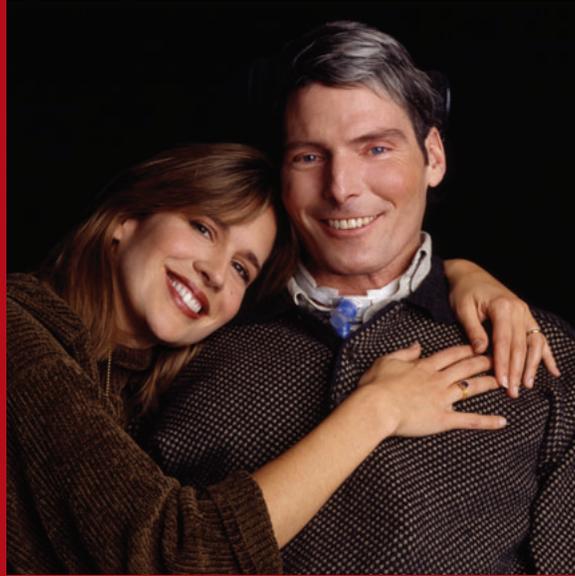




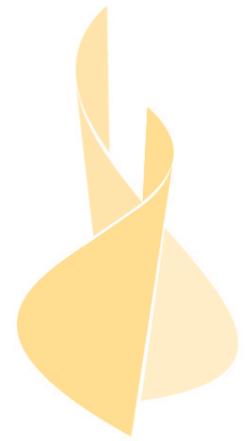
One Degree of Separation | *Paralysis and Spinal Cord Injury in the United States*





“Nothing of any consequence happens unless people get behind an idea. It begins with an individual and they share the idea with more individuals... and eventually it becomes a movement.”

—Christopher Reeve, 2002



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Daryl "Chill" Mitchell is an actor.



Molly Farrell was named one of the "20 Teens Who Will Change the World."



Ruben Anthony Rios is a painter.



Alan Brown is the CEO of a successful public relations firm.

Daryl, Molly, Ruben, and Alan are very different people. But they have one thing in common: **They are all living with paralysis.** And they are part of a much larger population facing the same challenges.

According to a recent study initiated by the Christopher & Dana Reeve Foundation, there are nearly 1 in 50 people living with paralysis—approximately 6 million people. That's the same number of people as the combined populations of Los Angeles, Philadelphia, and Washington, D.C. **And that number is nearly 40 percent higher than previous estimates showed.**

It means that we all know someone—a brother, sister, friend, neighbor, or colleague—living with paralysis. These aren't strangers. They are only one degree of separation from all of us. But their lives are different. They live with a condition that affects their family life, their ability to work, and their capacity to enjoy even the most routine everyday activities that others take for granted.

The Christopher & Dana Reeve Foundation wants to change that.

Through support of ground-breaking research, education, and advocacy, the Reeve Foundation and other organizations are racing toward the finish line: finding a cure for paralysis. Today, millions of Americans living with paralysis who were once told they "couldn't or shouldn't do it" or "didn't have it in them," are now able to lead normal, healthy, and productive lives, thanks to extraordinary advances in treatment, rehabilitation, medicine, and product engineering that have helped to shatter barriers that once were thought to be insurmountable.

But they haven't reached the finish line yet. People living with paralysis still face considerable challenges—among them, exorbitant health care costs and workplace discrimination. Those challenges and others demand a continued commitment to developing better interventions to improve quality of life, advocating for better health care coverage, and conducting research that will lead to a cure.

To help achieve those goals, in 2004, the Reeve Foundation convened more than 60 of the nation's preeminent scientists, scholars, health advocates, and experts from the U.S. Centers for Disease Control and Prevention (CDC) and the

Ruben Anthony Rios | Los Angeles, California

Ruben Anthony Rios, 38, is a ventilator-dependent quadriplegic with no movement below his shoulders, due to a gunshot wound he suffered in 1988 as a teenager. After spending almost a year at the Los Angeles County General Hospital, he lived with his mother for the next 18 years, who was his primary caregiver. During that time, Ruben learned to use mouth sticks to function and with them, became able to read books, type and draw. Today he is a professional artist who uses a mouth stick with a paint brush attached and is a scholarship holder with the Association of Mouth and Foot Painting Artists. Ruben is engaged and lives in Lancaster, California with his fiancée and her three children.



nation's top universities, policy centers, and nonprofit health care organizations to identify what was needed to improve the quality of life for people living with paralysis.

This *Paralysis Task Force* quickly discovered that there was insufficient reliable information about the prevalence of paralysis. Without that information, it would be impossible to devise new or evaluate existing policies, programs, and services for people living with paralysis. As a result, the Task Force's first recommendation for advancing paralysis as a public issue was to build a more robust and comprehensive national knowledge base about it.

Now, five years later, that knowledge base has been established, supported by data from a project led by researchers at the University of New Mexico's Center for Development and Disability (CDD) from 2006 to 2008.

Working in partnership with the Christopher & Dana Reeve Foundation's Paralysis Resource Center (PRC)—the nation's leading information clearinghouse on paralysis and spinal cord injury—researchers designed and conducted an exhaustive survey of more than 33,000 households across the country. More than 30 experts in paralysis and statistics, including those from the CDC and 14 leading universities and medical centers helped to develop and set the parameters for the study.

Today, this study represents one of the largest population-based samples of any disability ever conducted.

This research revealed some important findings:

- **Paralysis is dramatically more widespread than previously thought.** Approximately 1.9 percent of the U.S. population, or 5,596,000 people reported they were living with some form of paralysis, defined by the study as a central nervous system disorder resulting in difficulty or inability to move the upper or lower extremities. This is about one-third more Americans living with paralysis than previously estimated (4 million).¹ The leading cause of paralysis was stroke (29 percent), followed by spinal cord injury (23 percent) and multiple sclerosis (17 percent).
- **Spinal cord injury is also more prevalent than previously estimated.** Data indicate that 1,275,000 people in the United States are living with spinal cord injury—more than five times the number of Americans previously estimated in 2007 (255,702).²
- **Paralysis appears to be disproportionately distributed among some minority communities—such as African Americans and Native Americans—but not all.** Hispanics who are living with paralysis represent approximately the same percentage as those who report being Hispanic in the United States census.
- **People living with paralysis have households with lower incomes.** Household income for those with paralysis is heavily skewed towards lower-income brackets and is significantly lower than household income for the country as a whole. Roughly 25% of households with a person who is paralyzed make less than 10k per year, compared with only 7% of households in the general population.

¹ Reeve Foundation Paralysis Resource Center

² Spinal Cord Injury Information Network at the University of Alabama at Birmingham

These findings have major implications for the treatment of spinal cord and paralysis-related diseases—not only for those living with these conditions, but also for their families, caregivers, health care providers, and employers. As the number of people living with paralysis and spinal cord injuries increases, for example, so do the costs associated with treating them. Each year, paralysis and spinal cord injuries cost the health care system billions of dollars. Spinal cord injuries alone cost roughly \$40.5 billion annually—a 317 percent increase from costs estimated in 1998 (\$9.7 billion).³

People living with paralysis and spinal cord injuries are also often unable to afford health insurance that adequately covers the complex secondary or chronic conditions that are commonly linked with these conditions. And, like many of those living with chronic illness, they are frequently forced to rely on friends or family members to serve as their primary caregivers. More than 50 million people each year provide this kind of care,⁴ the value of which is estimated to be \$306 billion annually, twice the \$158 billion spent on home care and nursing home services combined.⁵

Ensuring that the millions of people living with paralysis and spinal cord injuries have access to the health care they need, as well as quality jobs and education, requires a reinvigorated and informed national discussion about how better therapies, services, and policies for people living with paralysis and spinal cord injuries (as well as about preventing these injuries) will not only help save billions of dollars but, above all, lay the groundwork for finding a cure.

