH

**National
Rehabilitation
Hospital**



Developing Health Care Environment

- ◆ Changing health care models
- ◆ Changing health care problems
- ◆ Widespread acceptance of biopsychosocial model of pain
- ◆ Increased demands on patients and families



Traditional Health Care Models

- ◆ Characterized by several overarching themes
 - Focus on pathology
 - Focus on acute care
 - Primary focus on biology, with limited recognition of psychological and social factors in determining health
 - Emphasis on provider, not patient or behavior



Traditional Health Care

- ◆ Resulted in an exciting, successful, and almost exclusive, focus on pathology and repairing damage within a disease model
- ◆ Model highly successful in developing new treatments and reducing mortality and morbidity related to disease



Unintended Side Effects of Traditional Health Care Models

- ◆ Encouraged passive role by patients
- ◆ Reduced import of patient-provider relationship
- ◆ Cast individuals with an illness/disability as persons with defects



“Disability is not Inability”



“Treatment is not just
fixing what is broken; it is
nurturing what is best”.

Mihaly Csikszentmihalyi



Developing Health Care Environment

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Changing Health Care Problems

- ◆ The worldwide, US national and personal health care burden associated with chronic diseases and disability is increasing and will continue to increase
- ◆ Individuals with chronic illness and disability are living longer and increasingly reside in non-institutional settings
- ◆ Patients, along with their providers, are being held accountable for good outcomes

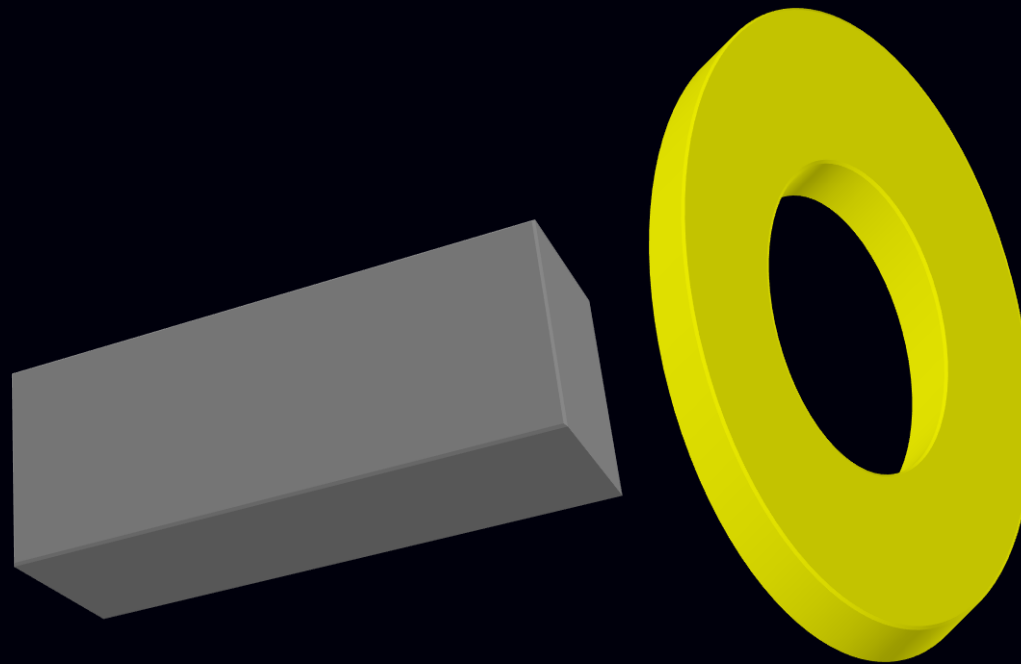


Changing Health Care Problems

- ◆ The majority of health care resources have been directed at acute care not rehabilitation or improving independence
- ◆ There is growing recognition of the increased role of persons with illnesses; however, the resources to support this increased burden are not well developed
- ◆ Traditional medical care and the acute care system encourage a focus on “what the doctor is going to do”



What's Wrong Here?



Chronic
conditions

Acute care
system



Developing Health Care Environment

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Biopsychosocial Model in Rehabilitation Outcomes

- ◆ Psychosocial variables - depression and coping strategies play a large role in explaining the variance in functional outcomes (Kennedy 2011)
- ◆ Meta-analysis indicate exercise can have a small to medium effect on HRQOL outcomes but cease after exercise is terminated (Chen & Rimmer, 2011)



Developing Health Care Environment

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The Work of Chronic Conditions

- ◆ Direct illness related work
 - Identifying providers, appointments, medication regimen, treatment regimen, rehabilitation program
- ◆ Indirect illness related work
 - Insurance issues, managing care, transportation, researching accessibility, advocacy, pursuing treatment options



