

History

The prevalence of individuals with spinal cord injuries in the United States is estimated at 250,000-320,000 individuals, with approximately 15,000 new cases each year. Until World War II, the average life expectancy for a spinal cord injured patient was 6-12 months post injury with up to 80% of patients dying in the first two weeks. This short life expectancy was secondary to sepsis from kidney or bladder infections, pneumonia or pressure sores. Since about 1940, the life expectancy of spinal cord patients has improved significantly and now approaches that of the average population, depending upon level of and age at injury. This improved life expectancy reflects not only the advent of antibiotics and improved management of medical problems, but the initiation of a more comprehensive continuum of care from the acute onset of injury to discharge into the community and long-term follow-up. The development of the resources and networks to provide comprehensive care for spinal cord injury has been a major goal for the Arkansas Spinal Cord Commission since its inception.

Initially in the United States, the Veterans Administration was the leader in the development of a system of comprehensive care for spinal cord injured individuals. However, this was only available to veterans. With the passage of the Rehabilitation Act of 1973, the Rehabilitation Services Administration began setting up a system of regional spinal cord injury centers to provide the same comprehensive rehabilitation services to civilians and to explore and develop new treatment and rehabilitation methods for spinal cord injured patients.

In Arkansas, about 100 new cases of spinal cord injury are identified each year. Efforts to improve the care of the Arkansans with spinal cord injuries began in the 1950's. One of the pioneers of this effort was Mrs. Jane Smith whose mother sustained a spinal cord injury resulting in tetraplegia due to a motor vehicle crash in Memphis, TN in 1956. When Mrs. Smith brought her mother home to Cross County, Arkansas after nearly a year in the hospital, her doctors told her that they had nothing to offer her mother, and she should just be made comfortable until she died. Mrs. Smith would not accept this poor prognosis. A librarian, she was adept at researching resources and learned about the spinal cord rehabilitation treatment available at the Memphis Veterans Administration hospital. Since her mother was not eligible for care there, she was referred to Dr. Howard Rusk at the New York University Rehabilitation Institute in New York where Mrs. Smith's mother eventually received her rehabilitation. Kathleen Murray, Mrs. Smith's mother, benefitted from the rehabilitation treatment and her family learned how to manage the secondary conditions and she lived until 1978. When Mrs. Smith returned to Arkansas from New York, she began her tireless battle to make citizens in Arkansas aware of the plight of Arkansans with spinal cord injuries in this state and to organize them to find a solution.

Others in the state were working toward the same goal. In 1960, Arkansas Rehabilitation Services, the state designated vocational rehabilitation agency, opened the Hot Springs Rehabilitation Center (HSRC), a vocational rehabilitation facility in Hot Springs, Arkansas. The first patient admitted to the Center had a spinal cord injury and at the completion of her training, assumed a career as a secretary. Other individuals with spinal cord injuries followed.

In 1972, one of the first meetings to discuss how to improve the quality of care for individuals with spinal cord injuries was held at the Hot Springs Rehabilitation Center. At this time, vocational rehabilitation was available in Arkansas but few Arkansans with spinal cord injuries could participate because of the lack of basic rehabilitation to help them achieve functional independence. Jane Smith organized this meeting in hopes of establishing a Regional Spinal Cord Injury Center in Arkansas as part of the federally funded SCI Model Systems program. being established by the Department of Health Education and Welfare. This was followed in 1973 by a meeting hosted by then First Lady Betty Bumpers. With this meeting, the Spinal Cord Injury Task Force of the Arkansas League of Nursing was established and Governor Dale Bumpers provided a grant of \$50,000 to conduct a survey of SCI in Arkansas. Mrs. Bumpers, who had an interest in child health, asked that individuals with spina bifida be included in the survey. Elaine Wilcox, PhD, an epidemiologist who had conducted similar surveys in Alabama and Hawaii was hired to come to Arkansas to conduct the survey with a grassroots effort to collect the data through numerous state agencies and health care providers.