This report is an effort to launch that national discussion. In addition to providing a detailed overview of the research findings, it offers a description of some of the most promising developments in tackling paralysis and spinal cord injury and provides a set of recommendations outlining what is needed to remove the obstacles to freedom faced by people living with paralysis, and, ultimately, to eradicate it.

³ Retrieved on April 3, 2009 at www.cdc.gov/ncipc/factsheets/scifacts.html

⁴ Retrieved on April 3, 2009 at www.nfcacares.org/who_are_family_caregivers/care_giving_statistics.cfm

⁵ Arno, Peter S., "Economic Value of Informal Caregiving," presented at the Care Coordination and the Caregiving Forum, Dept. of Veterans Affairs, NIH, Bethesda, MD, January 25-27, 2006.





THE FIRST STEP:

Documenting the Problem

The first step to improving the quality of life for people living with paralysis is knowing how many people are living with this condition and who they are. To that end, in 2004, the Christopher & Dana Reeve Foundation, in cooperation with the Centers for Disease Control and Prevention (CDC), convened a 63-member task force—comprising some of the nation’s most preeminent public health leaders—to develop a framework for a public health action plan on paralysis.

The Paralysis Task Force issued a series of recommendations, one of the most urgent being the implementation of a core paralysis survey. As the panel noted, “a necessary first step in advancing paralysis as a public health issue is to enlarge our national knowledge base about paralysis. Significantly more valid, reliable information is needed about such issues as how many people live with paralysis [prevalence]; how many people become paralyzed each year [incidence]; and what quality of life issues are faced by people with paralysis.”

To address this gap, in 2004, the Christopher & Dana Reeve Foundation developed a multi-year cooperative agreement with researchers at the University of New Mexico’s Division of Disability and Health Policy at the Center for Development and Disability (CDD) to oversee a landmark national study. More than 30 experts in paralysis and statistics, including those from the CDC, as well as 14 leading universities and medical centers, helped to develop and set the parameters for the study.

METHODOLOGY

Researchers collected and analyzed data from more than 33,000 randomly sampled households with a telephone in the United States to document the prevalence of paralysis, including spinal cord injury. With the exception of annual surveys sponsored by the federal government (such as the

Behavioral Risk Factor Surveillance Survey (BRFSS) or the National Health Interview Survey), this is the largest population-based sample of any disability ever conducted of which we are aware.

The study comprised four components:

Assessment of existing surveys, registries, and data collection efforts. A team from the University of Kansas conducted this assessment to determine how paralysis was defined by different organizations and surveys, as well as how data about paralysis had previously been collected.

A “**consensus conference.**” This conference, held in Atlanta in 2006, convened more than 30 experts in statistics and paralysis to develop a functional definition of paralysis that could be used in a national survey and to draft a survey instrument for it.

The development and testing of a pilot instrument. Researchers used cognitive testing to create the final instrument—a process that helps to ensure that questions on a newly-developed survey are clear to respondents and mean the same thing as they do to the survey creators. They then administered the instrument by phone to more than 100 people, who then participated in follow-up interviews or focus groups about their understanding of the questions. Next, two waves of 1,000 people each participated in the survey (by phone). These activities led to four revisions of the instrument.

Administration of the final survey. The final survey was administered by ICR International, a nationally-recognized research and polling firm, during 26 weeks in 2008. ICR conducted telephone interviews nationally between May and August 2008 with adults in 33,348 households in the United States. Since African Americans and Hispanics are usually under-represented in random national surveys, these groups were oversampled.

Molly Farrell | Chicago, Illinois

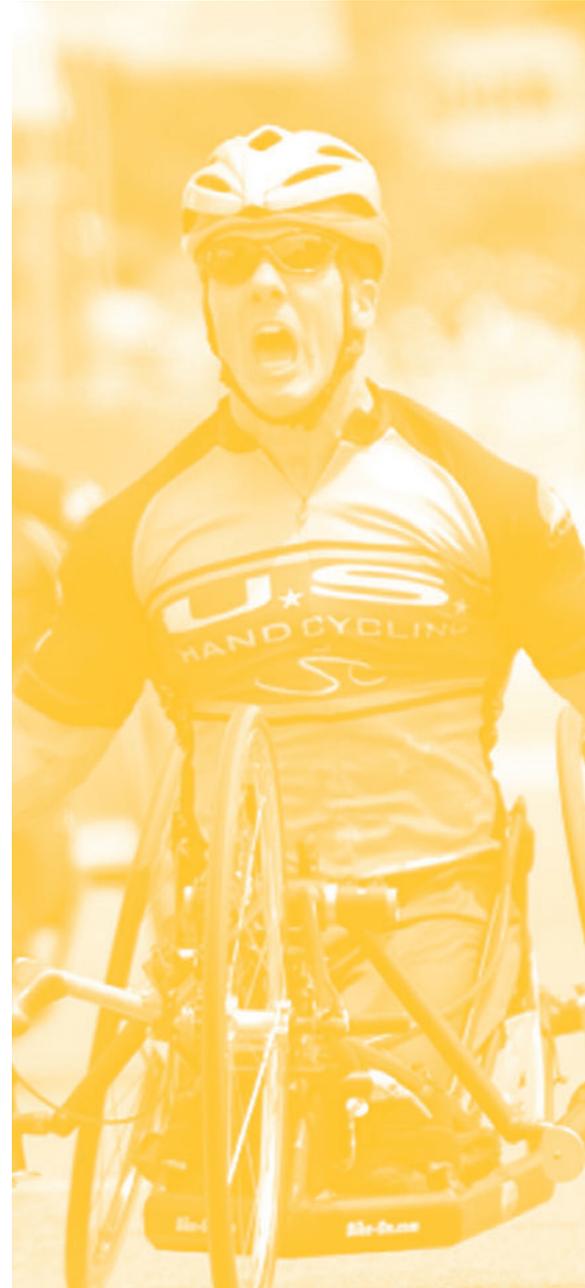
When she was 13 years old, Molly was spinal cord-injured in a diving accident during her swim team practice. The doctors told her she was paralyzed from the neck down with little chance for recovery. Today, however, due to intensive activity-based therapy covered by her family's health insurance, she can walk without crutches and, in 2006, she was named one of *Teen People's* "20 Teens Who Will Change the World." Molly has also appeared on the Oprah Winfrey and Today shows and has spoken at the Reeve Foundation's "A Magical Evening" gala.