The Work of Chronic Conditions

◆ Personal

- reconstituting the self
- accommodating to change

◆ Everyday life work

- Additional time required for ADLs, developing work/school options, keeping up, covering up, pacing



The Work of Chronic Conditions

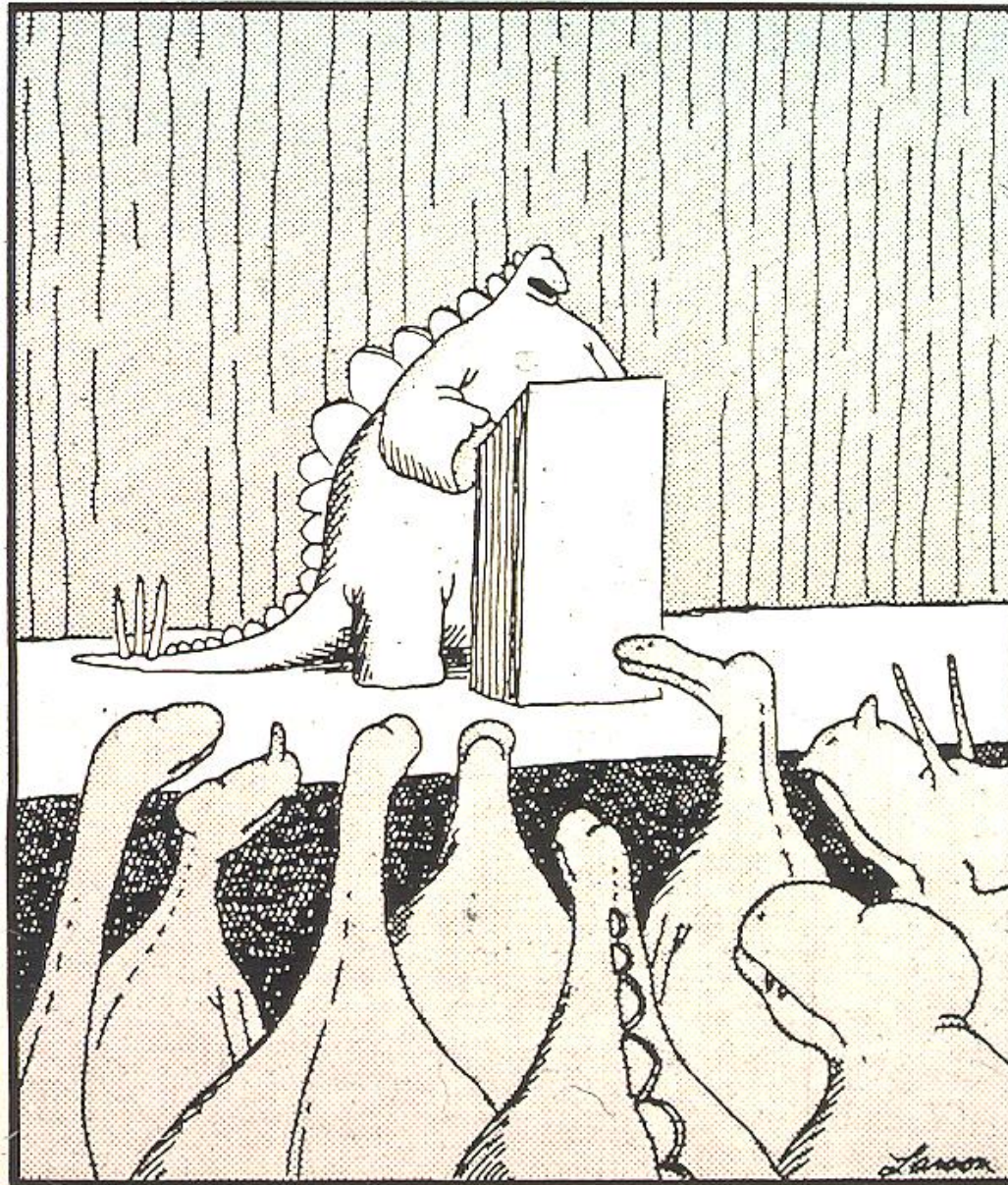
- ◆ Multiple types of work to accomplish
- ◆ Most of this work is invisible thus not valued
- ◆ Environment is often not supportive
- ◆ Untrained, unacknowledged and unpaid
- ◆ Unlimited commitment
- ◆ Patient and their families are the central workers



Health Care Challenges in Rehabilitation

- ◆ Long term patient outcomes in terms of employment and community participation are less than optimal.
- ◆ Length of stays are likely to decrease
- ◆ Availability of outpatient services in areas outside of major metropolitan areas are often limited





"The picture's pretty bleak, gentlemen. ... The world's climates are changing, the mammals are taking over, and we all have a brain about the size of a walnut."

