

Executive Summary

Developing an Action Plan to Improve the Quality and the Quantity of Data about Paralysis

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Identifying the scope and impact of functional limitations for people with disabilities is an important step toward improving quality of life and the ability to live independently for the estimated 54 million Americans who report having some form of disability. Among people with paralysis, many of whom live in poverty or who lack social support, severe functional restrictions 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 to addressing this problem.

At this time, reliable estimates of the number of persons with paralysis in the United States do not exist. By not having accurate prevalence data that help describe the full nature of the condition, developing a comprehensive public health response becomes problematic. To address this, in May 2004 the Christopher Reeve Paralysis Foundation (CRPF) solicited research proposals that would increase understanding of the availability, accuracy and quality of data quantifying paralysis in this country. 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 federal 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, ultimately leading to policies and strategies that can improve their quality of life.

Research Questions

In October, 2004, a team of researchers from the University of Kansas Medical Center and the University of Kansas' Research and Training Center on Independent Living began work on a one year project to investigate ways in which paralysis are currently being measured. The goals have been to:

- 1. Investigate ways in which paralysis are currently being measured in this country;*

2. *Examine the validity of prevalence and incidence estimates based on these approaches; and*
3. *Identify promising measurement reporting systems.*

Definition of Paralysis

For the purposes of this study, paralysis has been defined by the CRPF as: “related disorders, diseases, birth defects, and injuries that affect ambulation or paralysis of the extremities (arms). This does not include disorders like vocal cord paralysis, gastrointestinal paralysis and facial paralysis.”

Research Components

There were three major components to the investigative research:

1. *Review existing national, state, and organization surveys to examine questions related to paralysis that could be used to estimate the number of persons with this condition;*
2. *Survey state and federal agencies and organizations representing persons with disabilities related to paralysis to assess their surveillance capacities;*
3. *Follow up survey findings with more in-depth discussions with, or site visits of, potential ‘best practice sites’ to determine more accurately the nature of elements in data systems or organizational structures that could lend themselves to collecting more reliable paralysis estimates.*

Findings

National, state, and organization surveys were analyzed to determine whether there were questions within these instruments that specifically measure paralysis. Overall, our findings indicate measures of paralysis within national and state surveys, and those used in clinical data sets and registries, are primarily proxy measures based upon functional limitations or clinical diagnoses such as International Classification of Disease (ICD) codes. Spinal cord injury scales, such as that of the American Spinal Injury Association (ASIA), are more specific measures of function and diagnosis but may not be suitable for other conditions associated with paralysis.

Review of National Surveys

- National surveys such as the National Health Interview Survey (NHIS) include questions to adults 18 and over about functional limitations based upon equipment use, such as wheelchairs or scooters, or the primary reasons for these limitations. Reasons may range from general descriptions such as *back problem* to more specific diagnoses such as *spinal cord injury*. While giving rough estimates of the nature of a disability for the adult population, these descriptions are less useful when assessing symptoms, such as paralysis, that may be associated with multiple disabilities or conditions.

Surveys of State Agencies

State sites were randomly selected from among the 10 federal regions within the United States. Within each region, agency types were identified that provided a cross-section of state data surveillance systems, including: birth defects registries, hospital discharge datasets, cancer registries, trauma system registries/databases, and CDC funded state disability and health programs.

- State hospital discharge datasets and registries that collect trauma and spinal cord injury data often use ICD coding to indicate paralysis. Some ICD codes represent specific symptomology, including paralysis, associated with conditions such as spinal cord injury or stroke. However, there may not be specific paralysis codes for other conditions involving varying degrees of paralysis such as Multiple Sclerosis. Registries also have specific mandates tied to their purpose and funding, leading to limitations in the scope of related conditions or co-morbidities they capture.

Surveys of Organizations

Organization representatives from disability groups associated with paralysis were contacted and interviewed by telephone.

- Most organizations representing persons having conditions associated with paralysis, such as the Amyotrophic Lateral Sclerosis (ALS) or American Stroke Associations, do not ask constituents detailed questions about their conditions. The Multiple Sclerosis Society is the exception and has been conducting a longitudinal survey of its members; however, this survey doesn't collect information specific to paralysis.

Survey Results

Completed interviews were obtained from 56 state and federal agencies and 83 condition-specific organizations for two separate but similar survey instruments.

Federal and State Results

- 30/56 (54%) of state and federal agencies interviewed collect paralysis information.
- 22/30 (73%) of federal and state agencies collecting paralysis information report collecting ICD clinical diagnosis codes, with others reporting External (E)-codes, research intake forms, state registry information, and special surveys.