WHAT MAKES THIS STUDY DIFFERENT

Three factors distinguish this study from those previously undertaken about this issue:

- It used a sophisticated sampling strategy that randomly surveyed people across the country, rather than in only one state or sub-state regions.
- It did not use clinical data (e.g., diagnoses that were given at one or more hospitals during a specific time period) for counting people with paralysis. While clinical data is an excellent source of information about the specific health issues faced by people who are paralyzed, it is generally not a good source of prevalence data because sometimes people with paralysis-related injuries seek care from health care providers for secondary health conditions that may result from—but occurred long after—their injury, meaning that they would not necessarily be diagnosed or, in turn, counted as those living with paralysis.
- It used a more comprehensive definition of paralysis than that in previous studies, allowing for greater accuracy in determining who is living with paralysis. Specifically, this study based the definition of disabilities used by the World Health Organization (WHO), which uses function, rather than impairment (the medical model), as its frame: *A central nervous system disorder that results in difficulty or inability to move the upper or lower extremities.* Individuals, therefore, who were included in this survey as respondents were those who said “yes” to two questions: 1) “Do you or does anyone in this household have any difficulty moving their arms or legs?” and 2) “Can you give the specific cause of that difficulty?”



RESEARCH FINDINGS

People Living with Paralysis and Spinal Cord Injury

This unprecedented national study to document the prevalence of people living with paralysis and spinal cord injury unearthed some surprising findings that have—and will continue to have—considerable implications for current discussions and agenda-setting about health care reform, insurance coverage, treatments for disabilities and the chronic secondary conditions that often emerge from them, and other issues that have profound effects on millions of Americans living with paralysis.

In addition to looking at the prevalence of paralysis more broadly, researchers and the Reeve Foundation decided to include in this study a deeper examination of a particular form of paralysis—in this case, spinal cord injury, the second most common cause of paralysis. Only two decades ago, spinal cord injury—one of several forms of paralysis—was thought to be an irreversible condition. Its severely debilitating effects on the quality of life for those living with it made some consider it a death sentence.

Not everyone, however, did. In 1982, a small but determined group of people committed themselves to challenging the dogma that once damaged, the spinal cord could never be repaired. Led by Hank Stifel, the father of Henry Stifel, a 17-year-old who had been injured in a car accident that left him with quadriplegia, this group of friends, neighbors, scientists, bankers, and local political leaders formed a foundation to raise money for spinal cord research.

A few years later, the Stifel Paralysis Research Foundation merged with the American Paralysis Association (APA), an organization founded with a similar mission by a group of spinal cord injured individuals and their families. By joining forces in the mid-1980s under the APA banner, the group was able to operate more efficiently, reach out to more people, and significantly increase its annual research budget. Through its support of cutting-edge basic science,

the APA changed the field of paralysis research, transforming it from an obscure specialty practiced by a few scientists in isolated labs to one of the most exciting areas of neuroscience.

In 1995, when Christopher Reeve was injured, the APA was one of the first places that he and his wife, Dana, turned to for help in forming his own foundation. Soon thereafter, Christopher, who was impressed by the passion of the APA's members and the daring research they were funding, offered to lend his name, creativity, energy, and fundraising muscle to their shared commitment to finding a cure. In 1999, they merged and became the Christopher Reeve Foundation.

Since 1982, the Reeve Foundation has provided more than \$80 million in research grants to more than 750 researchers. It has also provided \$12.3 million to 1,500 organizations across the country working on improving the quality of life for people living with paralysis since 1999.

In 2004, the Reeve Foundation, in a cooperative agreement with the U.S. Centers for Disease Control and Prevention (CDC), funded the paralysis study, which had a two-fold purpose: 1) to raise awareness of spinal cord injury, and 2) to contribute to the knowledge base of the paralysis field overall.

Findings, for example, show that the prevalence of paralysis and spinal cord injury is dramatically more widespread than previously thought; it is disproportionately distributed among African Americans and Native Americans, but not with Hispanics; and that people with paralysis tend to have lower-income households. These are just a few of the striking findings from this landmark study.

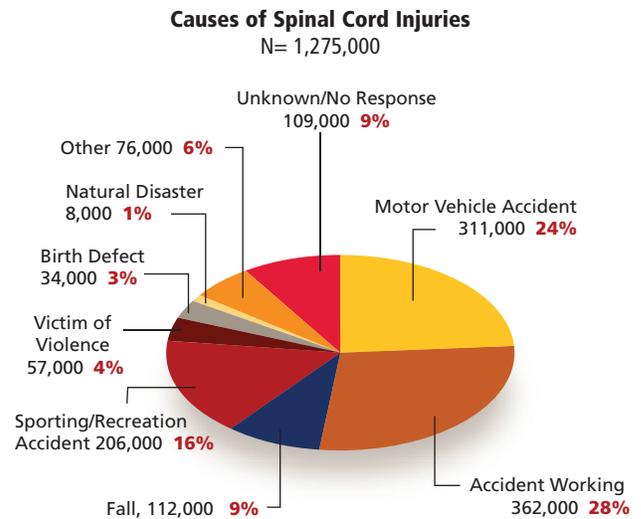
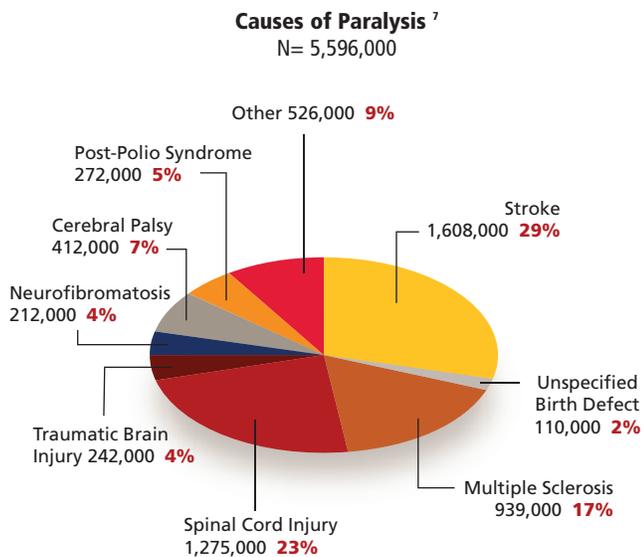
THE PREVALENCE AND DEMOGRAPHICS OF PARALYSIS AND SPINAL CORD INJURY

Prevalence

- Approximately 1.9% of the U.S. population, or some 5,596,000 people, reported some form of paralysis based on the functional definition used in the survey.
- Approximately 0.4% of the U.S. population or some 1,275,000 people reported being paralyzed due to a spinal cord injury.⁶

Causes of Paralysis and Spinal Cord Injury

- The leading cause of paralysis was stroke (29%), followed by spinal cord injury (23%) and multiple sclerosis (17%).
- Various types of accidents accounted for the great majority of spinal cord injuries.



Degree of Difficulty in Moving

- 36% of those who reported being paralyzed said they had “a lot of difficulty” in moving; 29% said “some difficulty”; 17% said “a little difficulty”; and 16% said they were “completely unable to move.”
- 35% of those who reported being paralyzed due to a spinal cord injury said they had “a lot of difficulty” in moving; 29% percent said they had “some difficulty”; 20% said they had “a little difficulty”; and 13% were “completely unable” to move.