Responding to Challenges in Rehabilitation

- ◆ Called to modify our models of care and develop programs that will:
 - sustain the progress begun during the acute rehabilitation process
 - recognizes the need for patients and their families as central workers
 - assist health care system and providers in preparing and supporting patients and families

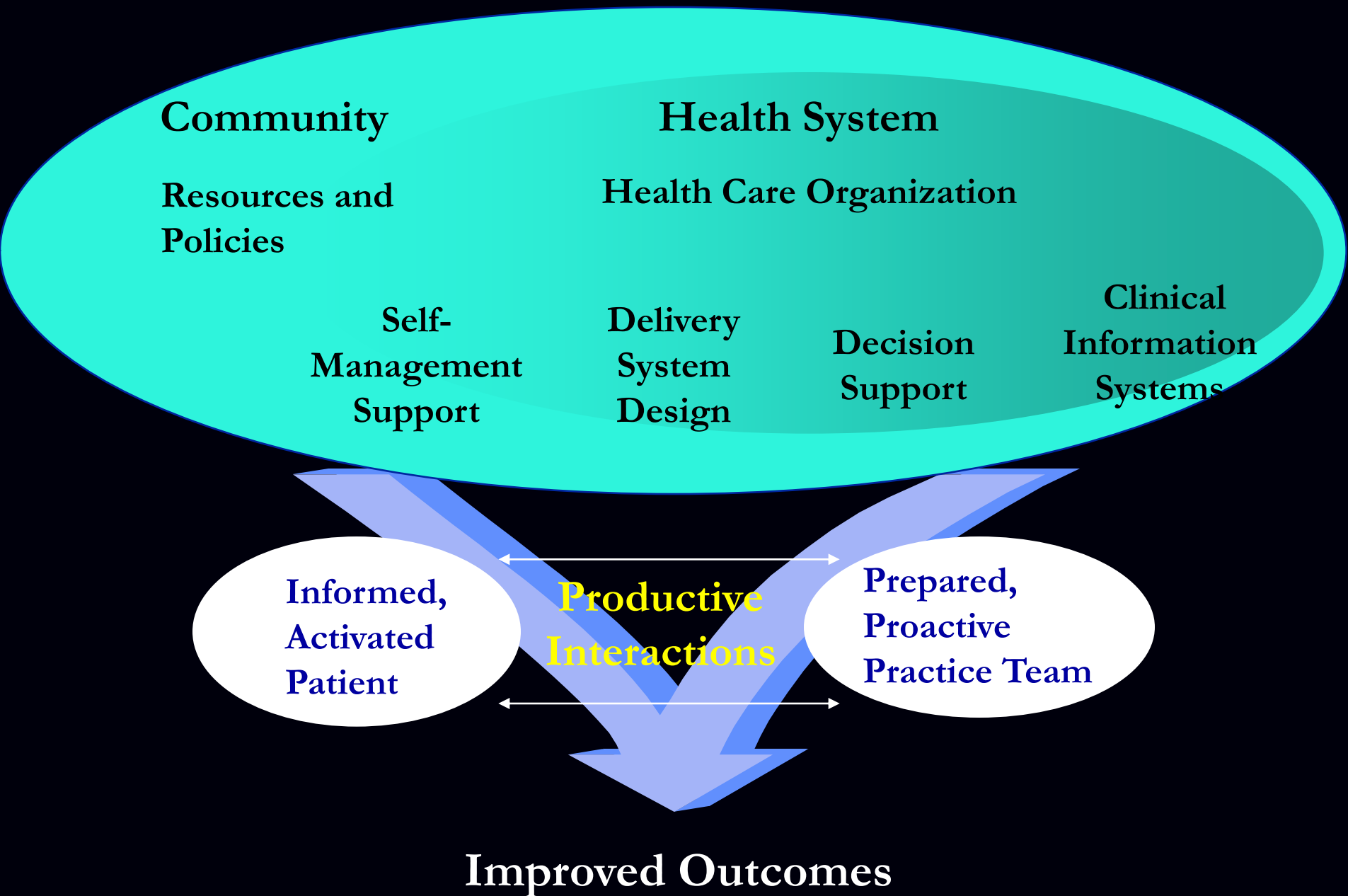


Responding to Challenges in Rehabilitation

1. Adopting collaborative care models for service delivery
2. Using patient centered principles in health care interactions
3. Developing self-management programs to prepare patients and families to carry the work of rehabilitation forward
4. Tracking long term outcomes that are important to patients, families and society



Collaborative Care Model (Wagner et al 1996)



Responding to Health Care Challenges in Rehabilitation

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Patient Centered Care (PCC)

- ◆ In 2001 the U.S. Institute of Medicine issues a report- *Crossing the Quality Chasm* – that challenged the American health care system to improve by addressing six major areas: safety, effectiveness, **patient-centeredness**, timeliness, efficiency, and equity.

