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About This Report

This report was prepared under a multi-year cooperative agreement between the Christopher and Dana Reeve Foundation Paralysis Resource Center (PRC) and the Division of Disability and Health Policy, Center for Development and Disability (CDD) of the University of New Mexico School of Medicine. The opinions expressed in the report are solely those of the authors, and do not represent the official views of the Paralysis Resource Center or the Center for Development and Disability.

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Introduction
“Estimates of paralysis vary widely, largely owing to a lack of standard definition and non-targeted survey approaches…. To have accurate data describing the number of persons with paralysis is an important part of developing policies and practices leading to improved health and quality of life for all persons with disabilities…”¹

“Population-based sampling methods are the criterion standard in research….”²

One major goal of **Healthy People 2010** is to improve available information about people with disabilities. Identifying the scope and impact of functional limitations for people who are paralyzed is an important step toward improving their quality of life. Functional limitations faced by people who are paralyzed can potentially lead to reduced quality of life and extreme challenges to living independently in the community. Knowing how many people in the United States have some form of paralysis is an important first step in addressing this problem.

Until now, reliable estimates of the number of persons with paralysis in the United States did not exist. By not having accurate prevalence data that helps describe the full nature of the condition, developing a comprehensive public health response is impossible. To address this, the Christopher and Dana Reeve Paralysis Foundation’s Paralysis Resource Center (PRC), under the leadership of Joseph Canose, Vice President, Quality of Life of the Foundation and PRC Director, initiated a three-year process that culminated in a random digit dial population survey of over 33,000 United States households designed to capture prevalence data on paralysis.

This report details the process used to develop, administer and analyze the results of the survey. The project was directed by Dr. Anthony Cahill, Director of the Division of Disability and Health Policy of the University of New Mexico under a multi-year cooperative agreement between the PRC and the University. This document reports on the methodology used to develop the survey, including the four major phases of the project:

- Assessment of Existing Surveys, Registries and Data Collection Efforts (2005);
- A national consensus conference to develop a functional definition of paralysis and an initial version of the population survey instrument (2006);
- Cognitive testing and revision of the initial instrument (2007); and


Assessment of Existing Paralysis Data Collection Efforts: The University of Kansas Study
Under a grant from the PRC, a team from the University of Kansas led by Dr. Michael Fox conducted a national assessment to see how paralysis was defined by different organizations and surveys, and how data was collected about paralysis.\(^3\) Tasks included:

- A review of current surveys for questions related to paralysis that could be used to accurately identify persons with this condition;
- A survey of government agencies and organizations representing persons with paralysis-related disabilities to assess their surveillance capacities;
- Follow up in-depth interviews or site visits of potential ‘best practice sites’; and
- Recommendations for future paralysis-related data collection efforts targeted at collecting accurate prevalence data for paralysis.

The key finding of the University of Kansas study related to existing paralysis-related data collection efforts is that there is no uniform definition of paralysis used to capture data and that existing efforts use different methods, have different time periods and employ different sampling designs based upon different assumptions.

Key findings on existing data collection efforts included the following.

- Of the 56 state and federal agencies interviewed, 30 (54%) collected paralysis information. 22 of the 30 (73%) collected ICD codes.
- Of the 83 organizations interviewed, 14 (17%) collected some form of paralysis information. Of the 14, all reported collecting some form of state registry information.
- Of the 14 organizations collecting paralysis information, 8 (57%) considered their primary mission to be providing services or information to individuals seeking assistance.
- Of the 26 state and federal agencies not collecting paralysis information, most were Traumatic brain injury registries or Federal offices with other charges.
- Of the 69 organizations not collecting paralysis information, most were consumer and service groups.

The key finding of the study related to existing paralysis-related data collection efforts is that there is no uniform definition of paralysis used to capture data and that existing efforts use different methods, have different time periods and employ different sampling designs based upon different assumptions. Most indicators of paralysis are proxies using functional limitations.

\(^3\) Michael Fox, ScD, et. al., *Developing and Action Plan to Improve the Quality and the Quantity of Paralysis Data*. Department of Health Policy and Management, University of Kansas Medical Center, September, 2005.
on activities of daily living (e.g., walking), use of assistive equipment or International Classifi-
cation of Disease (ICD) diagnosis coding.

Based on this finding, the report made four primary recommendations.

- Develop a uniform definition of paralysis that captures the breadth of possible ways that pa-
ralysis can manifest itself. As part of initial efforts to explore this issue on the national level,
researchers need to develop a definition of paralysis that includes all people who experience
functional limitation. A conference of paralysis stakeholders could draft this paralysis defini-
tion. The goal is to have a widely accepted definition that could improve paralysis surveil-
lance and strengthen the validity and uniformity of measurement systems.

- Develop paralysis survey questions on ways that people with paralysis are limited function-
ally. This paradigm shift parallels recent changes by the World Health Organization’s (WHO)
International Classification of Functioning, Disability and Health (ICF), adopted in 2001, to
replace the International Classification of Impairment, Disability and Handicap (ICIDH) sys-
tem that focused on diagnosis from a deficit perspective.

- A national advisory group should be convened to help interpret improved surveillance infor-
mation to ensure that these data are used to benefit people who are paralyzed. Interven-
tions are practical ways that data can be used to impact daily lives and may include referrals
to organization-specific services such as health promotion programs focused on increasing
physical activity, or increased access to clinical, social, and individual information. This
group should also be involved in interpreting findings to make policy recommendations to
improve the quality of life of people who are paralyzed.

- Findings from this research can be used to recommend ways to help improve the quality
and quantity of paralysis data available to program managers and policymakers on the fed-
eral and state levels, as well as to those in private and non-profit sectors. Through improved
surveillance and understanding of paralysis and similar mobility limitations, it is hoped that
public health priorities for persons with these conditions can be more clearly identified, ulti-
imately leading to policies and strategies that can improve their quality of life.
The next step in the process of moving towards a national population survey was to implement the recommendations contained in the University of Kansas report. To begin this process, the PRC convened a two-day meeting in Decatur, Georgia on June 1st and 2nd, 2006. The **Consensus Conference to Develop a Paralysis Survey Module and an Implementation Strategy to Gather National-Level Data on Paralysis** brought together nearly thirty experts in research methodology, disability statistics, disability policy and advocacy⁴ to accomplish four tasks:

- Identify a sound theoretical framework which would inform the development of survey questions about paralysis;
- Develop a definition of paralysis that was consistent with the constituency served by the PRC and Christopher and Dana Reeve Foundation;
- Develop draft survey items and response scales that could be used to capture information on five key domains: presence or absence of paralysis consistent with the definition that was to be developed; cause; severity; duration and impact; and
- Develop potential strategies that can be used to implement a national data collection strategy regarding paralysis data.

**Theoretical Framework**

Participants adopted the conceptual framework developed by Saad Nagi⁵ which organizes information about disability on a four-step continuum (see Figure One).

---

⁴ A list of participants at the Consensus Conference may be found in Appendix A.

### Figure One

**Key Elements of Nagi’s Conceptual Framework on Disability**

<table>
<thead>
<tr>
<th>PATHOLOGY</th>
<th>IMPAIRMENT</th>
<th>FUNCTIONAL LIMITATION</th>
<th>DISABILITY</th>
</tr>
</thead>
<tbody>
<tr>
<td>Definition:</td>
<td>Interruption or interference of normal bodily processes or structures</td>
<td>Loss of physiological, anatomical or mental structure or function</td>
<td>Restriction or lack of ability to perform an action or activity in the same manner as before the impairment</td>
</tr>
</tbody>
</table>

**Level of Reference:**

<table>
<thead>
<tr>
<th></th>
<th>Cells and tissues</th>
<th>Organs and organ systems</th>
<th>Action or activity performance consistent with the purpose of the function of the organ or organ system</th>
<th>Task performance within the social and cultural environment</th>
</tr>
</thead>
</table>

**Example:**

<table>
<thead>
<tr>
<th></th>
<th>Denervated muscle in arm due to trauma</th>
<th>Atrophy of muscle</th>
<th>Cannot pull with arm</th>
<th>Change of job; can no longer swim recreationally</th>
</tr>
</thead>
</table>

Adapted from Andrew Pope and Alvin Tarloff (editors): *Disability in America: Towards a National Agenda for Prevention*. Institute of Medicine, 1991.