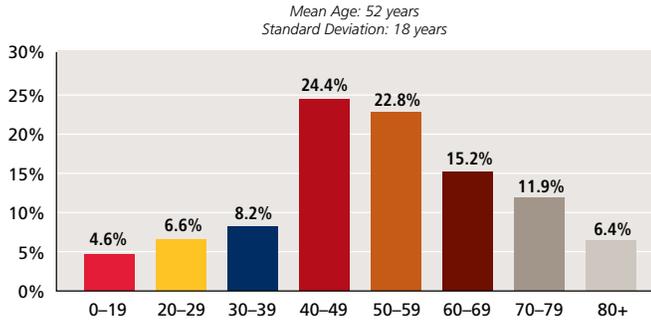
⁶ Margin of error: ± 8.66%

⁷ Prevalence estimates in this graph are specific to individuals who indicated that they are paralyzed due to these causes. Therefore, these figures may differ from estimates derived solely or primarily from medical diagnoses alone.

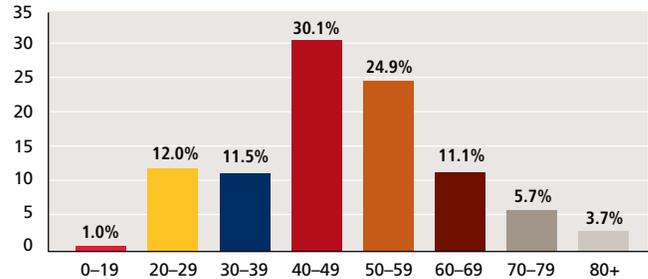
Average Age

- The average age of those who reported being paralyzed was 52.
- The average age of those who reported being paralyzed due to a spinal cord injury was 48.

Age Distribution for Respondents Indicating They are Paralyzed
N=5,503,000



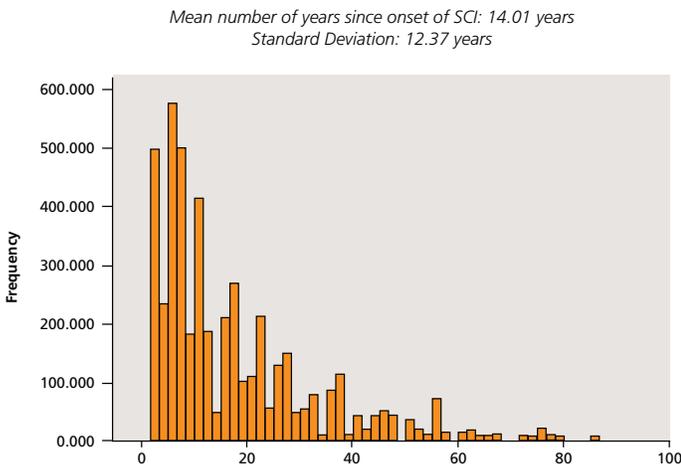
Age Distribution for Respondents Indicating They Have a Spinal Cord Injury
N=1,263,000



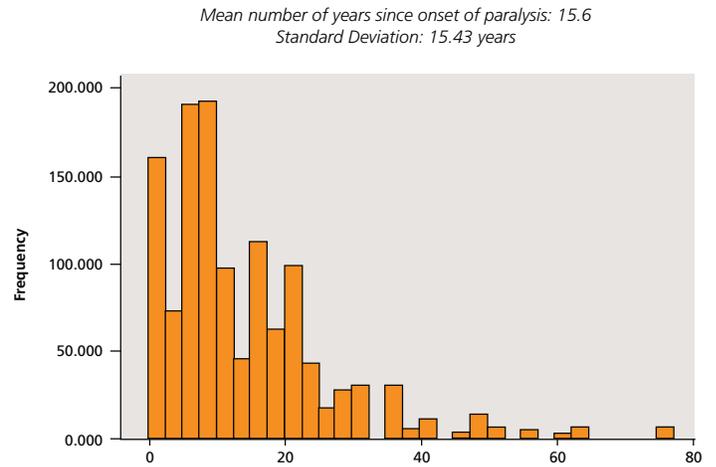
Average Length of Time Since Paralysis and Spinal Cord Injury

- The average length of time since the paralysis occurred was 14 years.
- The average length of time since the spinal cord injury occurred was 15.6 years.

Years Since Onset of Paralysis
N=5,250,085



Years Since Onset of Spinal Cord Injury
N = 1,246,403



Gender

- 54% of those who reported being paralyzed were males, while 46% were females.
- 61% of those who reported being paralyzed due to a spinal cord injury were males, while 39% were females. Males were nearly twice as likely (1.77) to incur a spinal cord injury as females.

Ethnicity and Hispanic Identity

- Just over three-quarters of those who reported being paralyzed were White (77.8%); 17.2% were African American; 12.1% were Hispanic; 3.7% were Native American/Alaskan Native; 0.1% were two or more races; and 0.8% were other.

Paralysis is disproportionately distributed among minority communities, including African Americans and Native Americans, when compared to ethnicity data from the United States Census. Among Hispanics⁸, however, those who reported being paralyzed represented approximately the same percentage as those who reported being Hispanic in the United States Census.

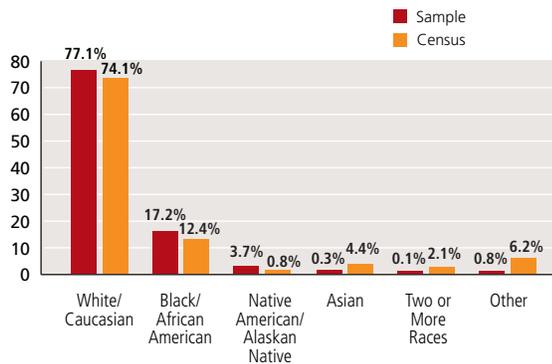
- Approximately three-quarters of those who reported being paralyzed due to a spinal cord injury are White; 15.6% are Black/African American; and 7.3% are Native American/Alaskan.

Data suggest that spinal cord injury is disproportionately distributed among minority communities, including African Americans and Native Americans, when compared to ethnicity data from the United States Census.

12.7% of those who reported being paralyzed due to a spinal cord injury identified themselves as Hispanic,⁸ approximately the same percentage as those who reported being Hispanic in the United States Census.

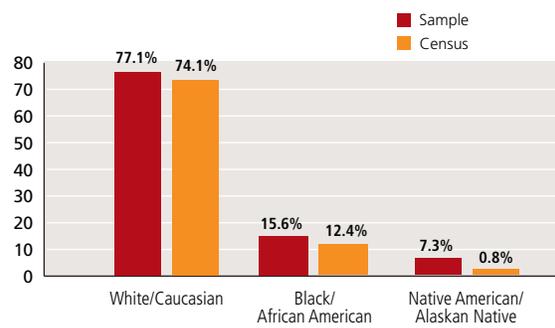
Ethnic Identity of Paralyzed Respondents Compared to Ethnic Identity in the U.S.

N (Paralyzed) = 4,796,000



Ethnic Identity of Respondents With a Spinal Cord Injury Compared to Ethnic Identity in the U.S.

N (SCI) = 1,043,000



Census figures taken from the 2005-2007 American Community Survey Three-Year Estimates, U.S. Bureau of the Census

⁸ The survey on which these results are based follows the format used for acquiring self-reported Hispanic identity by the United States Census, which separates racial identity from Hispanic identity, thus allowing respondents to identify themselves as Hispanic as well as with a separate racial identity.