- ◆ PCC widens the focus from the patient's acute medical needs to the needs of the patient as a whole, integration of care services, and patient education, family involvement, and emotional support.



Core Values of Patient Centered Care



- ✓ Empowers patients to become active participants in their own care
 - ✓ Patients (and their providers) are held accountable for good outcomes
 - ✓ Empowerment occurs through the interaction of “informed, activated” patients with “prepared, proactive practice teams”.
-

Patient Centered Care

- ◆ Programs and services that empower patients to become active participants in their care respond to the need for patients to assume greater responsibility for their care and recovery.
- ◆ Strategies to achieve this goal include:
 - Training in self-management
 - Peer support and education
 - Computer-based health information
 - Redesign of health care delivery systems and infrastructure



Sheikh Zayed Tower



The Charlotte R. Bloomberg Children's Center



Responding to Health Care Challenges in Rehabilitation

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2. Using patient centered principles in health care interactions
3. **Developing self-management programs to prepare patients and families to carry the work of rehabilitation forward**
4. Tracking long term outcomes that are important to patients, families and society



Self-Management is a philosophy and tool

- ◆ Recognizes patients and families must be active managers of their health care
- ◆ Recognize individuals bring strengths and resources abilities persons bring to their medical problem
- ◆ Requires that clinicians serve as teachers, resources and guides
- ◆ Recognizes individuals may have different goals and that health enhancement is as important as symptom relief



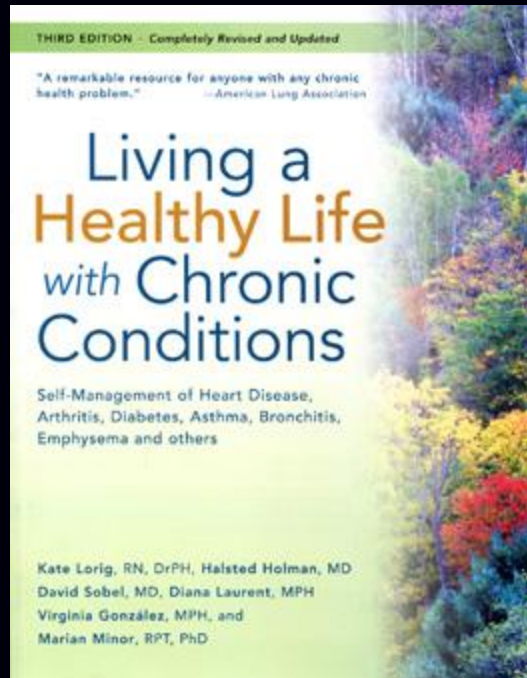
Data on Self-management

- ◆ SM interventions have widespread application with illnesses and conditions in which chronic impairments, pain or disability are common (rheumatic disease, diabetes mellitus, headaches, back pain, amputation, SCI, MS).
- ◆ The strength of the efficacy and effectiveness data vary from condition to condition, the population studied and depending on the end point chosen. (Foster et al , 2007)



Self-Management Programs

Chronic Disease Self-Management Course & the Stanford Patient Education Center



<http://patienteducation.stanford.edu/>



for Survivors

Join the Trauma Survivors Network (TSN) for free today! Learn more about your injuries from the experts and connect with other survivors. Share your experiences, learn how to better manage your life after a serious injury and gain support and hope from others.

[+ Learn more](#)



for Friends & Family

Join the Trauma Survivors Network (TSN) for free today! Connect with family and friends through CarePages® and learn more about your trauma center and what to expect in the hours and days after the injury. Benefit from programs and services available to you and your loved one as you move together on the road to recovery.

[+ Learn more](#)



for Trauma Centers

Join the Trauma Survivors Network (TSN) as a member hospital and partner with the American Trauma Society in providing the services that patients and families tell us they need to navigate their stay in the hospital and help them on the road to recovery.

[+ Learn more](#)

Featured Survivor Story: William "Tipper" Thomas

Vestibulum interdum tincidunt massa. Nulla malesuada rhoncus lorem. Donec rhoncus placerat nisi.

Donec rhoncus placerat nisi. Vestibulum interdum tincidunt massa. Nulla malesuada rhoncus lorem. Quisque massa. Sed feugiat, elit a lacinia faucibus, elit purus fermentum nisi, in tristique felis nibh vel magna. Aliquam erat volutpat.



[Read more](#)

Featured Expert: Dr. Daniel Kerryanski, M.D.

Donec rhoncus placerat nisi. Vestibulum interdum tincidunt massa. Nulla malesuada rhoncus lorem. Quisque massa. Vestibulum interdum tincidunt massa.