This framework identifies disability not as some failure or “problem” with a person, but as the interaction between a particular individual’s capabilities and the characteristics of the physical and social environment within which he or she operates.

Some of the terms used in the classification scheme are not without controversy. For example, “impairment” has a cultural as well as a medical meaning. However, it was felt that the
schema was of value in providing conceptual clarity among the multiple, often confusing levels of analysis when categorizing paralysis or even disability.

In terms of the five domains or constructs of interest (presence/absence of the condition, severity, duration, cause and impact), participants at the consensus conference agreed that the domain of “presence/absence of paralysis” is most appropriately defined at the “impairment” level of Nagi’s continuum, while the “pathology” level can be thought of as the cause. The domain of “severity” is most closely related to the functional limitation portion of the continuum.

“Disability” - the interaction between the individual’s characteristics or capabilities and the environment - is most closely linked to the “impact” domain. Conference participants decided to focus their efforts on developing items in the first three levels of the continuum, leaving the issue of developing items regarding the impact of paralysis - the “disability” level - to a later date.

In order to adequately address the impact of disability, items that focus on the complex interactions between a specific individual and his or her environment (the primary definition of “disability” in Nagi’s framework) will need to be developed from scratch or adapted from existing surveys. In addition, impact items go beyond the current needs of the PRC. While getting this information is critical over time, the initial need is to gather data on prevalence of paralysis that can be used to inform policy, programs and services.

Finally, participants decided that initial data gathering efforts should focus only on prevalence. A number of additional tasks must be undertaken, including follow-up surveys, periodic reinterviews and/or retrospective items in order to collect incidence data.

DEFINING PARALYSIS

With the adoption of this conceptual framework and subsequent agreement that the core item or items defining paralysis would be at the “impairment” level of Nagi’s classification scheme, participants developed a working definition of the term “paralysis” that incorporated the primary constituency of the PRC. The definition agreed to by participants was

**Paralysis is a central nervous system disorder resulting in difficulty or inability to move the upper or lower extremities.**
In addition to being consistent with the needs of the PRC, this definition contains explicit “counting rules” - rules that allow researchers to assign an individual as either having the condition or not. To be counted as having paralysis under this definition, the cause of an individual’s paralysis must lie within the central nervous system and it must result in some degree of difficulty or inability to move the upper or lower extremities. Thus, a range of causal conditions (“pathologies” under Nagi’s classification scheme) are excluded.

Using this definition, researchers developed an “operational definition” of paralysis. For someone to be counted as “paralyzed” in this national survey, they had to (a) answer yes to the initial screening question “Do you or does anyone in this household have any difficulty moving their arms or legs?” and (b) give one of the following causes of the difficulty:

- Spinal Cord Injury
- Traumatic Brain Injury
- Stroke
- Poisoning
- Complications from surgery
- ALS/Lou Gehrig’s
- Guillain Barre Syndrome
- Multiple Sclerosis
- Neurofibromatosis
- Epidural Infection
- Chiari malformation
- Syringomyelia
- Post-Polio Syndrome
- Spinal Muscular Atrophy
- Fredrich’s Ataxia
- Transverse Myelitis
- Cerebral palsy
- Spina Bifida

Finally, participants at the consensus conference developed an initial version of a survey instrument. The logic flow diagram of the initial instrument may be found on the following page, followed by the original version of the survey developed at the Consensus Conference.
Figure Two
Logic Flow of Original Paralysis Prevalence Surveillance Instrument

Q1.1: Difficulty in moving arms or legs?
   Yes: Q1.2: Severity

   Q1.3: Cause
   - Accident/Injury
   - Disease or Condition
   - Birth Defect
   - No Response

   Q1.4: Type of Accident
   Q1.5: Disease/Condition
   Q1.6: Birth Defect
   Q1.7: “Catch-All”

   Q1.8: When did it happen?
Figure Three
Initial Paralysis Surveillance Instrument Developed at the National Consensus Conference

[Note: response items in green in items below are included in the operational definition of paralysis.]

1.1 Do you have any difficulty moving your arms or legs?
   1 Yes Go to Q1.2
   0 No Stop

1.2 Currently, how difficult is it for you to move your arms and/or legs?
   1 No difficulty
   2 A little difficulty
   3 Some difficulty
   4 A lot of difficulty
   5 Completely unable

1.3 This difficulty in movement is due to:
   1 An accident or injury Go to Q1.4
   2 A condition or disease Go to Q1.5
   3 Something you were born with Go to Q1.6
   7 DK/NS Go to Q1.7

1.4 What accident or injury caused your difficulty in moving?
   (note: response items in green are included in the definition of “paralysis”)

   Read Only if Necessary

   01 Spinal Cord Injury
   02 Traumatic Brain Injury
   03 Stroke
   04 Poisoning
   05 Complications from surgery
   06 Brachial Plexus
   07 Broken arm or leg
   08 A soft tissue injury such as torn ligament, ACL
   09 Amputation
   10 Sacral Plexopathy
   11 Burn and Contractures

   Go to Q1.8

   Do not read 77 DK/NS

   Stop
1.5 What condition or disease caused your difficulty in moving?
(note: response items in green are included in the definition of "paralysis")

Read Only if Necessary

12 Amyotrophic Lateral Sclerosis (ALS/Lou Gehrig’s Disease)
13 Guillain Barre Syndrome
14 Multiple Sclerosis
15 Neurofibromatosis
16 Epidural infection
17 Chiari malformation
18 Syringomyelia
19 Post-Polio Syndrome
20 Fredrich’s Ataxia
21 Spinal Muscular Atrophy
22 Transverse Myelitis
23 Myasthenia Gravis
24 Muscular Dystrophy
25 Lyme Disease

Do not read 77 DK/NS

1.6 What condition were you born with that caused your difficulty in moving?

Read Only if Necessary

26 Cerebral palsy
27 Spina Bifida

Go to Q 1.8

1.7 I am going to list some possible things that could have caused your difficulty moving.
Which of these do you think caused your difficulty in moving?

01 Spinal Cord Injury
02 Traumatic Brain Injury
03 Stroke
04 Poisoning
05 Complications from surgery
12 Amyotrophic Lateral Sclerosis (ALS/Lou Gehrig’s Disease)
13 Guillain Barre Syndrome
14 Multiple Sclerosis
15 Neurofibromatosis
16 Epidural infection
17 Chiari malformation
18 Syringomyelia
19 Post-Polio Syndrome
20 Fredrich’s Ataxia
21 Spinal Muscular Atrophy
22 Transverse Myelitis
26 Cerebral palsy
26       Spina Bifida

Do not read  77       DK/NS
1.8  When did this happen?

Read Only if Necessary

1       Less than a year ago
2       1 year ago
3       2-5 years ago
4       6-14 years ago
5       15+ years ago

Do not read  7       DK/NS
The Cognitive Testing Process
In an eighteen month period following the Consensus Conference, project research staff began the cognitive testing process of the initial instrument. Cognitive pre-testing uses a combination of qualitative and quantitative methods to examine items on an instrument to:

- Ensure that the items are understood by respondents in the same way as developed by researchers (ensure shared meaning between item developers and respondents);
- Ensure that items are understood in the same way across respondents (ensure shared meaning across respondents);
- Identify items or sets of items that are confusing or ambiguous to respondents, thus leading to high error rates in response or high rates of responses such as "don't know," "not sure" or even "refused to answer"; and
- Identify gaps in the logical flow of instruments that interfere with its ability to produce valid responses.

The cognitive pre-testing process was completed over a period of eighteen months, and included the following components:

- **Expert panel review:** the initial draft of the instrument was reviewed by an expert panel of physicians from the University of New Mexico School of Medicine to assess inclusion rules used to categorize causes into central nervous system disorders or exclude them.

- **Reactor panel at the June, 2006 meeting of the Paralysis Task Force:** approximately sixty participants at this meeting in Washington, D.C with and without paralysis completed a paper-and-pencil version of the initial instrument. Results were complied and presented to participants, who then took part in a reactor panel the next day in which they critiqued the instrument and made suggestions for revisions.