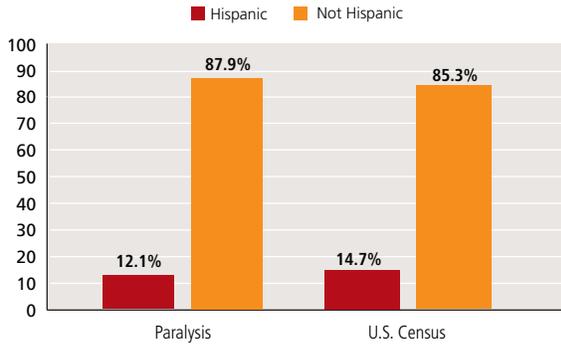
Alan T. Brown | Hollywood, Florida

In 1988, Alan Brown was hit by a wave while swimming and suffered a spinal cord injury that left him paralyzed from the chest down. Today, he is President of PrimeTime Public Relations & Marketing, a public relations firm in Hollywood, Florida. Alan has worked for Slim-Fast Foods, for which he organized advertising campaigns for top celebrities; managed community affairs for the Florida Marlins; and launched a sports radio station. He has also completed two New York City marathons and is a sky and scuba diving enthusiast. Despite his progress, Alan still struggles with issues related to his condition. Since January of 2004, he has spent time in the hospital, as well as been bedridden at home, and had his health insurance discontinued. Over the past few months his medical situation has become more difficult. As he states, "Almost 21 years in a wheelchair is catching up with me, my body is tired, shoulders and back are hurting more than ever, bladder infections, blood problems, pain, passing out and more. We are realizing that our bodies are not made for this constant wear and tear and over time it slowly catches up with you. The doctors have told me to slow down, listen to my body and change up my routine in order to keep going." Alan is married and has two sons, and, with his family, established the Alan T. Brown Foundation to Cure Paralysis in 1989 to find a cure.



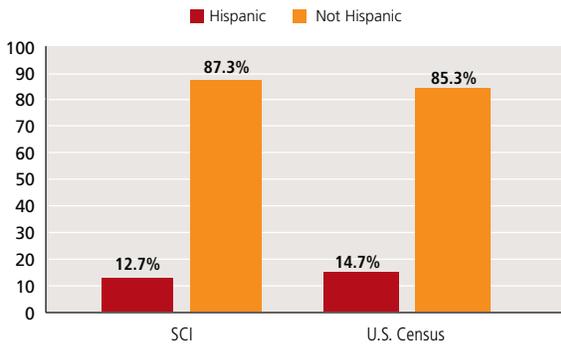
Hispanic Status of Paralyzed Respondents Compared to Hispanics in the U.S.

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



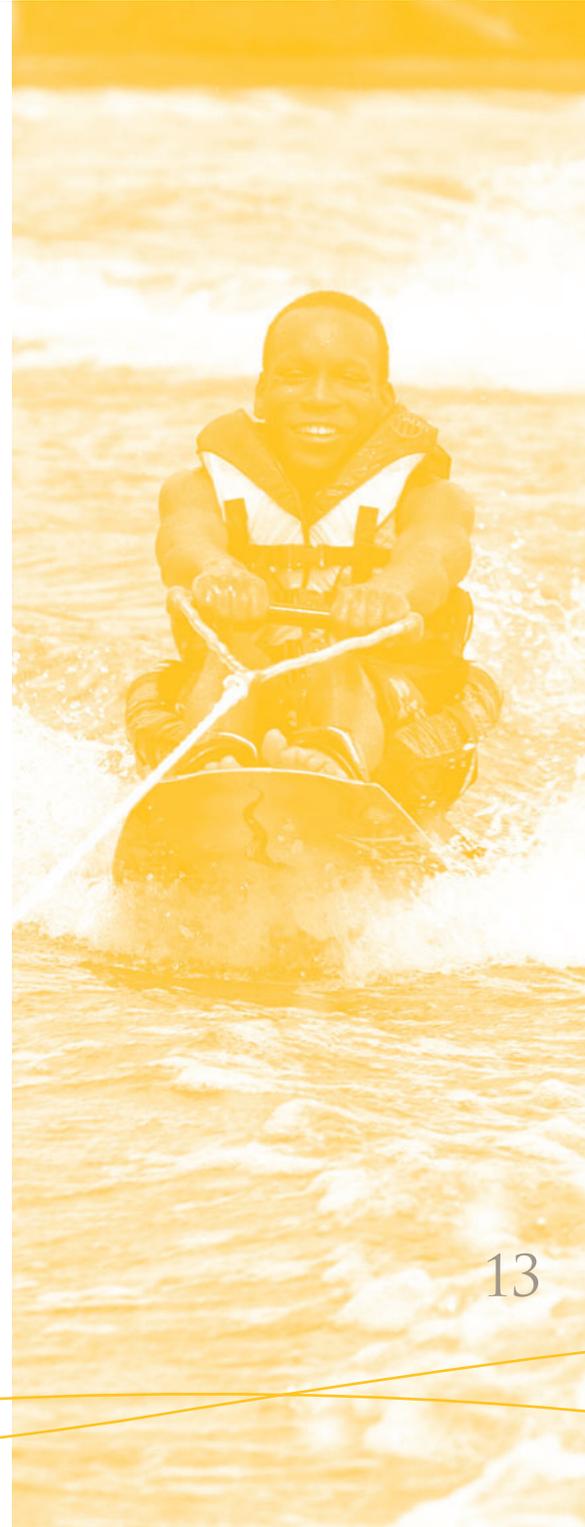
Hispanic Identity of Respondents Indicating They Have a Spinal Cord Injury In Comparison to Hispanics in the U.S.

N (Hispanic SCI)=161,000
 N (Non-Hispanic SCI)=1,108,000
 N (Both)=1,269,000



Paralysis and Military Service

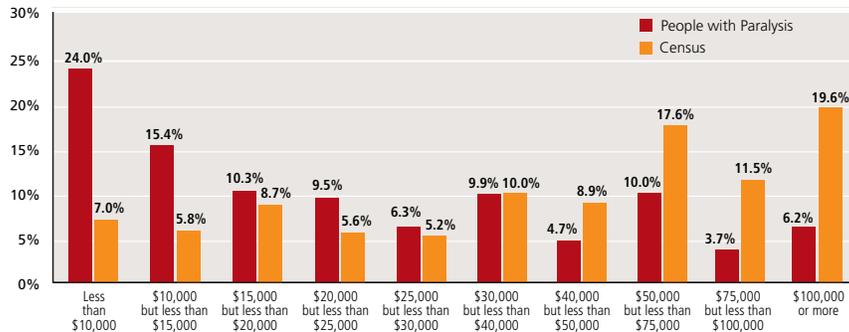
- 67,000 (7%) of respondents who said they became paralyzed as a result of an accident or injury reported the paralyzing accident or injury occurred while serving in the military.