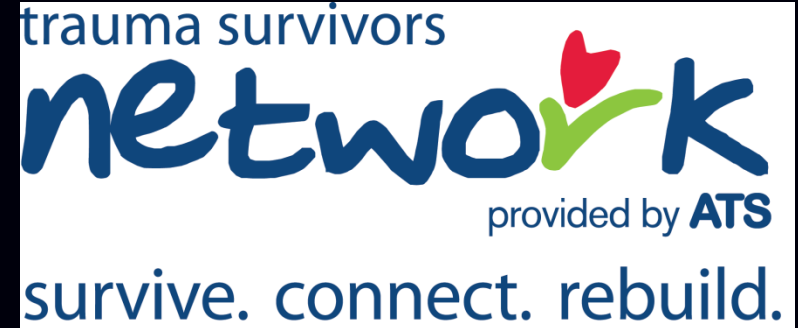


[Read more](#)

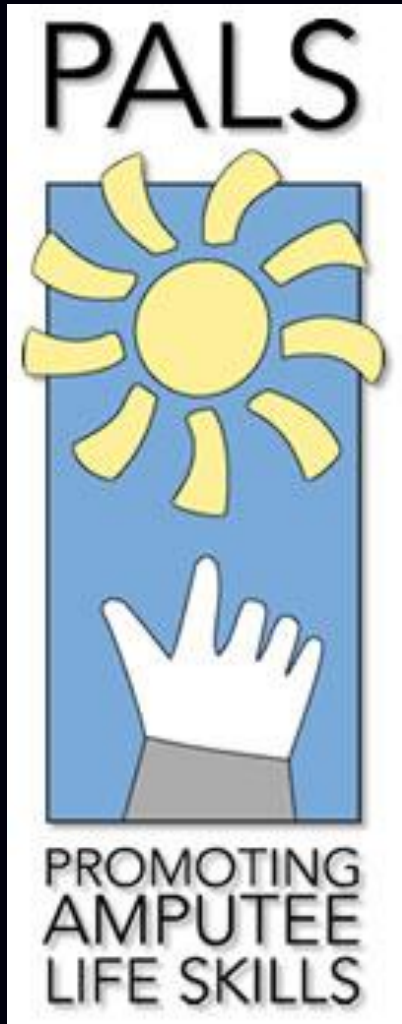
Join the **TRAUMA SURVIVOR'S NETWORK** for free!

Donec rhoncus placerat nisi. Vestibulum interdum tincidunt massa. Nulla malesuada rhoncus lorem. Quisque massa. Sed feugiat, elit a lacinia faucibus, elit purus fermentum.

[Join the Trauma Survivors Network for free now](#)



Promoting Amputee Life Skills



*A Program of the
Amputee Coalition of America*

*Developed in collaboration with the
Johns Hopkins University School of Public Health
& Dept of Physical Medicine and Rehabilitation
University of Washington*

Dept of Physical Medicine and Rehabilitation

Funded in part by the CDC

PALS Program

- ◆ 8 Weekly Group Sessions + Booster
- ◆ Facilitated by 2 Trained Leaders – one is a person with limb loss
- ◆ Emphasis in each session on:
 - *Knowledge*
 - *Problem Solving*
 - *Skill Acquisition*
 - *Self Monitoring*
 - *Self Empowerment*



