Paralysis in the United States, Public Health, and the Christopher & Dana Reeve Foundation

Joe Canose
Vice President, Quality of Life
Christopher & Dana Reeve Foundation
Just after I regained consciousness. Dana and I dealt with ICU psychosis and prepared for surgery.
CHRISTOPHER AND DANA REEVE FOUNDATION
MISSION STATEMENT

The Christopher and Dana Reeve Foundation is dedicated to curing spinal cord injury by funding innovative research, and improving the quality of life for people living with paralysis through grants, information and advocacy.
Individual Grants
Basic – Applied Science
New Knowledge, New Talent

Spinal Cord Therapies
Recovery of Function
Improved Health
Enhanced Quality of Life

NACTN
Delivering Therapies to the Clinic

Research Consortium
Basic - Translation

NeuroRecovery Network
Translation
Fourth Task Force Meeting
Last in 2007
Guiding Document: The Public Health Action Plan
Survey Development Process 2005 - 2008

1. Assessment of Existing Data Collection Efforts
2. National Consensus Conference
3. Cognitive Testing
4. Survey Administration and Analysis
paralysis

Noun: Singular: /pa·ral·y·ses/ – Plural /pa·ral·y·sēz/

1: complete or partial loss of function especially when involving the motion or sensation in a part of the body

2: loss of the ability to move

3: a state of powerlessness or incapacity to act
First Report Of The Working Group
On Developing A Paralysis Survey Module
And An Implementation Strategy To
Gather National-Level Data On Paralysis

November, 2006

Members of the Working Group

Organizational affiliations are listed for identification purpose only, and do not imply that the findings or recommendations contained in this report have been approved by these organizations or represent the official opinions or conclusions of these organizations. Members of the working group did not attend the working on which this report is based as representatives of their organizations.

Dr. Elena Andresen
University of Florida, Gainesville

Dr. Anthony Cahill
Christopher Reeve Foundation

Dr. Michael Fox
University of Kansas

Dr. Andrew Houtenville
Cornell University

Ms. Bridgid Isworth
University of New Mexico

Dr. Gwen Jones
Centers for Disease Control and Prevention

Dr. Susan Kinne
University of Washington

Mr. Michael Manganiello
Christopher Reeve Foundation

Dr. Jennifer Rowland
University of Illinois - Chicago

Dr. David Tulsky
Kessler Rehabilitation Hospital

Dr. Glen White
University of Kansas

Ms. Mary Helen Witten
Centers for Disease Control and Prevention

Ms. Wendy Barrington
University of New Mexico

Dr. Vince Campbell
Centers for Disease Control and Prevention

Dr. John Crews
Centers for Disease Control and Prevention

Ms. Heidi Fredine
University of New Mexico

Ms. Leslie Hudson
Shepard Center

Mr. Mark Johnson
Shepard Center

Mr. Mike Jones
Shepard Center

Dr. Doug Landsman
Christopher Reeve Foundation

Mr. Dave Martin
Delta Airlines

Dr. Mark Swanson
Centers for Disease Control and Prevention

Dr. Dee Vernberg
University of Kansas

Dr. Steve Williams
Boston Medical Center

Ms. Lesley Wolf
Centers for Disease Control and Prevention
Many of us have strongly embraced the functional model of disability and...coordinate programs...not around the cause of their disability but focusing on improving their quality of life. [The functional approach to disability] offers the advantage of shared resources across condition groups...

Ed Trevathan in Drum, Krahn and Bersani, *Disability and Public Health*
Definitions

“Paralysis is a central nervous system disorder resulting in difficulty or inability to move the upper or lower extremities.”

Accident

Spinal Cord Injury

Disease or Condition

Stroke
Neurofibromatosis
Muscular Atrophy
Guillain Barre Syndrome
Cerebral Palsy
Spina Bifida

ALS/Lou Gehrig’s
Syringomyelia
Post-Polio Syndrome
Transverse Myelitis
Fredrich’s Ataxia

Multiple Sclerosis
Poisoning
Epidural infection
Chiari malformation
Surgery Complications
Other Study Phases

- Cognitive Testing
- Survey Administration by ICR between May and September, 2008
- 33,348 households in the United States
- Stratified, single-stage random-digit-dialing sample of telephone households
- Weighted: total population = 304,228,800 vs. current US Census = 305,371,797
- Oversampling of African Americans and Hispanics
One Degree of Separation
Paralysis and Spinal Cord Injury
In the United States
Prevalence of Paralysis

Margin of Error: ± 3.91%
Range = 5,377,196 to 5,814,804 at 95% confidence interval