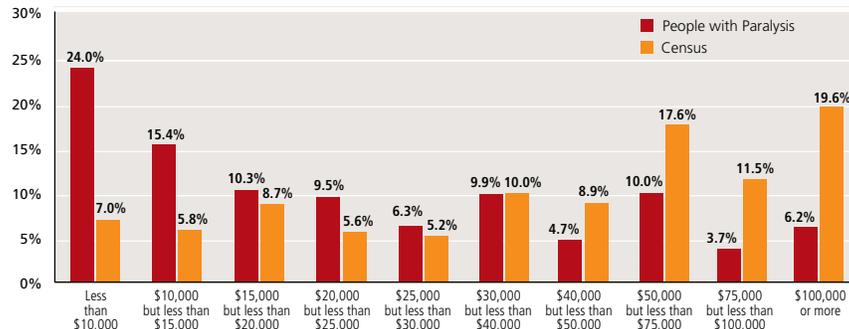
Household Income

- Household income for those who reported being paralyzed is heavily skewed towards lower income brackets and is significantly lower than household income for the country as a whole as reported by the United States Census.
- Household income for those who reported being paralyzed due to a spinal cord injury is heavily skewed towards lower income brackets and is significantly lower than household income for the country as a whole as reported by the United States Census.

Annual Household Income of Paralyzed Respondents Compared to Annual Household Income in the U.S.
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



Daryl "Chill" Mitchell | Atlanta, Georgia

Daryl "Chill" Mitchell is a rap musician and actor who has appeared in numerous films, among them, *House Party*, *Boomerang*, *House Party 2*, *Sergeant Bilko*, *Home Fries*, *10 Things I Hate About You*, *Galaxy Quest*, and others. On television, Chill has appeared in the *Fresh Prince of Bel Air*, *Law and Order*, *The Cosby Show*, *John Larroquette Show*, and *Veronica's Closet*. In November 2001, Chill was sidelined by a motorcycle accident, which left him paralyzed from the waist down. Although Chill was a successful actor, he faced the hardships of spinal cord injury like anyone else—he had to re-learn how to dress himself, how to drive again, fight with the insurance companies, and his family was faced with the burden of making their house accessible. Once he left rehab, Chill was determined to go back to work. And he did, signing on as a regular on the television show, *Ed*, as well as making guest appearances on several other popular programs. He currently resides in Atlanta with his wife and three children.



A BETTER FUTURE

for People Living with Paralysis and Spinal Cord Injury

While the data show a greater prevalence of paralysis and spinal cord injury than previously thought, the story behind the research is that enormous progress has been made in dramatically improving the quality of life of people living with these conditions. Much of this progress is the result of extraordinary advances in rehabilitation, technology, surgery, medicine, and innovations in product design and engineering.

This is in stark contrast to generations ago, when people living with paralysis would have been confined to institutions or been unable to perform even the simplest daily tasks like driving a car or getting dressed without major struggles. Today, however, people living with paralysis can live healthy, productive, and independent lives, and serve as engaged and vibrant members of their communities. In short, people living with paralysis now have more hope than ever before. Hope for a better quality of life. Hope for more independence. And hope for the future.

That hope is well placed, given the array of ground-breaking tools, resources, products, and services for people living with paralysis. Among these are:

- **Computer technology** that allows people who cannot move a muscle to access the power of the PC.
- **Personal mobility devices** such as wheelchairs, scooters, and seating systems.
- **Environmental control systems** such as central switch boxes that manage home appliances and electrical functions.
- **Home modifications** such as tools and architectural design elements that allow homes or workplaces to accommodate people with restricted mobility.
- **Automobiles** that are designed and equipped for people with disabilities (e.g., hand controls, shortened foot pedals, etc.)

- **Orthoses and bracing devices** that improve function and, in some cases, ambulation.
- **Clothing** that is specially tailored for people with limited function or for those who sit a great deal.
- **Service animals** such as dogs or monkeys that provide assistance and companionship.

While these and other advancements have dramatically improved the lives of people living with paralysis, they have been particularly valuable to the 1.275 million Americans with spinal cord injuries (SCI). Until recently, rehabilitation for people with SCI focused primarily on compensating for a lost function (e.g., learning how to use the right hand instead of the left).

Today, however, their rehabilitation is changing, due to increasing evidence showing that activity-based therapies can help restore function. More than 200 people, for example, have enrolled in “Locomotor Training” at the Reeve Foundation’s NeuroRecovery Network Centers—a network of cutting-edge rehabilitation centers whose staffs have been trained in intensive activity-based treatments. Funded by the Christopher & Dana Reeve Foundation in a cooperative agreement with the CDC, the network is an exciting example of how basic science is being applied to “real life”—and changing lives.

The training involves suspending people who are unable to walk in a harness over a treadmill while therapists move their legs to simulate walking. The therapy is based on a belief that the spinal cord is hardwired with a “backup program” for walking—one that can take over when the brain stops signaling. Patients who have undergone these kinds of therapies report improved cardiovascular, pulmonary and bladder function, increased bone density, and recovery of standing and stepping ability.

Michael Murphy | McLean, Virginia

Michael Murphy, now 23, graduated from The Potomac School, where he played football and baseball. He continued playing both sports at Randolph-Macon College. On April 27, 2007, he was at a fraternity party with friends, hanging out on the roof, when he fell off and landed flat on his back. As a T-9 paraplegic, whose injury is "complete," Michael only has feeling and movement from about two inches above his belly button and up. After his injury, Michael had five weeks of in-patient therapy, relearning the basics of how to take care of himself, and how to deal with the complications that come from being paralyzed. He spent the next 12 weeks as an out-patient, in rigorous therapy. At the end of the summer, he got his driver's license. By the end of the 12 weeks of therapy, he went back to school and graduated in early summer 2008 with a major in History and a double minor in Art History and Classics. Michael is studying for his GREs for graduate school, hoping to study military history, and to eventually work for the U.S. Military. Michael raced for Team Reeve in the Marine Corps Marathon on October 26, 2008.



Other promising interventions for people living with SCI include:

- **Functional electrical stimulation (FES) bicycles** enable persons with little or no voluntary leg movement to pedal a stationary leg-cycle called an ergometer. Computer generated, low-level electrical pulses are transmitted through surface electrodes to the leg muscles, causing coordinated contractions and pedaling motion. Abundant medical literature documents the effectiveness of FES to increase muscle mass and improve cardiopulmonary function. There are also studies that link FES to a reduced frequency of pressure sores, improved bowel and bladder function, and decreased incidence of urinary tract infections.
- **Coordinated care/chronic disease management** has been shown to help improve health outcomes, avoid crises, and reduce costs by integrating medical, educational, functional, and emotional services and treatment plans for patients and their families.

THE MOST IMPORTANT CAUSE FOR HOPE: A CURE

A generation ago, a "cure" for spinal cord injury or other paralyzing conditions seemed inconceivable, but today, the field of restorative neuroscience is moving from basic to translational research that is influencing the lives of people living with paralysis all over the world. There are more scientists working on brain and spinal cord dysfunction now than at any time in history. Clinical trials for innovative interventions and therapies are steadily increasing and expected to continue to increase in the near future. Today neuroscientists around the world agree that repairing the damaged spinal cord is not a question of *if*, but a question of *when*.



NEXT STEPS:

Improving Quality of Life and Finding A Cure

Our knowledge of the brain and spinal cord has progressed far beyond what it was just a few years ago, but it's still limited. Many more discoveries are needed to ensure that therapies are effective and safe. And much still needs to be done to help people living with paralysis, many of whom continue to face barriers that impede their ability to be employed in fulfilling jobs, have access to quality health care, and manage their treatments so they can live healthy and normal lives.

One of the most serious and daunting barriers that people living with paralysis continually face is their inability to obtain adequate health insurance coverage or to pay for it. Today, a significant percentage of people living with paralysis and SCI are either uninsured and/or lack adequate coverage for their condition, which can be extremely expensive.