PALS Groups



Average Group Size: 10



TAS Devils PALS Group, May 12, 2005

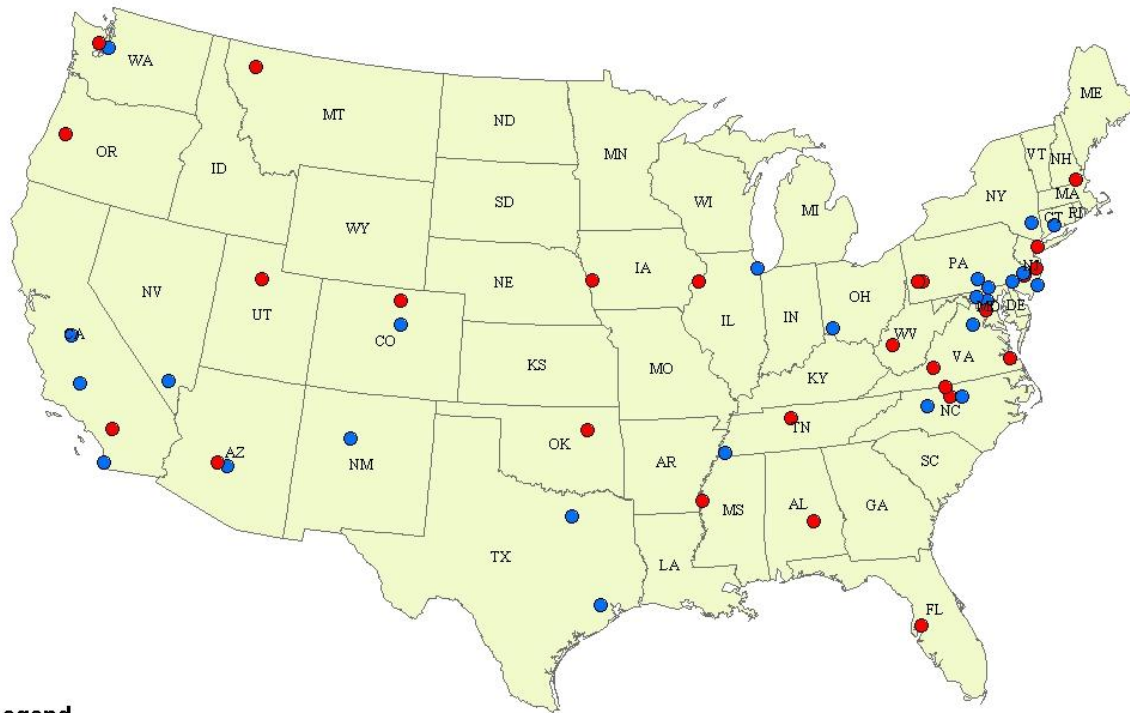
84% attended \geq 5 sessions



On average, participants attended 86% of PALS classes



PALS RCT Study

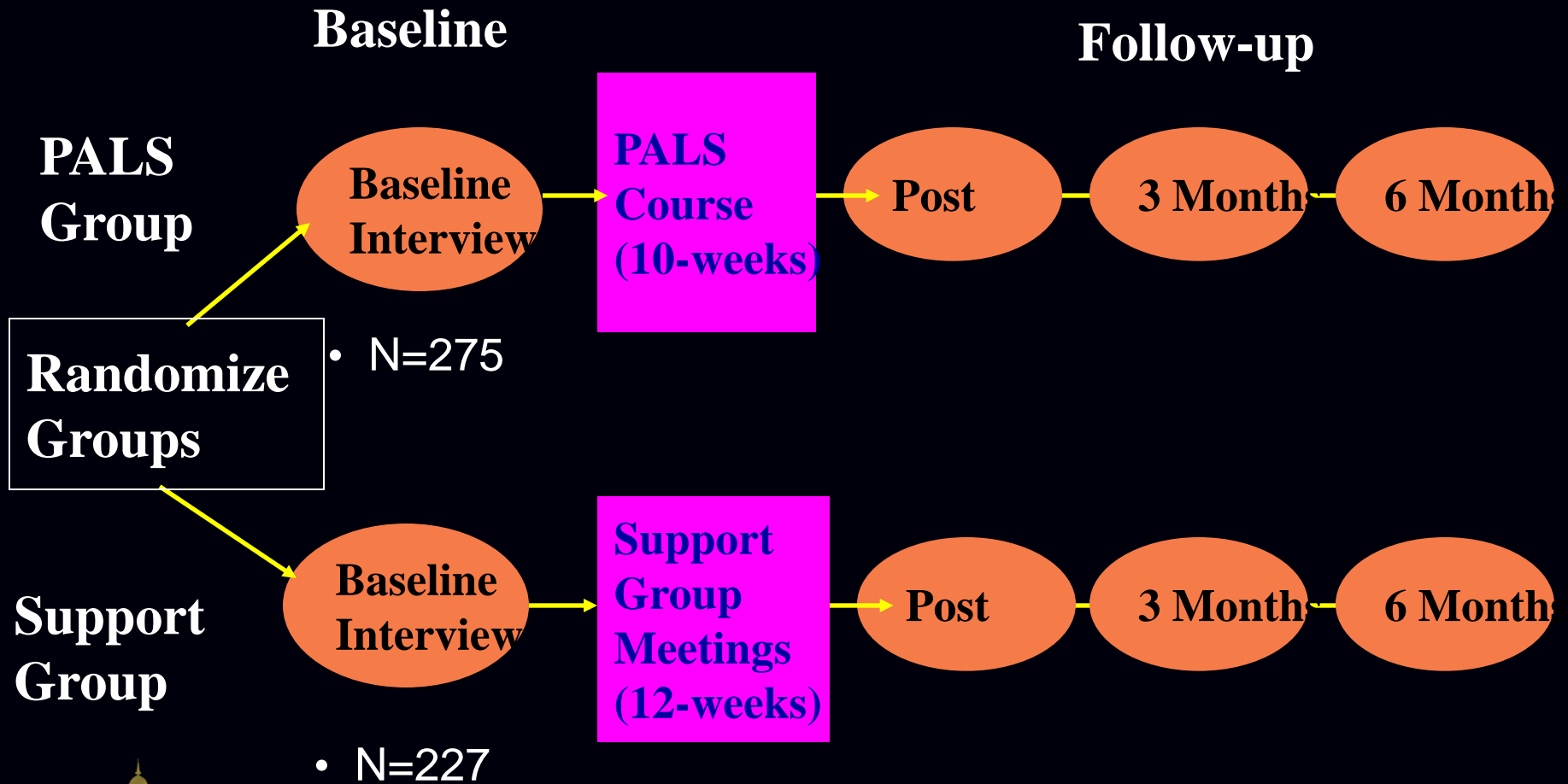


Legend

- Control
- Intervention

91 Eligible
Groups
Identified:
52 randomized

PALS RCT



PALS RCT: Results

◆ Participant Assessment