Organization Results

- 14/83 (17%) of organizations interviewed collect some form of paralysis information.
- 14/14 (100%) of organizations collecting paralysis information report collecting some form of state registry information, with some also collecting ICD codes, information from people seeking services, research intake forms, and special surveys.
- 8/14 (57%) of organizations collecting paralysis information considered their primary mission to provide services or information to individuals seeking assistance; the remaining 6/14 (43%) considered themselves research institutions.

Importance of Paralysis Data Collection

- When asked to rate the importance of collecting information for their agency or organization: 43% (13/30) state and federal agencies and 64% (9/14) of organizations rated paralysis as important information to collect.

Possible Best Practice Sites

In-depth discussions with sites in which elements of data collection or system organization appeared promising suggested the following:

1. States in which paralysis surveillance appears most promising have empowering legislation in place that allows state agencies to collect, link and use data in ways that could lead to still more comprehensive information networks.

2. States that have empowering data surveillance legislation in place are those in which there appears to be a history of data-driven public policy, and in which there is a tradition of governmental cooperation with health care entities.
3. Persons in positions of leadership who have extensive experience in both disability and public health are critical to moving a paralysis surveillance agenda forward.
4. Organizations may be able to commit resources to undertaking member surveys if there is a clear rationale behind doing so.

Summary and Recommendations

Two primary types of data are being collected at the national and state levels regarding paralysis: (1) diagnostic and (2) functional limitation. Because data specific to paralysis are not currently available through existing surveillance, our recommendations focus on future ways to collect this information. A major target of the Healthy People 2010 initiative is to improve surveillance of people with disabilities. Our work supports this Healthy People 2010 initiative and addresses ways these data could be used to change policies and to improve services for people with disabilities who are affected by conditions associated with paralysis.

Our specific recommendations are as follows:

1. Develop a uniform definition of paralysis that captures the breadth of possible ways that paralysis 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 and resulting decreased social participation. A conference of stakeholders of paralysis convened by the CRPF and CDC and supported by The Institute of Medicine or organizations of similar stature could draft this paralysis definition that includes persons with similar mobility impairments. The goal is to have a widely accepted definition that could improve paralysis surveillance and strengthen the validity and uniformity of measurement systems.
2. Develop paralysis survey questions on ways that people with paralysis are limited functionally. 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) system that focused on diagnosis from a deficit perspective. A 'disability module' could be added to many existing state and federal surveys if incentives were available to support these efforts. A recent pilot module has been proposed to be included in the 2006 Kansas Behavioral Risk Factor Surveillance System (BRFSS) [see full report on pp. 28-29]. Future steps may include adding such questions to the national BRFSS core module or to other national surveys such as the National Interview Health Survey (NHIS) and the National Health and Nutrition Examination Survey (NHANES). Working with other states, the validity and usefulness of these data for informing policy and enhancing existing services can also be tested.

3. Provide incentives to encourage organizations representing persons with conditions where paralysis exists, such as the MS Society and the ALS Foundation, to add items to an ongoing data collection system to collect more detailed information on severity or nature of the condition. Seed money and development of a data and outcomes exchange among participating organizations could provide incentives to increase compliance. Collecting data on the severity and nature of a condition would provide organizations with a better picture of the range of disability experienced by their constituents and could allow these organizations to better tailor services to their constituents. Because this information could be added to existing collection methods such as a constituent intake questionnaire, it is unlikely to be administratively burdensome.
4. Improve future data collection efforts by working more closely with participating states that have data-driven public policy capacities in place (e.g., Minnesota, South Carolina, Ohio, Alaska, Colorado, etc.). The goal is to support the development of demonstration programs through grants or contracts to build capacity for ongoing state paralysis surveillance independent of state surveys or registries. Approaches could include linking existing data sources or working toward other forms of surveillance that states deem most suited to broader public health needs, of which paralysis would be one. One important outcome would be to develop strategies that could be transferable to other states with less sophisticated information systems.
5. Further involve consumers in the process of data use to translate improved surveillance information into practice. A national advisory group comprised exclusively of persons

with paralysis should be convened to help interpret improved surveillance information to ensure that these data are used to benefit people who have been diagnosed with conditions associated with paralysis. Interventions 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 quality of life.

Note: A related document to this project is *Whitepaper: Paralysis Task Force Meeting on the Development of a Public Health Action Plan on Paralysis and Similar Mobility Impairments*.