Although the most obvious way to reduce health care costs from paralysis is to prevent them in the first place, there is evidence that these costs could be trimmed significantly with changes to the current health care system, especially the way in which people living with paralysis are treated and the way in which insurance covers those interventions. The lack of coordination across providers, a resistance to using behavioral (and often less expensive) protocols in treating secondary and chronic health conditions, and the often confusing and different systems various insurance companies use in determining benefits for people living with paralysis are just a few of the inefficient practices that have led to exorbitant health care costs among this population.

In short, there is a “penny wise and pound foolish” approach to covering people with paralysis that has led to spiraling costs for insufficient health care. A woman living with spinal cord injury that needs a seat cushion that costs \$400-500, for example, would not be reimbursed for it, but *would* be covered for painful pressure sores that could result from not having that cushion—treatment that can cost anywhere from \$75,000 to \$100,000.

Insurance coverage and access to health care generally is only one set of barriers that confront people living with paralysis. Others include:

- **Employment:** Scattershot or lackluster adherence of the Americans with Disabilities Act (ADA) has left many workplaces ill-equipped to handle the employment of people with paralysis, leaving them with fewer job opportunities.
- **Caregiving:** The staggering number of family caregivers supporting a population of 1.3 million individuals with spinal cord injury need respite and better support systems.
- **Limited number of personal care attendants:** More and better trained and paid attendants are needed to provide morning and evening care to people with spinal cord injuries to allow many to return to work.
- **Growing population with disabilities:** The number of people living with spinal cord injury and paralysis is growing, living longer, and facing health-related and quality-of-life issues as they age.



Overcoming these challenges will require major changes in the ways in which health care is delivered, covered, and improved for people living with paralysis and spinal cord injury. It will also require more research that will help develop new and better therapies and tools that help improve the quality of life for people living with these conditions and, ultimately, find a cure for them.

This kind of research is painstaking and expensive, but as history has shown, it can lead to more efficient, and ultimately, less expensive treatments that improve the ability of people living with paralysis to lead normal, healthier, and more independent lives.

Nevertheless, research about paralysis and spinal cord injury is significantly under-funded, especially in light of the number of Americans living with these conditions. Research by the National Institutes of Health on these issues, for example, was cut by \$10 million between fiscal years 2007 and 2008.

Private funding can and does help. The most recent available data show that research about spinal cord injury annually receives approximately \$32 million from a handful of private funding sources. This funding, however, barely scratches the surface of the hundreds of millions of dollars that will be needed to find cures, once and for all, for paralysis and spinal cord injury.

Joel Heifitz | Glencoe, Illinois

In December 2002, Joel Heifitz, who is co-founder and CEO of Concept Laboratories, Inc., a Chicago-based health and beauty manufacturer, went on vacation in Puerto Vallarta, Mexico. While body surfing with some friends, Joel noticed an enormous wave approaching. As he tried to pull his friends out of harm's way, he was slammed into the sea floor, which broke his neck. The break was incomplete, however, meaning that Joel was left with feeling in his limbs, but that didn't make the rehabilitation process any easier. "I spent a lot of time thinking about how this was going to affect my family, as well as how I was going to be able to do the simplest things," Joel says. Just getting out of bed was a barrier to living. The worst barrier, though, was getting over feeling like he couldn't do something because it was just too difficult. "A lot of people with spinal cord injuries," Joel says, "feel trapped because of all the challenges they face, so they stop trying." Luckily, Joel wasn't one of them. After spending months at the Rehabilitation Institute of Chicago, Joel persevered, continuing his own rehabilitation regimen at home using special equipment designed for his wheelchair and an electric stimulation bike. Since then, Joel has restructured his job so that he doesn't have to travel but can still work with salespeople to develop new ideas. Still, he's sometimes frustrated that he isn't able to attend the sales shows and big events he once looked forward to. Nevertheless, Joel says, "I am grateful for everything I have—even with this injury—because it's exposed me to folks with similar conditions who have nothing. That's the reason the Reeve Foundation is important. Not for me, but for all of them."



RECOMMENDATIONS

Concrete and Actionable Steps

The Christopher & Dana Reeve Foundation has long recognized that finding cures and improving the quality of life for people living with paralysis and spinal cord injury requires working on several fronts: research, information and education, and advocacy. Since its inception, it has served as one of the most recognized and respected advocates for this issue in the United States and internationally.

Using this knowledge—and the expertise of an extensive network of health care providers, scholars, community leaders, scientists, business leaders, people living with paralysis and others with whom the Reeve Foundation partners on this work—the Foundation developed what it believes to be the most important recommendations for policymakers and others to consider seriously in all discussions about health care policy and programs.

These recommendations provide policymakers with concrete and actionable steps that will be crucial to remove obstacles for people living with a disability, such as paralysis; reduce the crushing health care costs they often face; and expanding and supporting research that will find cures and better treatments for them.

IMPLEMENT THE CHRISTOPHER AND DANA REEVE PARALYSIS ACT (CDRPA)

The CDRPA, the first national public health bill to directly address paralysis, was signed into law by President Obama on March 30, 2009. Congress must now fund this legislation and work with administration officials to implement it by:

- Establishing the Christopher Reeve Paralysis Consortia at the National Institutes of Health (NIH) to promote collaboration among scientists doing similar work in multiple fields to enrich understanding and speed up the discovery of better interventions and cures;
- Expanding rehabilitation research, including clinical trials, to improve daily function for people with paralysis, prevent secondary complications, and develop better assistive technology;
- Developing and expanding programs at the Centers for Disease Control & Prevention (CDC), such as grants to non-profit health and disability organizations for educating the public about paralysis, improving access to services, integrating life with paralysis into society, and coordinating services within each state.

IMPROVE THE QUALITY OF LIFE FOR PEOPLE WITH DISABILITIES BY REFORMING HEALTH CARE

Nearly 47 million Americans are currently underinsured or not insured, 20 percent of whom are people with disabilities. People with disabilities also tend to earn below-average incomes but incur significantly more health care expenses than Americans without disabilities. According to the U.S. Census Bureau, Current Population Survey, 2008 Annual Social and Economic Supplement, 27.1% of the U.S. population's annual household income is \$25,000 or less. The paralysis population survey indicates 59.2% of annual household incomes for people living with paralysis is \$25,000 or less, and 62.7% of the annual household incomes for people with spinal cord injuries is \$25,000 or less.