- **Focus Groups:** PRC Research staff at the University of New Mexico conducted recruited approximately fifty individuals to have the instrument administered to them over the phone and then participate in one of five focus groups, including one targeted specifically at members of the Native American community.

- **Pilot Telephone Administration:** the firm selected to conduct the national survey, ICR International of Media, Pennsylvania, ran the initial instrument with a random-dial telephone survey of approximately 1,200 individuals across the country.

**Results and Revisions to the Instrument**

Based on this multi-method cognitive pre-testing process, a number of weaknesses were identified in the initial instrument. These are identified below, along with a discussion and changes (if any) made to the initial instrument as a result. Item numbers on the pages that follow refer to items in the initial version of the survey above.
One: Birth Defect as a Category of Cause of Paralysis

**Issue:** Many respondents were unclear as to which conditions were birth defects and which were acquired after birth, resulting in an inability to answer item 1.3 (category of causal condition).

**Discussion:** Instrument developers assumed a level of knowledge among respondents that was not born out in the cognitive pre-testing.

**Revision:** Item 1.3 was provisionally revised to include only two categories - accident/injury or condition/disease. This revised item was later deleted.

Two: Categorization of Causes Into Accident/Injury or Disease/Condition

**Issue:** While subsequent versions of the instrument did not contain “birth defect” as a category, the pre-categorization of responses remained confusing to test respondents.

**Discussion:** Some respondents were immediately able to specify a cause such as “spina bifida” or “spinal cord injury,” others responded that they were in an accident. The logic flow of the initial survey clearly did not match the thought processes of respondents. A more flexible logic flow was needed that was able to lead respondents to the ultimate cause of the paralysis.

**Revision:** The item that contained pre-categorizations of paralysis causes was eliminated, and replaced by a question that was able to accommodate answers (a specific disease or a result of an accident such as spinal cord injury) while at the same time providing branches that led respondents through question chains designed to capture specific cause information regardless of their initial response to the item.

Three: Elapsed Time Since Paralysis Began

**Issue:** The initial version of the instrument pre-categorized elapsed time since the respondent had been paralyzed (see item 1.8). High numbers of respondents paused before answering the question, or were unable to provide an answer.

**Discussion:** Follow-up focus groups and interviews revealed that most respondents were most familiar with the specific year that they had become paralyzed, and the numerous pauses occurred while they were counting elapsed years and converting that number into the categories supplied. Instrument developers assumed a level of knowledge among respondents that was not born out in the cognitive pre-testing.

**Revision:** Item 1.8 was revised to ask for the year in which they became paralyzed.
**Four: Inability to Capture Specific Information on Types of Accidents and Injuries**

**Issue:** While the initial version of the instrument sought to capture the result that occurred from an injury or accident (e.g., spinal cord injury, traumatic brain injury, etc.) it was not able to capture the type of accident that caused these and other disabilities listed (see item 1.4).

**Discussion:** Information on what type of accident or injury caused the paralysis would be helpful to the PRC and Foundation, as well as the policymaking community and other disability organizations.

**Revision:** A new item was developed that asks for the type of accident that caused the paralysis. The new item was developed based on a framework developed by the Centers for Disease Control and Prevention categorizing causes of external injuries.6 This item was incorporated into the revised logic flow of the instrument (see below).

**Figure Four**
**Added Item on Type of Accident or Injury That Caused Paralysis**

<table>
<thead>
<tr>
<th>READ:</th>
<th>What type of accident or injury caused your difficulty in movement?</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>Motor Vehicle Accident</td>
</tr>
<tr>
<td>2.</td>
<td>Victim of violence, (either attack by someone else or accidental (shooting, assault, knife wound,))</td>
</tr>
<tr>
<td>3.</td>
<td>Accident in Sporting / Recreation / Athletic event (sports, waterskiing, skiing, etc.)</td>
</tr>
<tr>
<td>4.</td>
<td>Fall (at home, in the workplace, while walking, in shower, etc.)</td>
</tr>
<tr>
<td>5.</td>
<td>Fire or burn</td>
</tr>
<tr>
<td>6.</td>
<td>Accident working w/ machinery (home or workplace)</td>
</tr>
<tr>
<td>7.</td>
<td>Other:________________________________________________________</td>
</tr>
</tbody>
</table>

---

**Five: Incomplete Response List For Conditions and Diseases**

**Issue:** Respondents gave conditions or diseases not on the item response list in the initial version of the survey.

**Discussion:** While these responses are not disorders of the central nervous system, it was decided to list them to capture information on causes both within and outside the definition of paralysis used by the PRC.

**Revision:** The following additions were made to item 1.4: "Embolism/Blood Clot", and "Pinched Nerve / Nerve Damage / Slipped Disk."

**Six: Additional Information**

**Issue:** Additional types of missing information were noted, including whether the accident that caused paralysis was the result of serving in the military.

**Discussion:** This and other types of information were thought to be useful.

**Revision:** An item was added on military-related accidents.

The revised logic flow of the final instrument may be found on the next page, while a copy of the final instrument follows.
Note: numbers in boxes refer to item response codes in final version of the instrument.
Figure Six
Final Paralysis Prevalence Instrument

PA-1 Do you or does anyone in this household have any difficulty moving their arms or legs? (IF YES, PROBE IF SELF OR SOMEONE ELSE IN HOUSEHOLD)

1 Yes, Respondent ASK PA-2
2 Yes, Other In Household ASK PA-2
3 No SKIP TO NEXT INSERT
D Don't Know SKIP TO NEXT INSERT
R Refused SKIP TO NEXT INSERT

PA-2 What caused this difficulty in movement? (DO NOT READ) (ACCEPT ALL THAT APPLY)

01 Accident/Car accident/Injury/Fall
02 Arthritis
03 Broken arm or leg
04 Cancer (any type)
05 Cerebral palsy*
06 Diabetes
07 Fibromyalgia
08 Heart problems/disease
09 Joint replacement (knee, hip, etc.)
10 Knee/ Foot/ Leg Problems/surgery
11 MD/ Muscular Dystrophy (DIS-TRO-FEE)
12 MS/ Multiple Sclerosis (SCLUURR-OH-SIS)*
13 Neurofibromatosis (N OR-OH-FIE-BRO-MAH-TOE-SIS)*
14 Old Age/ Years of hard work/wore out
15 Osteoporosis (OSS-TEA-OH-PORE-OH-SIS)
16 Pinched Nerve
17 Post-Polio Syndrome*
18 Sciatica Nerve
19 Slipped/ Herniated/ Ruptured Disc
20 Soft tissue injury such as torn ligament, ACL
21 Spinal Cord Injury/ SCI *
22 Stomach/ Liver/ Lung/ Kidney problem (other internal organ mentions)
23 Stroke*
24 Surgical Complications
25 Traumatic Brain Injury/ TBI*
26 Wrist/ Arm/ Shoulder problem
97 Other (SPECIFY) _______
DD Don't Know
RR Refused

(IF ONLY MENTION IS 02, 03, 04, 06, 07, 08, 09, 10, 11, 14, 15, 16, 18, 19, 20, 22, OR 26, SKIP TO NEXT INSERT)

PLEASE USE THE FOLLOWING QUALIFYING CONDITIONS FOR CODING BUT DO NOT SHOW ON CATI SCREEN:

27 ALS/ Lou Gehrig's Disease/ Amyotrophic Lateral Sclerosis*
28 Chiari malformation*
29 Epidural infection*
30 Fredrich's Ataxia*
31 Guillain Barre Syndrome*
32 Poisoning*
33 Spina Bifida*
34 Spinal Muscular Atrophy*
35 Syringomyelia*
36 Transverse Myelitis*

(If "Other" or "Don't Know/Refused" in PA-2, Ask PA-3. ALL OTHERS SKIP TO PA-4 Instruction.)

PA-3. Was this caused by an accident or being injured in some way or was it caused by a disease or medical condition?