- 95% would recommend PALS to a friend

- 77% rated PALS more helpful than a support group

- 58% rated PALS more important than other services provided



PALS RCT Results

◆ Outcome Assessment

- three fold reduction in likelihood of depression

- Increased self-efficacy

- Increased positive mood

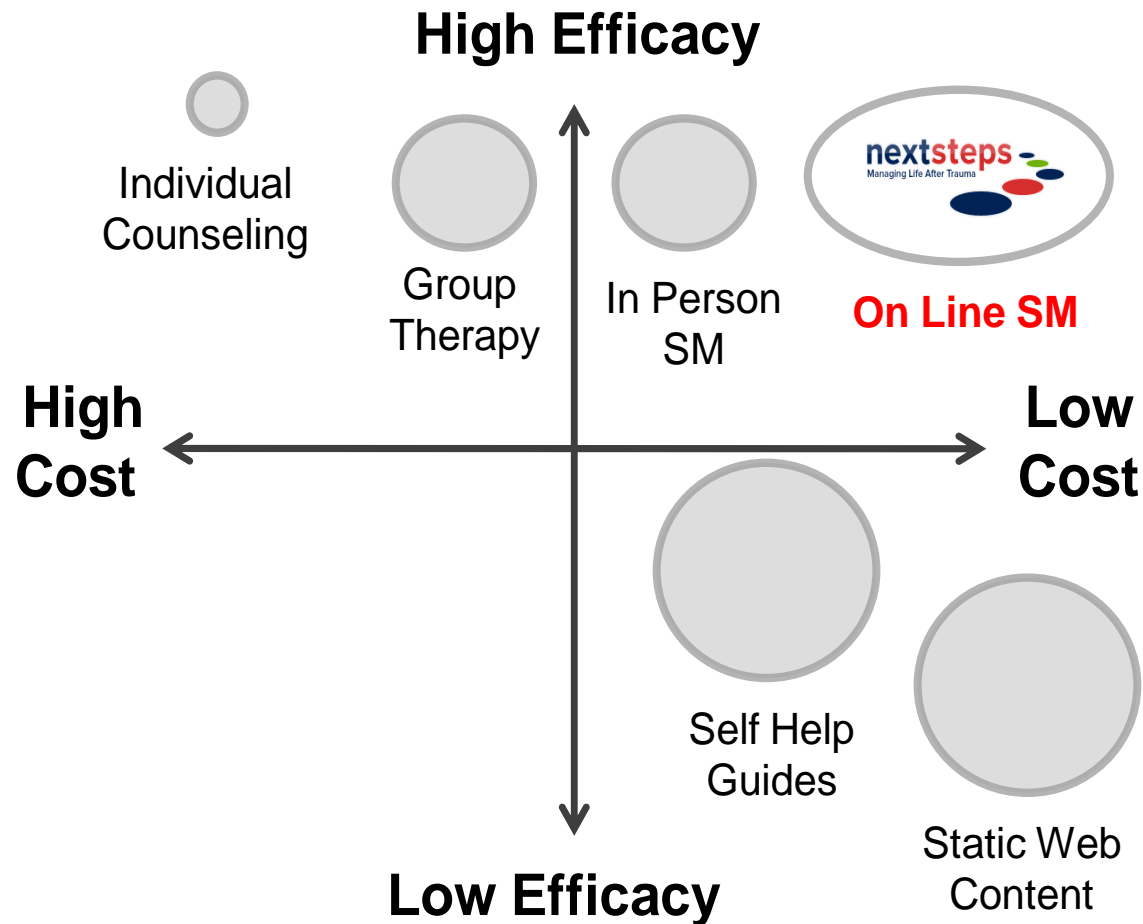
- Less likely to experience

limitations in function (Wegener, et al 2008)