As the debate around health care reform heats up, there are six specific areas that will be important to focus on to ensure that people with disabilities, including those with paralysis, are guaranteed adequate coverage and support:

- Develop and provide resources for streamlined, centralized, and coordinated health care systems. Medical services for people with disabilities and chronic conditions (who often experience a unique confluence of secondary and complex conditions) must be coordinated across health care providers, functions, activities, locations, and time to increase effectiveness and efficiency, as well as to prevent duplication, misdiagnoses, and unnecessary hospitalization and costly interventions.
- Lift or significantly raise caps on lifetime insurance benefits. Many insurance plans now cap their lifetime benefits at \$2 million and/or do not index them for inflation. Given the exorbitant health care costs that confront people living with paralysis and their families—which often force them to turn to Medicare or Medicaid to pay them—benefit lifetime caps should be raised to at least \$10 million and indexed to inflation.
- Remove the two-year waiting period for Medicare coverage. Unlike older Americans, who typically enroll and become eligible for coverage within months of turning age 65, disabled beneficiaries must wait two years before their coverage takes effect. A 2004 Commonwealth Fund study that the Reeve Foundation co-sponsored found that people with catastrophic injuries, who can least afford waiting for treatment, either forgo medications and other medical treatments during this waiting period or go broke trying to pay for their own coverage.
- Remove the current in-the-home rule. Medicare currently pays for the cost of power wheelchairs only if people with disabilities can prove that their chairs are needed in their homes. Many people with paralysis can achieve mobility using a manual wheelchair or a walker at home, but need power for mobility outside the home. Without access to power wheelchairs, they are unable to leave their homes at all for work or other activities.
- Increase insurance coverage for outpatient physical therapy. Insurance policies currently do not differentiate between severe injuries—such as spinal cord injuries—and injuries such as sprained ankles. As a result, the number of physical therapy sessions insurance provides on an annual basis is the same for both. More attention needs to be paid to the specific types of injuries so that treatment plans are developed accordingly and, in turn, insurance coverage is tailored to them, rather than using a blanket approach to injuries that can vary widely in how they are treated.
- Support family caregivers. While Congress recognized the importance of respite care for family caregivers by passing the Lifespan Respite Care Act in 2006 (which authorizes \$289 million in competitive grant funding to states to train volunteers and provide other services to an estimated 50 million family caregivers nationwide), it must follow through and fully fund these programs.

PROVIDE BETTER EDUCATIONAL OPPORTUNITIES TO AMERICANS WITH DISABILITIES

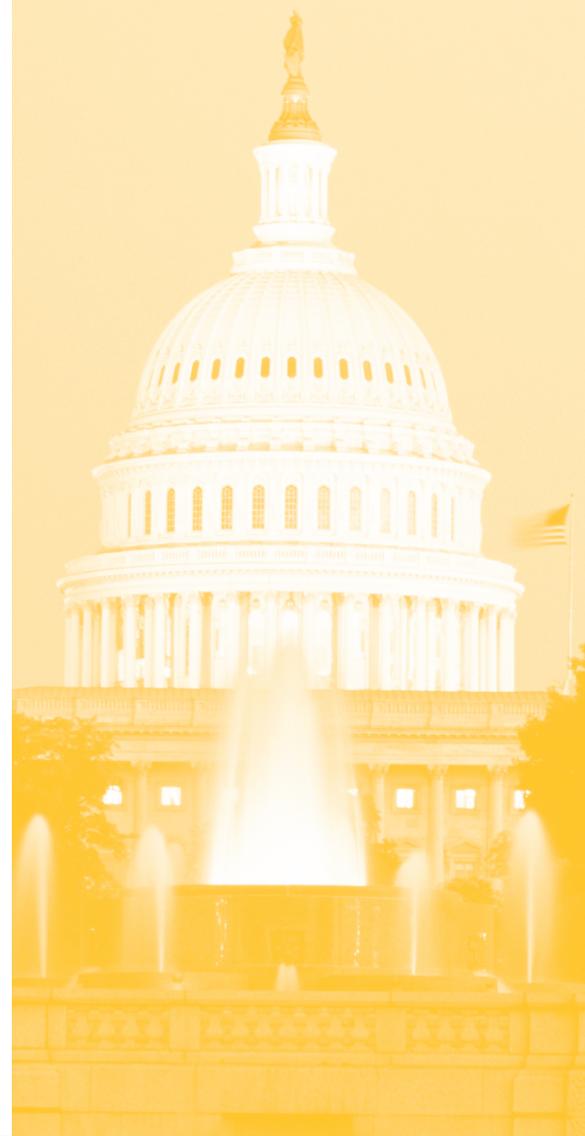
- Provide full federal funding for the Individuals with Disabilities Education Act (IDEA), rather than forcing states and local school districts to shoulder the burden as they do now.
- Support universal screening and early intervention such as scientifically-based literacy instruction and instruction on the use of adaptive and educational software for children with disabilities.
- Expand access to college opportunities for high school graduates with disabilities by making college more affordable, ensuring campus accessibility, offering special loans, and improving distance-learning technology.
- Authorize a comprehensive study of students with disabilities and issues relating to transition to work and higher education.

INCREASE EMPLOYMENT AMONG PEOPLE WITH DISABILITIES AND INSTITUTE PROTECTIONS FOR THEM FROM WORKPLACE DISCRIMINATION

- Protect and keep, rather than eliminate, Medicare coverage for people with disabilities who are returning to the workforce.
- Establish workplace programs that include disability as part of diversity training and education programs.
- Create and support incentives for employers to offer accessible transportation to work for employees with disabilities.
- Offer more vocational training and placement support for people with disabilities.

SUPPORT INDEPENDENT, COMMUNITY-BASED LIVING FOR AMERICANS WITH DISABILITIES

- Pass the Community Choice Act, which would allow Americans living with severe disabilities the opportunity to continue to live at home, rather than in institutions (which the Supreme Court has recently ruled as “unnecessary segregation” and “discrimination based on disability”).



Krista Rausin | Cape Coral, Florida

On Thanksgiving Day in 2003 while vacationing with her husband, Krista Rausin received a phone call telling her that her parents, sister and children had been in a terrible car accident. The accident left Krista's 10-year-old daughter, Arielle, paralyzed in the lower half of her body.

Determined to get the best care possible for her daughter, Krista quickly discovered how difficult that can be for people living with paralysis and their families. Stymied not only by her insurance company—which told her that she had to come up with \$10,000 to fly her daughter to rehab—Krista was also given little help from other providers, including her state. Other than two visits from a social worker, Krista and her family received virtually nothing in terms of help, including basic information about what Arielle's immediate and long-term health care needs might be and how to meet them.

Krista took matters into her own hands, becoming Arielle's primary caregiver. As part of her caregiving plan, Krista used travel as a way in which to help Arielle become more independent and self-sufficient. Together—and with other family members—Krista and Arielle navigated subways, hotels, planes, and trains to figure out how to overcome potential obstacles in these situations, as well as others that Arielle would potentially face in her life. The confidence Arielle gained from these experiences has since become a driving force behind her becoming a wheelchair racer and, with her mother, passionate advocate for schools to provide more competitive athletic opportunities for school-age disabled athletes. Today, Arielle is a freshman member of the North Fort Myers High School track team, but she is still competing alone. “This is a good beginning,” she says, “but I look forward to the day when people like me can compete for their schools just like able-bodied athletes do.”



PARTICIPANTS

at The Paralysis Consensus Conference

The 2006 Consensus Conference convened over 30 experts in statistics and paralysis in Atlanta to develop a functional definition of paralysis that could be used in a national survey and a draft survey instrument that could be used in a national survey. Organizational affiliations are listed for identification purposes only and do not imply that the

findings of the Consensus Conference or recommendations contained in this report have been approved by these organizations or represent the official opinions or conclusions of these organizations or individuals. Any opinions or policy recommendations contained in this report are solely those of the Christopher & Dana Reeve Foundation.

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**For everyone who thought I couldn't do it,
For everyone who thought I shouldn't do it,
For everyone who said I didn't have it in me,
See you at the finish line....**

—Sign posted in Christopher Reeve's exercise room



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