1 An accident or injury ASK PA-4
2 A disease or condition SKIP TO PA-6 INSTRUCTION
D (DO NOT READ) Don't Know SKIP TO PA-6 INSTRUCTION
R (DO NOT READ) Refused SKIP TO PA-6 INSTRUCTION

(If PA-2 = ACCIDENT/INJURED, SPINAL CORD INJURY OR TRAUMATIC BRAIN INJURY, OR IF PA-3 = ACCIDENT/INJURY, ASK PA-4- USE ALTERNATE WORDING) (ALL OTHERS SKIP TO PA-6 INSTRUCTION).

PA-4 (IF PA-2 OR 3 = ACCIDENT/INJURED, READ AS:)
What type of accident or injury caused the difficulty in movement?
(IF PA-2 = SPINAL CORD INJURY, READ AS: What caused the spinal cord injury?
(IF PA-2 = TRAUMATIC BRAIN INJURY, READ AS:)
What caused the traumatic brain injury?
(READ LIST IF NEEDED. ACCEPT MULTIPLES.)

01 Accident in Sporting / Recreation / Athletic event (sports, waterskiing, skiing, etc.)
02 Accident working (home or workplace)
03 Fall (at home, in the workplace, while walking, in shower, etc.)
04 Fire or burn
05 Motor Vehicle Accident
06 Victim of violence, (either attack by someone else or accidental - shooting, assault, knife wound,)
97 Other (SPECIFY) ________
DD Don't Know
RR Refused

(If PA-4 = 02,03,04, 06 OR 97, DD, RR ASK PA-4a)
PA-4a Was this a result of serving in the military?

1 Yes
2 No
D Don't Know
R Refused

(If PA-2 OR 3 = ACCIDENT/INJURED, OR PA-2 = SURGICAL COMPLICATIONS (USE ALTERNATE WORDING IN QUESTION), ASK PA-5. OTHERS SKIP TO Q.PA-6 INSTRUCTION.)

PA-5 Can you recall the diagnosis (you/this person) received from the accident or injury/surgical complications)?
(READ IF NEEDED)

01 Spinal Cord Injury/SCI
02 Traumatic Brain Injury/TBI
03 "C"/cervical mentions (eg. C-5) (spine location)
04 "L"/lumbar mentions (eg. L-3) (spine location)
05 "T"/Thoracic mentions (eg. T-1) (spine location)
06 Amputation
07 Back Injury/Lower Back Injury
08 Broken/Injured arm/leg/ankle/wrist/shoulder
09 Bullet/Military Wound
10 Knee/Hip Injury/Replacement/Problems
11 Nerve Damage
12 Pinched Nerve
13 Slipped/Herniated/Ruptured Disc
14 Spine/Spinal Disc Injury
15 Torn/sprained ligament/rotary cup/cartilage/meniscus/ ACL (soft tissue injury)
97 Other (SPECIFY) _____
DD Don’t Know
RR Refused

(IF PA-5=03,04, 05,07,09,11,12,13,14,97, DD OR RR, ASK PA-5a. OTHERS SKIP TO PA-6 INSTRUCTION)
PA-5a Did this result in damage to (your/this person’s) spinal cord?
1 Yes
2 No
D Don’t Know
R Refused

(IF PA-2= 05,12,13,17,21,23,25 OR PA-3=2DR OR PA-5=01,02 OR PA-5a=1DR, ASK PA-6. ALL OTHERS SKIP TO NEXT INSERT.)
PA-6 Currently, how much difficulty (do you/does this person) have moving (your/their) arms and/or legs? (READ LIST)
1 No difficulty
2 A little difficulty
3 Some difficulty
4 A lot of difficulty
5 Completely unable
D (DO NOT READ) Don’t Know
R (DO NOT READ) Refused

PA-7 What year did this happen or first start?
(INTERVIEWER NOTE: IF RESPONDENTS SAYS “AT BIRTH” OR “THEY WERE BORN LIKE THAT” THEN ENTER THE YEAR OF BIRTH HERE.)

___________ ENTER A YEAR (4 DIGITS) (RANGE 1910-2008)
DD Don’t Know
RR Refused

(IF PA-1=^2, ASK PA-8. OTHERS SKIP TO NEXT INSERT.)
PA-8 Please tell me who in your household has the difficulty moving their arms or legs?
01 Aunt
02 Brother
03 Daughter
04 Father
PA-9. How old is this person who has difficulty moving their arms and legs?

_____ ENTER AGE (1-97)
LL Less than one year old
DD Don't Know
RR Refused

PA-10 What is the last grade of school they have completed?

01 Too young for school
02 Eighth Grade
03 Less than High School
04 High School
05 Some college
06 Graduated College
07 Technical School
08 Post Graduate
DD Don't Know
RR Refused

PA-11 Are they of Hispanic origin or background?

1 Yes
2 No
D Don't Know
R Refused

PA-12 Would you consider this person with moving difficulties to be White, Black or of some other race?

If "other" say: "I'm not referring to their nationality. I just want to know if you consider them to be white or black."

1 White
2 Black or African American
3 Asian/Oriental/Chinese/Japanese
4 Native American/American Indian/Alaskan Native
5 Native Hawaiian and other Pacific Islander
7 Other (SPECIFY)________________
R Refused
Geographic Region:
STATE

Coded 1-51 alphabetically: Alabama to Wyoming and including District of Columbia

METRO

1 Center City (Metro)
2 Center City Country (Metro)
3 Suburban (Metro)
4 Non Center City (Metro)
5 Non-Metro

REGION

1 North East
2 North Central
3 South
4 West

DIVISION

1 New England
2 Mid Atlantic
3 East North Central
4 West North Central
5 South Atlantic
6 East South Central
7 West South Central
8 Mountain
9 Pacific

Z-1. IS YOUR HOME OWNED OR RENTED?

1 Owned
2 Rented
8 Don’t Know
9 Refused

Z-2. ARE YOU ...?

1 Single, never married
2 Single, living with a partner
3 Married
4 Separated
5 Widowed
6 Divorced
9 Refused

Z-3. WOULD YOU CONSIDER YOURSELF TO BE THE (MALE/FEMALE) HEAD OF THIS HOUSEHOLD?

1 Yes
2 No
3 Don’t Know
4 Refused
Z-4. CURRENTLY, ARE YOU YOURSELF EMPLOYED FULL-TIME, PART-TIME, OR NOT AT ALL?

1. Full-time
2. Part-time
3. Not Employed
4. Refused

Z-5. ARE YOU ...?

0. Other
1. Retired
2. A Homemaker
3. A Student
4. Temporarily unemployed
5. Disabled/Handicapped
8. Don't Know
9. Refused

Z-6. INCLUDING YOURSELF, HOW MANY PEOPLE ARE THERE LIVING IN YOUR HOUSEHOLD?

1. One
2. Two
3. Three
4. Four
5. Five
6. Six
7. Seven
8. Eight or more
9. Refused

Z-6A. HOW MANY OF THESE ARE ADULTS, 18 OR OLDER?

1. One
2. Two
3. Three
4. Four
5. Five
6. Six
7. Seven
8. Eight or more
9. Refused

Z-6AA. HOW MANY OF THESE ADULTS ARE MALE?

0. None
1. One
2. Two
3. Three
4. Four
5. Five
6. Six
7. Seven
8. Eight
9. Refused

Z-6AB. HOW MANY OF THESE ADULTS ARE FEMALE?