Not Reporting Paralysis
298,632,000 98.16%

Reporting Some Form of Paralysis
5,596,000 1.84%
Causes of Paralysis

N = 5,596,000

- Spinal Cord Injury: 1,275,000 (23%)
- Multiple Sclerosis: 939,000 (17%)
- Stroke: 1,608,000 (29%)
- Other: 526,000 (9%)
- Traumatic Brain Injury: 242,000 (4%)
- Cerebral Palsy: 412,000 (7%)
- Neurofibromatosis: 212,000 (4%)
- Post-Polio Syndrome: 272,000 (5%)
- Unspecified Birth Defect: 110,000 (2%)
Causes of Spinal Cord Injuries
N=1,275,000

- Accident Working: 362,000 (28%)
- Motor Vehicle Accident: 311,000 (24%)
- Sporting/Recreation Accident: 206,000 (16%)
- Fall: 112,000 (9%)
- Victim of Violence: 57,000 (4%)
- Birth Defect: 34,000 (3%)
- Natural Disaster: 8,000 (1%)
- Other: 76,000 (6%)
- Unknown/No Response: 109,000 (9%)
Age Distribution for Respondents Indicating They are Paralyzed
N= 5,503,000

Mean Age: 52 years
Standard Deviation: 18 years
Age Distribution for Respondents Indicating They Have a Spinal Cord Injury
N = 1,263,000

Mean Age: 48 years
Standard Deviation: 15 years
Paralysis By Gender  
N = 5,588,000

Margin of Error: ± 1.474%  
Range (Females): 2,536,059 to 2,611,941  
Range (Males): 2,969,574 to 3,058,426 at 95% confidence interval

Female 2,574,000  
46%

Male 3,014,000  
54%
Spinal Cord Injury by Gender
N = 1,270,000

Margin of Error: ± 1%
Range (Females): 490,050 to 499,950
Range (Males): 766,260 to 781,740 at 95% confidence interval

Female 495,000
39%

Male 774,000
61%
Degree of Difficulty in Moving Extremities at the Current Time Reported by Individuals Indicating They are Paralyzed
N = 5,541,000

- No Difficulty: 94,000 (2%)
- Completely Unable: 903,000 (16%)
- A Little Difficulty: 921,000 (17%)
- A Lot of Difficulty: 2,043,000 (36%)
- Some Difficulty: 1,580,000 (29%)
Degree of Difficulty in Moving Extremities Reported by Those With a Spinal Cord Injury

N = 1,268,000

- No Difficulty: 37,000 (3%)
- Completely Unable: 160,000 (13%)
- A Little Difficulty: 248,000 (20%)
- Some Difficulty: 362,000 (29%)
- A Lot of Difficulty: 461,000 (35%)
Annual Household Income of Paralyzed Respondents Compared to Annual Household Income in the United States

N (Paralyzed) = 4,075,000
Annual Household Income Of Respondents Who Report a Spinal Cord Injury Compared to Annual Household Income in the United States
N (SCI) = 904,000

Ethnic Identity Of Respondents Indicating They Are Paralyzed
N = 4,796,000

- White/Caucasian: Sample 77.1%, Census 74.1%
- Black/African American: Sample 17.2%, Census 12.4%
- Native American/Alaskan Native: Sample 3.7%, Census 0.8%
- Asian: Sample 0.3%, Census 4.4%
- Two or More Races: Sample 0.1%, Census 2.1%
- Other: Sample 0.8%, Census 6.2%
Ethnic Identity Of Respondents Indicating They Have a SCI
N (SCI) = 1,043,000

Hispanic Status: Paralysis

Figure Eighteen
Hispanic Status of Paralyzed Respondents Compared to Hispanics in the United States

N (Hispanic Paralyzed) = 671,000; N (Non-Hispanic Paralyzed) = 4,874,000;
N (Both) = 5,544,000

Margin of Error: ± 1.85%
Range (Hispanic): 658,586 to 683,414 at 95% confidence interval

Hispanic Status: SCI

Figure Nineteen
Hispanic Identity Of Respondents Indicating They Have a Spinal Cord Injury
In Comparison to Hispanics in the United States
N (Hispanic SCI) = 161,000; N (Non-Hispanic SCI) = 1,108,000; N (Both) = 1,269,000

Margin of Error: ± 2%
Range (Hispanic): 157,780 to 164,220 at 95% confidence interval

Health Promotion for People with Paralysis

✓ Higher than previously estimated prevalence rate
✓ Large unmet need
✓ Study also provides information about disparities within the paralysis population indicating which cohorts could benefit most from targeted health promotion
✓ Issues around utilization of existing health promotion interventions to these populations
To designate certain land as components of the National Wilderness Preservation System, to authorize certain programs and activities in the Department of the Interior and the Department of Agriculture, and for other purposes.
TITLE XIV: Christopher and Dana Reeve Paralysis Act

Subtitle A
Paralysis Research

Subtitle B
Paralysis Rehabilitation Research and Care

Subtitle C
Improving Quality of Life for Persons with Paralysis and Other Physical Disabilities
Dana Reeve—widow of actor Christopher Reeve—shares the ways she has coped with loss and how she and her son are carrying on.

We Were Given A Gift
An Interview By Lisa Birnbach