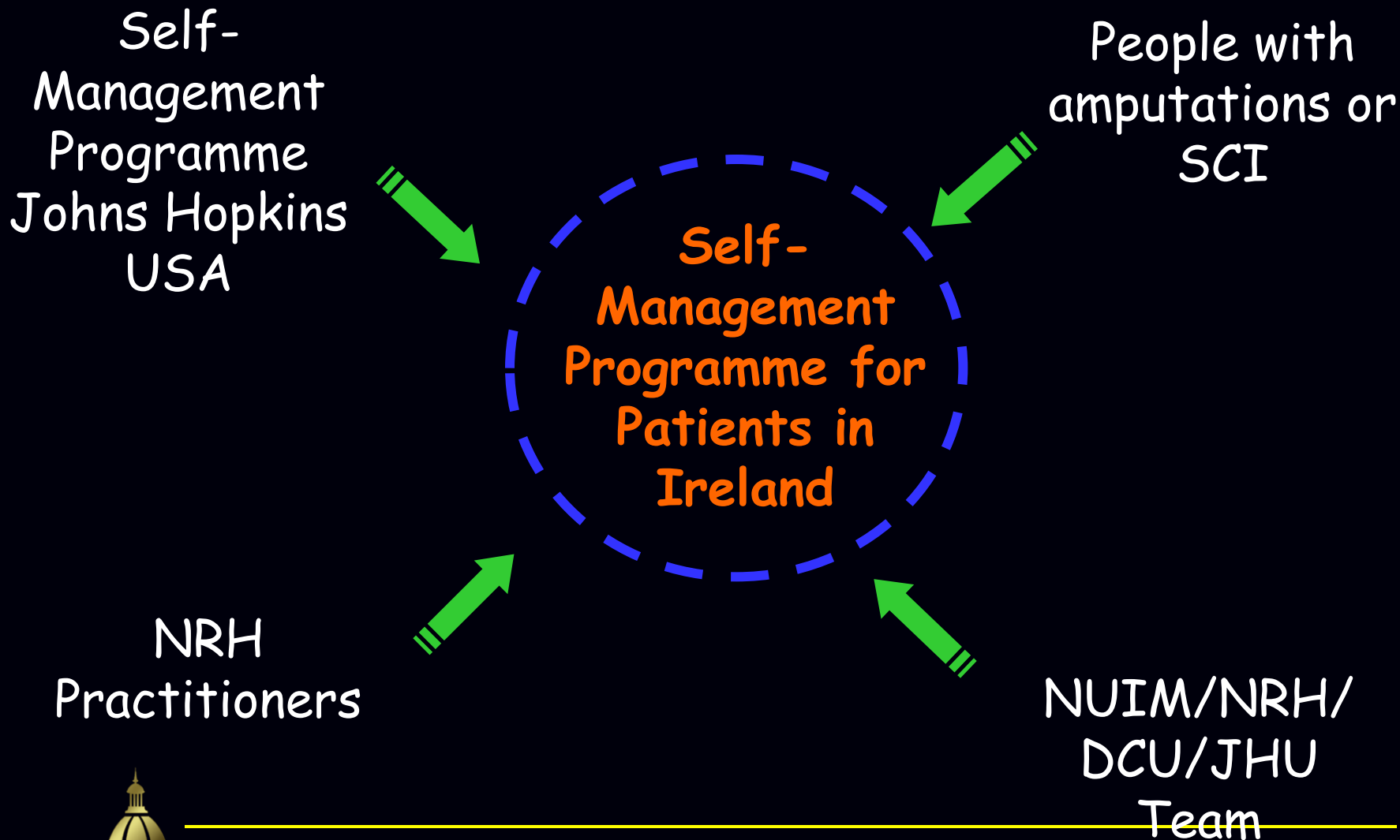


Relative Advantages of Interventions Designed to Modify Behavior

Adapted from www.healthmedia.com



Self-Management in Ireland



PARTICIPANT WORKBOOK



Self-Management Programme

Ireland and United Kingdom Edition

Sustaining Rehabilitation Outcomes

- ◆ Think evidence based policy
 - Utilize Care Standards (moderate support)
 - » Evidence based care guidelines
 - » CARF
 - Link to State/local government (limited support)
 - » Help them define disability as diversity
 - » Link disability to their mission
 - ◆ e.g Self- management programs for persons with disability



Sustaining Rehabilitation Outcomes

- ◆ Create a Supportive Culture (moderate support)
 - Patient Centered Care

 - Build prepared, proactive teams
 - » Ground providers and programs in PCC culture (moderate support)
 - » Train providers (medical, nursing, rehabilitation therapies) in use of motivational interviewing techniques to guide patients in using self-management and engaging in adaptive health behaviors (strong support)



Develop peer mentors (limited support)

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Sustaining Rehabilitation Outcomes

- ◆ Develop Continuum of Care – (strong support)
- ◆ Long term outcome monitoring – (moderate support)
 - Determine selected outcomes important to stakeholders – patients, families, society
 - Create system to monitor those outcomes
 - Maintain over years



Sustaining Rehabilitation Outcomes

- ◆ Partner with consumer and government organizations
- ◆ Explore how technology can extend your reach



Move from
a focus on
disease....



...to
creating
health

swegener@jhmi.edu