0. None
1. One
2. Two
3. Three
4. Four
5. Five
Six
Seven
Eight
Refused

Z-6B. HOW MANY ARE CHILDREN 12 TO 17?
None
One
Two
Three
Four
Five
Six
Seven
Eight or more
Refused

Z-6C. HOW MANY ARE CHILDREN 6 TO 11?
None
One
Two
Three
Four
Five
Six
Seven
Eight or more
Refused

Z-6D. HOW MANY ARE CHILDREN UNDER 6?
None
One
Two
Three
Four
Five
Six
Seven
Eight or more
Refused

Z-7. WHAT IS YOUR AGE?
Enter AGE ___ ___

Z-8. WHAT IS THE LAST GRADE OF SCHOOL YOU COMPLETED?
Less than High School Graduate
High School Graduate
Some College
Graduated College
Graduate School or More
Technical School/Other
Refused
Z-9. IS YOUR TOTAL ANNUAL HOUSEHOLD INCOME FROM ALL SOURCES, AND BEFORE TAXES ...?
1 Less than $10,000
2 $10,000 but less than $15,000
3 $15,000 but less than $20,000
4 $20,000 but less than $25,000
5 $25,000 but less than $30,000
6 $30,000 but less than $40,000
7 $40,000 but less than $50,000
8 $50,000 but less than $75,000
9 $75,000 but less than $100,000
10 More than $100,000
13 $50,000 and over
14 Under $50,000
98 Don’t Know
99 Refused

Z-10. ARE YOU OF HISPANIC OR BACKGROUND?
1 Yes
2 No
8 Don’t Know
9 Refused

Z-10a. ARE YOU WHITE HISPANIC OR BLACK HISPANIC?
1 White
2 Black
9 Refused

Z-11. WOULD YOU CONSIDER YOURSELF TO BE WHITE, BLACK OR OF SOME OTHER RACE?
0 ther
1 White
2 Black or African American
3 Asian/Oriental/Chinese/Japanese
4 Native American/American Indian /Alaskan Native
9 Refused

Z-11a. GENERALLY SPEAKING, DO YOU USUALLY THINK OF YOURSELF AS:
0 Other
1 A Republican
2 A Democrat
3 An Independent
8 Don’t Know
9 Refused

Z-11b. ARE YOU REGISTERED TO VOTE AT YOUR PRESENT ADDRESS?
1 Yes
2 No
8 Don’t Know
9 Refused

Z-12. BESIDES THE TELEPHONE NUMBER I REACHED YOU ON, HOW MANY OTHER TELEPHONE NUMBERS, IF ANY, DOES YOUR HOUSEHOLD HAVE?
0 None
1 One
2 Two
<table>
<thead>
<tr>
<th>Number</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>3</td>
<td>Three</td>
</tr>
<tr>
<td>4</td>
<td>Four or more</td>
</tr>
<tr>
<td>9</td>
<td>Refused</td>
</tr>
</tbody>
</table>

Enter Sex of Respondent

<table>
<thead>
<tr>
<th>Number</th>
<th>Sex</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>Male</td>
</tr>
<tr>
<td>1</td>
<td>Female</td>
</tr>
</tbody>
</table>
Survey Administration
The final version of the survey was administered by ICR International, a nationally-recognized research and polling firm over twenty-six weeks in 2008. ICR conducted telephone interviews nationally between May and August 2008 with adults in 33,348 households in the United States. Since both African Americans and Hispanics are under represented in random national surveys, oversamples were conducted with both groups to obtain larger sample sizes for analysis. The 33,348 surveys were split by the following three methodologies:

- ~30,000 national household surveys using ICR’s EXCEL Omnibus (~1,000 in each of 30 waves)
- ~2,000 using ICR’s HispanicEXCEL Omnibus (~1,000 in each of 2 waves)
- ~1,000 via a custom study of African Americans

The average survey length was five minutes (the questionnaire follows in the appendix).

Because this is a sample, and not an actual population, an associated margin of error applies. At a 95% level of confidence, the margin of error for the 33,348 total respondents is +/- .54. This essentially means that we can be 95% certain that, for any percentage result for the total sample, the “true” percentage is within the .54 percentage points of that which is actually reported.7

ICR EXCEL and Hispanic EXCEL Questionnaire Design and Respondent Information

Each EXCEL and HispanicEXCEL is composed of two distinct parts. The first part is the series of inserts containing proprietary questions. Because of the broad range of subjects in any particular wave, an appropriate transitional statement introduces each section to ensure complete respondent understanding and attention. Placement of each insert is determined by overall question flow.

The second part of the questionnaire includes standard demographic/classification data:

<table>
<thead>
<tr>
<th>Respondent Demographics</th>
<th>Household Characteristics</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Age</td>
<td>• Income</td>
</tr>
<tr>
<td>• Sex</td>
<td>• Own/Rent</td>
</tr>
<tr>
<td>• Education</td>
<td>• Household Size/Composition</td>
</tr>
<tr>
<td>• Employment Status</td>
<td>• Number of telephone numbers serving sample household</td>
</tr>
<tr>
<td>• Race</td>
<td></td>
</tr>
<tr>
<td>• Marital Status</td>
<td></td>
</tr>
<tr>
<td>• Political Affiliation</td>
<td></td>
</tr>
</tbody>
</table>

7 Confidence intervals are reported in the briefing documents containing survey results where applicable.
For HispanicEXCEL, additional characteristics were obtained:

**Hispanic Characteristics**
- Country of Origin
- Language
- Acculturation

Detailed geographic data are also included in each respondent record. This facilitates the specification of custom geographic breaks for tabulation or sampling purposes. The standard geographic information consists of:
- Census Region (4) / Division (9)
- Time Zone
- State/County Code
- MSA/PMSA
- ADI
- County Size Designation (i.e., A, B, C, D counties)
- Metropolitan Status Code

1) Metro
   a) center city of metro area
   b) center city county of metro area
   c) county MSA (i.e., no designated central city)
   d) non-central city county of metro area

2) Non-metropolitan county

**Sample Design**

**ICR EXCEL Omnibus**

Each EXCEL survey consists of a minimum of 1,000 interviews, 1/2 with men and 1/2 with women. EXCEL uses a fully-replicated, stratified, single-stage random-digit-dialing (RDD) sample of telephone households. Sample telephone numbers are computer generated and loaded into on-line sample files accessed directly by the CRT system. Within each sample household, one adult respondent is randomly selected using a computerized procedure based on the "Most Recent Birthday Method" of respondent selection.

**ICR Hispanic EXCEL Omnibus**

A stratified sample via the Optimal Sample Allocation sampling technique is used for HispanicEXCEL. This technique provides a highly accurate sampling frame thereby reducing the cost per effective interview. In this case, we examine a list of all telephone exchanges within the contiguous United States and list them in descending order by concentration of
Latino households. We then divide these exchanges into various groups, or strata, based on the coverage of Latino households per stratum.

The primary stratification variables are the estimates of Latino household incidence and surname status in each NPA-NXX (area code and exchange) as provided by the GENESYS System – these estimates are derived from Claritas and are updated at the NXX level with each quarterly GENESYS database update. The basic procedure is to rank all NPA-NXXs in the US by the incidence of Latino households. This array is then divided into five sets of NXXs, each with a different grouping of exchanges based on incidence and surname status. Sample generation within each defined stratum utilized a strict epsem sampling procedure, providing equal probability of selection to every telephone number.

**Custom African American Oversample**

A stratified sample via the Optimal Sample Allocation sampling technique similar to that used for the for HispanicEXCEL sample was used for the African American oversample. The sample of telephone exchanges was divided by the likelihood of reaching an African American household. Specifically, the 25% of African Americans who reside in exchanges with the greatest incidence of reaching an African American household are placed into a "very high" strata. This is subsequently done for the rest of the sample, as the next 25% are placed into a High strata, followed by a Medium and a Low strata. Strata with high incidences of reaching African Americans (Very High) are disproportionately sampled so that a greater number of interviews are attained in these strata than one would attain in a non-stratified sample. Conversely, fewer African American interviews are conducted in the Low and Medium as would be expected based on the proportion of households one finds in the telephone exchanges that reside in this strata in the overall population. Again, a design weight rebalanced completed interviews back to nationally representative proportions.
Weighting

The customized weighting for this study was conducted in two stages. The first stage corrected for the disproportionality of the HispanicEXCEL design. This sample weight was then applied to the second stage, in which the data was weighted to 2008 Current Population Survey estimates on education, age, region, and gender. This was done separately for each racial group, and each group was balanced to their overall proportion in the population, so that when each group was combined with the other the sample, it was representative of the overall population. As well, this procedure ensures each racial group is representative in isolation.

One goal of this study was to be able to project the number of paralyzed individuals in the United States. The current weighted adult (18+) census population figure is 228,400,000. Since qualification for paralysis was asked in terms of anyone in household to boost incidence of reaching people with paralysis, we needed to project to the total population figure which would include under 18 year olds in the data. To accomplish this, after weighting the data using population weights of adults 18+ as described in the paragraph above, we took the adult population number and divided it by the weighted mean number of adults in a household that we encountered (2.14) to calculate the number of total households.

ICR then took that figure and multiplied it by the weighted mean number of total people (including children) in each household (2.85). The resulting total population figure was 304,228,800. As October 9, 2008, the US census estimate for current population is 305,371,797 which is virtually on target with the 304,229,000 figure that is the projected weighted total population. Percentage amounts on both weighted sets of tables (weighted adult population and weighted total population) are the same, it is just the projected weighted numbers for using to project number suffering the various conditions which are different.

Data Cleaning and Analysis

Survey results were transferred from the original dataset used by ICR and transferred to the Statistical Package for the Social Sciences (SPSS) and sent to the University of New Mexico for analysis. Project staff verified the data using possible code analysis and case-level verification of a random sample of the 33,000 household responses.

The data dictionary for the analysis database may be found on the next page.
### Figure Seven
Paralysis Survey Data Dictionary

<table>
<thead>
<tr>
<th>Variable Name</th>
<th>Label</th>
<th>Values or Definition</th>
</tr>
</thead>
<tbody>
<tr>
<td>ID</td>
<td></td>
<td>A combination of caseid and week, giving each case a unique identification.</td>
</tr>
<tr>
<td>caseid</td>
<td></td>
<td>Case identification which begins at 0001 for each week.</td>
</tr>
<tr>
<td>week</td>
<td></td>
<td>The number week that pertains to a specific wave of Omnibus, ICR's weekly survey tool.</td>
</tr>
<tr>
<td>hohwght</td>
<td></td>
<td>Household weight</td>
</tr>
<tr>
<td>popwght</td>
<td></td>
<td>Population weight for adults 18+ only</td>
</tr>
<tr>
<td>popfact</td>
<td></td>
<td>Population weight for entire population, adults and children</td>
</tr>
<tr>
<td>state</td>
<td></td>
<td>Abbreviation for state in the US</td>
</tr>
</tbody>
</table>
| neilsen       |       | A=highly urbanized counties  
B=relatively urmanized counties  
C=relatively rural counties  
D=very rural counties |
| metro         |       | 1= Center City (metro)  
2= Center City Country (metro)  
3= Suburban (metro)  
4= Non-Center City (metro)  
5= Non-metro |
| region        |       | 1= North East  
2= North Central  
3= South  
4= West |
| Division            | 1= New England      
|                    | 2= Mid Atlantic     
|                    | 3= East North Central
|                    | 4= West North Central
|                    | 5= South Atlantic   
|                    | 6= East South Central
|                    | 7= West South Central
|                    | 8= Mountain         
|                    | 9= Pacific          
| owner              | Is your house owned or rented? |
|                    | 1= Owned            
|                    | 2= Rented           
|                    | 3= Don't know       
|                    | 4= Refused          
| married            | Are you…            |
|                    | 1= Single, that is never married |
|                    | 2= Single, Living with a partner |
|                    | 3= Married          
|                    | 4= Separated        
|                    | 5= Widowed          
|                    | 6= Divorced         
|                    | 9=Refused           
| hoh                | Would you consider yourself to be the (male/female) head of this household? |
|                    | 1= Yes              
|                    | 2= No               
|                    | 8= Don't know       
<p>|                    | 9= Refused          |</p>
<table>
<thead>
<tr>
<th>Question</th>
<th>Details</th>
</tr>
</thead>
</table>
| **employ1** | Currently, are you yourself employed full-time, part-time, or not at all? | 1= Full-time  
2= Part-time  
3= Not employed  
9=Refused |
| **employ2** | Are you…? (Asked if employ1 = 3 (not employed)) | 0= Other  
1= retired  
2= A homemaker  
3= A student  
4= Or temporarily unemployed  
5= Disabled/Handicapped  
8= Don’t know  
9= Refused |
| **z6** | Including yourself, how many people are there living in your household? | 1= One  
2= Two  
3= Three  
4= Four  
5= Five  
6= Six  
7= Seven  
8= Eight or more  
9= Refused |
<table>
<thead>
<tr>
<th>Question</th>
<th>Options</th>
</tr>
</thead>
</table>
| How many of these are adults, 18 or older? | 1= One  
2= Two  
3= Three  
4= Four  
5= Five  
6= Six  
7= Seven  
8= Eight or more  
9= Refused |
| How many of these adults are male? | 0= None  
1= One  
2= Two  
3= Three  
4= Four  
5= Five  
6= Six  
7= Seven  
8= Eight  
9= Refused |
| How many of these adults are female? | 0= None  
1= One  
2= Two  
3= Three  
4= Four  
5= Five  
6= Six  
7= Seven  
8= Eight  
9= Refused |
| zxx10 | How many are children 12 to 17? | 0= None  
1= One  
2= Two  
3= Three  
4= Four  
5= Five  
6= Six  
7= Seven  
8= Eight or more  
9= Refused |
|-------|--------------------------------|--------------------------------------------------|
| zxx11 | How many are children 6 to 11? | 0= None  
1= One  
2= Two  
3= Three  
4= Four  
5= Five  
6= Six  
7= Seven  
8= Eight or more  
9= Refused |
| zxx12 | How many are children under 6? | 0= None  
1= One  
2= Two  
3= Three  
4= Four  
5= Five  
6= Six  
7= Seven  
8= Eight or more  
9= Refused |
<table>
<thead>
<tr>
<th>Variable</th>
<th>Question</th>
<th>Response Options</th>
</tr>
</thead>
<tbody>
<tr>
<td>ageques</td>
<td>What is your age?</td>
<td>Enter number (continuous variable)</td>
</tr>
</tbody>
</table>
| educ     | What is the last grade of school you completed? | 1= Less than high school graduate  
2= High school graduate  
3= Some college  
4= Graduate college  
5= Graduate school or more  
6= Technical school/other  
9= Refused |
| incomeq  | Is your total annual income household income from all sources, and before taxes...? | 1= LESS THAN $10,000  
2= $10,000 BUT LESS THAN $15,000  
3= $15,000 BUT LESS THAN $20,000  
4= $20,000 BUT LESS THAN $25,000  
5= $25,000 BUT LESS THAN $30,000  
6= $30,000 BUT LESS THAN $40,000  
7= $40,000 BUT LESS THAN $50,000  
8= $50,000 BUT LESS THAN $75,000  
9= $75,000 BUT LESS THAN $100,000  
10= $100,000 OR MORE  
13= $50,000 AND OVER  
14= UNDER $50,000  
98= Don't know  
99= Refused |
<table>
<thead>
<tr>
<th>Variable</th>
<th>Question</th>
<th>Options</th>
</tr>
</thead>
<tbody>
<tr>
<td>hispanc1</td>
<td>Are you of Hispanic origin or background?</td>
<td>1=Yes, 2= No, 8= Don't know, 9= Refused</td>
</tr>
<tr>
<td>hispanc2</td>
<td>Are you white Hispanic or black Hispanic?</td>
<td>1= White Hispanic, 2= Black or African American, 9= Refused</td>
</tr>
<tr>
<td>race</td>
<td>Would you consider yourself to be white, black or of some other race?</td>
<td>0= Other, 1= White, 2= Black or African American, 3= Asian/Oriental/Chinese/Japanese, 4= Native American/American Indian/Alaskan Native, 9= Refused</td>
</tr>
<tr>
<td>affili</td>
<td>Generally speaking, do you usually think of yourself as:</td>
<td>0= Other, 1= A Republican, 2= A Democrat, 3= An Independent, 8= Don't know, 9= Refused</td>
</tr>
<tr>
<td>register</td>
<td>Are you registered to vote at your present address?</td>
<td>1= Yes, 2= No, 8= Don't know, 9= Refused</td>
</tr>
<tr>
<td>Code</td>
<td>Question</td>
<td>Response Options</td>
</tr>
<tr>
<td>-------</td>
<td>--------------------------------------------------------------------------</td>
<td>---------------------------------------------------------------</td>
</tr>
</tbody>
</table>
| qz12  | Besides the telephone number I reached you on, how many other telephone numbers, if any, does your HH have? | 0= None
1= One
2= Two
3= Three
4= Four or more
9= Refused |
| sex   | Enter sex of respondent                                                  | 1= Male
2= Female                                                   |
| para1_1 | Do you or does anyone in this household have any difficulty moving their arms or legs? | 0= NOT Yes, Respondent
1= Yes, Respondent                                        |
| para1_2 | Do you or does anyone in this household have any difficulty moving their arms or legs? | 0= NOT Yes, Other in Household
1= Yes, Other in Household                                  |
<table>
<thead>
<tr>
<th>para1_3</th>
<th>Do you or does anyone in this household have any difficulty moving their arms or legs?</th>
<th>0=NOT No</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>1=No</td>
</tr>
<tr>
<td>para1_4</td>
<td>Do you or does anyone in this household have any difficulty moving their arms or legs?</td>
<td>0=NOT Don't Know</td>
</tr>
<tr>
<td></td>
<td></td>
<td>1=Don't Know</td>
</tr>
<tr>
<td>para1_5</td>
<td>Do you or does anyone in this household have any difficulty moving their arms or legs?</td>
<td>0=NOT Refused</td>
</tr>
<tr>
<td></td>
<td></td>
<td>1=Refused</td>
</tr>
<tr>
<td>Cause</td>
<td>Causes of Paralysis</td>
<td></td>
</tr>
<tr>
<td>---------------------------------------------------------------------</td>
<td>------------------------------------------------------------------------------------</td>
<td></td>
</tr>
<tr>
<td></td>
<td>1= Cerebral palsy*</td>
<td></td>
</tr>
<tr>
<td></td>
<td>2= MS/Multiple Sclerosis</td>
<td></td>
</tr>
<tr>
<td></td>
<td>3= Neurofibromatosis*</td>
<td></td>
</tr>
<tr>
<td></td>
<td>4= Post-polio syndrome*</td>
<td></td>
</tr>
<tr>
<td></td>
<td>5= Spinal cord injury/SCI*</td>
<td></td>
</tr>
<tr>
<td></td>
<td>6= Stroke*</td>
<td></td>
</tr>
<tr>
<td></td>
<td>7= Traumatic brain injury/TBI*</td>
<td></td>
</tr>
<tr>
<td></td>
<td>8= ALS/Lou Gehrig's disease/Amyotrophic Lateral Sclerosis*</td>
<td></td>
</tr>
<tr>
<td></td>
<td>9= Chiari malformation*</td>
<td></td>
</tr>
<tr>
<td></td>
<td>10= Epidural infection*</td>
<td></td>
</tr>
<tr>
<td></td>
<td>11= Fredrich's Ataxia*</td>
<td></td>
</tr>
<tr>
<td></td>
<td>12= Guillain Barre Syndrome*</td>
<td></td>
</tr>
<tr>
<td></td>
<td>13= Poisoning</td>
<td></td>
</tr>
<tr>
<td></td>
<td>14= Spina Bifida</td>
<td></td>
</tr>
<tr>
<td></td>
<td>15= Spinal Muscular Atrophy*</td>
<td></td>
</tr>
<tr>
<td></td>
<td>16= Syringomyelia*</td>
<td></td>
</tr>
<tr>
<td></td>
<td>17= Transverse Myelitis*</td>
<td></td>
</tr>
<tr>
<td></td>
<td>18= Back/Neck Injury/Surgery</td>
<td></td>
</tr>
<tr>
<td></td>
<td>19= Birth defect, unspecified</td>
<td></td>
</tr>
<tr>
<td></td>
<td>20= Paralysis/Paralyzed/Paraplegic/Quad</td>
<td></td>
</tr>
<tr>
<td></td>
<td>21= Spinal Cord Injury from pa5</td>
<td></td>
</tr>
<tr>
<td></td>
<td>22= Traumatic Brain Injury from pa5</td>
<td></td>
</tr>
<tr>
<td></td>
<td>23= C Cervical Mentions from pa5</td>
<td></td>
</tr>
<tr>
<td></td>
<td>24= L Lumbar Mentions from pa5</td>
<td></td>
</tr>
<tr>
<td></td>
<td>25= T Thoracic Mentions from pa5</td>
<td></td>
</tr>
<tr>
<td></td>
<td>26= Paralysis/Quadriplegic from pa5</td>
<td></td>
</tr>
<tr>
<td></td>
<td>27= Paralysis, unspecified</td>
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</tr>
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### Overview of Survey Methodology: Prevalence of Paralysis in the United States, 2008

#### para4

<table>
<thead>
<tr>
<th>What type of accident or injury caused the difficulty in movement?</th>
<th>1= Accident in sporting/recreation/athletic event (sports, waterskiing, etc.)</th>
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</thead>
<tbody>
<tr>
<td>2= Accident working (home or workplace)</td>
<td></td>
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<tr>
<td>3= Fall (at home, in the workplace, while walking, in shower</td>
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</tr>
<tr>
<td>4=Fire or burn</td>
<td></td>
</tr>
<tr>
<td>5= Motor Vehicle Accident</td>
<td></td>
</tr>
<tr>
<td>6=Victim of violence, (either attack by someone else or accidental)</td>
<td></td>
</tr>
<tr>
<td>7=Birth defect</td>
<td></td>
</tr>
<tr>
<td>8=Natural disaster</td>
<td></td>
</tr>
<tr>
<td>9= Surgical procedure</td>
<td></td>
</tr>
<tr>
<td>10=Other</td>
<td></td>
</tr>
<tr>
<td>98=Don't Know</td>
<td></td>
</tr>
<tr>
<td>99=Refused</td>
<td></td>
</tr>
</tbody>
</table>

#### para4a

<table>
<thead>
<tr>
<th>Was this a result of serving in the military?</th>
<th>1=Yes</th>
</tr>
</thead>
<tbody>
<tr>
<td>2= No</td>
<td></td>
</tr>
<tr>
<td>8=Don't Know</td>
<td></td>
</tr>
<tr>
<td>9=Refused</td>
<td></td>
</tr>
<tr>
<td>para5</td>
<td>Can you recall the diagnosis (you/this person) received from the accident or injury/surgical complications?</td>
</tr>
<tr>
<td>-------</td>
<td>----------------------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td></td>
<td>1= Spinal cord injury/SCI</td>
</tr>
<tr>
<td></td>
<td>2= Traumatic brain injury/TBI</td>
</tr>
<tr>
<td></td>
<td>3= &quot;C&quot;/cervical mentions</td>
</tr>
<tr>
<td></td>
<td>4= &quot;L&quot;/lumbar mentions</td>
</tr>
<tr>
<td></td>
<td>5= &quot;T&quot;/Thoracic mentions</td>
</tr>
<tr>
<td></td>
<td>6= Amputation</td>
</tr>
<tr>
<td></td>
<td>7= Back injury/Lower back injury</td>
</tr>
<tr>
<td></td>
<td>8= Broken/Injury arm/leg/ankle/wrist/shoulder</td>
</tr>
<tr>
<td></td>
<td>9= Bullet/Military Wound</td>
</tr>
<tr>
<td></td>
<td>10= Knee/Hip injury/Replacement/Problems</td>
</tr>
<tr>
<td></td>
<td>11= Nerve Damage</td>
</tr>
<tr>
<td></td>
<td>12= Pinched nerve</td>
</tr>
<tr>
<td></td>
<td>13= Slipped/Herniated/Ruptured Disc</td>
</tr>
<tr>
<td></td>
<td>14= Spine/Spinal Disc injury</td>
</tr>
<tr>
<td></td>
<td>15= Torn/sprained/ligament/rotary cup/cartilage/meniscus/ACL (soft tissue injury)</td>
</tr>
<tr>
<td></td>
<td>97= Other</td>
</tr>
<tr>
<td></td>
<td>98= Don't know</td>
</tr>
<tr>
<td></td>
<td>99 = Refused</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>para5a</th>
<th>Did this result in damage to (your/this person's) spinal cord?</th>
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<tbody>
<tr>
<td></td>
<td>1= Yes</td>
</tr>
<tr>
<td></td>
<td>2= No</td>
</tr>
<tr>
<td></td>
<td>8= Don’t know</td>
</tr>
<tr>
<td></td>
<td>9= Refused</td>
</tr>
<tr>
<td>para6</td>
<td>Currently, how much difficulty (do you/does this person) have moving (your/their) arms and/or legs?</td>
</tr>
<tr>
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<tr>
<td></td>
<td>What year did this happen or first start?</td>
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<td>para7</td>
<td>Please tell me who in your household has the difficulty moving their arms or legs?</td>
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</tbody>
</table>
| para8x | Please tell me who in your household has the difficulty moving their arms or legs? | 1=MALE  
2=FEMALE  
9=REFUSED |
|----------------|---------------------------------------------------------------------------------|----------------------------------|
| para9 | How old is this person who has difficulty moving their arms and legs? | Enter age  
1= Less than one year old  
99= Refused |
| para10 | What is the last grade of school they completed? | 1= Too young for school  
2= Eight grade  
3= Less than high school  
4= High school  
5= Some college  
6= Graduated college  
7= Technical school  
8= Post graduate  
98= Don’t know  
99= Refused |
| para11 | Are they of Hispanic origin or background? | 1= Yes  
2= No  
8= Don’t know  
9= Refused |
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<tr>
<th>para12</th>
<th>Would you consider this person with moving difficulties to be White, Black, or of some other race?</th>
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<tbody>
<tr>
<td></td>
<td>1= White</td>
</tr>
<tr>
<td></td>
<td>2= Black or African American</td>
</tr>
<tr>
<td></td>
<td>3= Asian/Oriental/Chinese/Japanese</td>
</tr>
<tr>
<td></td>
<td>4= Native American/American Indian/Alaskan Native</td>
</tr>
<tr>
<td></td>
<td>5= Native Hawaiian and other Pacific Islander</td>
</tr>
<tr>
<td></td>
<td>97= Other</td>
</tr>
<tr>
<td></td>
<td>99= Refused</td>
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<th>Paralysis yes no</th>
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<td>1=Yes</td>
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<th>SCI</th>
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<tr>
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<td>0=No</td>
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<tr>
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<td>1=Yes</td>
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<th>SCI cause</th>
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<td>1=01. Accident in Sporting</td>
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<td></td>
<td>2=02. Accident Working</td>
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<td>3=03. Fall</td>
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<td>4=04. Fire or burn</td>
</tr>
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<td>5=05. Motor Vehicle Accident</td>
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<td>6=06. Victim of Violence</td>
</tr>
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<td></td>
<td>7=07. Birth defect</td>
</tr>
<tr>
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<td>8=08. Natural disaster</td>
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<td></td>
<td>9=09. Surgical procedure</td>
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<td>10=10. Other</td>
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<td>11=11. Don't know</td>
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<td>12=12. Refused</td>
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<td><strong>Educ_all</strong></td>
<td>Education level all respondents and others in household</td>
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<tr>
<td>The person for whom this variable is completed is:</td>
<td></td>
</tr>
<tr>
<td>* if neither respondent or other person in household is paralyzed, refers to respondent</td>
<td></td>
</tr>
<tr>
<td>* if respondent, refers to respondent</td>
<td></td>
</tr>
<tr>
<td>* if other person in household is paralyzed, refers to household member</td>
<td></td>
</tr>
<tr>
<td>1= Too young for school</td>
<td></td>
</tr>
<tr>
<td>2= Eight grade</td>
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<tr>
<td>3= Less than high school</td>
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<tr>
<td>4= High school</td>
<td></td>
</tr>
<tr>
<td>5= Some college</td>
<td></td>
</tr>
<tr>
<td>6= Graduated college</td>
<td></td>
</tr>
<tr>
<td>7= Technical school</td>
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<tr>
<td>98= Don't know</td>
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<tr>
<td>99= Refused</td>
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<td>Age_Cat_AIl</td>
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<td>* if other person in household is paralyzed, refers to household member</td>
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<tr>
<td>1=0-19</td>
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<td>6=60-69</td>
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<td>7=70-79</td>
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<td>8=80+</td>
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</tr>
<tr>
<td></td>
<td>* if respondent, refers to respondent</td>
</tr>
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<td></td>
<td>* if other person in household is paralyzed, refers to household member</td>
</tr>
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<td>1=18-19</td>
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<td>4=40-49</td>
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<td>8=80+</td>
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<td>9=Refused</td>
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<tr>
<td>urban</td>
<td>urban or rural location of household</td>
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<tr>
<td>1=Urban</td>
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<td>2=Rural</td>
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<tr>
<td>Gender</td>
<td>Gender All Respondents and HH</td>
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<tr>
<td></td>
<td>* if respondent, refers to respondent</td>
</tr>
<tr>
<td></td>
<td>* if other person in household is paralyzed, refers to household member</td>
</tr>
<tr>
<td></td>
<td>1=MALE</td>
</tr>
<tr>
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<td>2=FEMALE</td>
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<tr>
<td>Hispanic_all</td>
<td>Hispanic all respondents and others in household</td>
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<td>* if respondent, refers to respondent</td>
<td></td>
</tr>
<tr>
<td>* if other person in household is paralyzed, refers to household member</td>
<td></td>
</tr>
<tr>
<td>1=Yes</td>
<td></td>
</tr>
<tr>
<td>2=No</td>
<td></td>
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<tr>
<td>race_all</td>
<td>Race All respondents and others in household</td>
</tr>
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<td>---------</td>
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<td>* if respondent, refers to respondent</td>
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<td></td>
<td>* if other person in household is paralyzed, refers to household member</td>
</tr>
<tr>
<td></td>
<td>1= White</td>
</tr>
<tr>
<td></td>
<td>2= Black or African American</td>
</tr>
<tr>
<td></td>
<td>3= Asian/Chinese/Japanese/Pacific Islander</td>
</tr>
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<td></td>
<td>4= Native American/American Indian/Alaskan Native</td>
</tr>
<tr>
<td></td>
<td>5= 2 or more races</td>
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<tr>
<td></td>
<td>8=Other</td>
</tr>
<tr>
<td></td>
<td>9=Refused</td>
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</tbody>
</table>

| zipcode | zip code (enter number) |
Participants at the 2006 Consensus Conference
Participants at the 2006 Consensus Conference developed the functional definition of paralysis on which the survey is based and an initial draft of the survey instrument. 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 or individuals. Members of the workgroup did not attend the consensus conference as representatives of their organizations.

<table>
<thead>
<tr>
<th>Name</th>
<th>Institution</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dr. Elena Andresen</td>
<td>University of Florida, Gainesville</td>
</tr>
<tr>
<td>Dr. Anthony Cahill</td>
<td>University of New Mexico</td>
</tr>
<tr>
<td>Mr. Joe Canose</td>
<td>Christopher Reeve Foundation</td>
</tr>
<tr>
<td>Dr. Michael Fox</td>
<td>University of Kansas</td>
</tr>
<tr>
<td>Dr. Andrew Houtenville</td>
<td>Cornell University</td>
</tr>
<tr>
<td>Ms. Bridgid Isworth</td>
<td>University of New Mexico</td>
</tr>
<tr>
<td>Dr. Gwen Jones</td>
<td>Centers for Disease Control and Prevention</td>
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<tr>
<td>Dr. Susan Kinne</td>
<td>University of Washington</td>
</tr>
<tr>
<td>Mr. Michael Manganiello</td>
<td>Christopher and Reeve Foundation</td>
</tr>
<tr>
<td>Dr. Jennifer Rowland</td>
<td>University of Illinois - Chicago</td>
</tr>
<tr>
<td>Dr. David Tulsky</td>
<td>Kessler Rehabilitation Hospital</td>
</tr>
<tr>
<td>Dr. Glen White</td>
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</tr>
<tr>
<td>Ms. Mary Helen Witten</td>
<td>Centers for Disease Control and Prevention</td>
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<tr>
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<tr>
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<tr>
<td>Ms. Leslie Hudson</td>
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<tr>
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<tr>
<td>Ms. Lesley Wolf</td>
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