About the same time, with the support of Dr. Mary Switzer, then Commissioner of the U.S. Rehabilitation Service Administration [RSA], Corbett Ready, Deputy Commissioner of the RSA met with Arkansas Rehabilitation Services Commissioner Russell Baxter and several Arkansas legislators and Rehabilitation personnel. This led to the Arkansas Rehabilitation Services being awarded an R.S.A. innovation and expansion grant of \$250,000/year to provide comprehensive rehabilitation services to Arkansans with spinal cord injuries. The project, lead by Buddy Carmack, also helped establish interagency linkages to facilitate care and rehabilitation of individuals with spinal cord injuries by establishing rehabilitation field counselors throughout the state. These counselors obtained referrals for spinal cord injured individuals within their assigned region, provided counseling, maintained family communication and monitored client progress while the patient was in acute, intermediate care and vocational rehabilitation. They helped to identify the needs of their spinal cord injured clients and to direct them to the agency or facility where these needs could be met. This project established the framework for the Arkansas Spinal Cord Commission Case Management program.

In 1974, Dr. Wilcox 's report A Statewide Survey of Spinal Cord injury / Spina Bifida in Arkansas was published. It identified 602 individuals with spinal cord injury and 284 living with spina bifida and provided a wealth of information about those individuals. With the results of the survey in hand, Jane Smith, with the help of her husband Maurice, a consummate politician, determined that the only way to get services for individuals with spinal cord disabilities in Arkansas was through legislation. Through their efforts, Dr. Howard Rusk addressed the Joint Budget Committee of the Arkansas Legislative Council at the State Capitol in November of 1974. He spoke of the benefits of spinal cord injury rehabilitation. Several individuals who lived with spinal cord disabilities, most notably Mr. Harold Thomas, a severely injured tetraplegic who had returned to work after his injury in order to support his family in 1963 and Marcus Orr, a professor at Rhodes College in Memphis who lived with paraplegia, also described the plight of individuals who had to leave the state to obtain basic rehabilitation treatment. The Legislative Council approved an appropriation for the Arkansas State Spinal Cord Commission to be established. At the 1975 legislative session in January, the members of the Arkansas Legislature

passed Act 311 to establish the Arkansas State Spinal Cord Commission. This was the first state agency in the United States to be responsible solely to individuals with spinal cord disabilities. In July 1975 the first Arkansas State Spinal Cord Commission was given the oath of office at the State Capitol by Governor David Pryor. Those members were Dr. Roger Bost, Dr. Stevenson Flanigan, Dr. Thomas Durham, Mrs. Jane Smith, Mrs. Patricia Birch, Miss June Garner, Dr. John Bowkers, Mr. Harold Thomas, Mr. Marshall Purvis, and Mr. Russell Baxter, ex officio. This Commission was responsible directly to the Governor's office and initially contracted with Arkansas Rehabilitation Services for administrative and fiscal management. The Arkansas State Spinal Cord Commission has never been a part of ARS, but works closely and has shared field offices for many years.

The first actions of the newly appointed Commission in July of 1975, when Act 311 became effective were to hire an Executive Director and establish an office and policies. ARS Commissioner Russell Baxter was integral in the early development of the state agency aspects of the Commission.

In 1977, the Arkansas State Legislature approved a second ASCC initiative. That was the establishment of the Arkansas Spinal Cord Disability Registry. Recognizing the value of the data collected by Dr. Wilcox, a mechanism was needed to identify and offer services to Arkansans with spinal cord disabilities. Act 330 of 1977 mandated The Arkansas Spinal Cord Commission shall establish and maintain a central registry of spinal cord disabled persons. Every public and private health and social agency and attending physician shall report to the commission within five (5) calendar days after identification of any spinal cord disabled person. However, the consent of the individual shall be obtained prior to making this report, except that every spinal cord disease or injury resulting in permanent partial, permanent.

The registry was one of the first in the country. The state of Florida mandated a similar registry in 1977. Today, a few other states maintain spinal cord injury registries, however only Arkansas and Florida maintain dynamic registries that update contact information on the individuals, similar to that maintained by the federal SCI model systems.

The new Commission was established as other complimentary initiatives were being set forth in the efforts to establish a continuum of care of individuals with spinal cord disabilities in Arkansas. On the medical front, Dr. Stevenson Flanigan, Professor and Chair of Neurosurgery at the University of Arkansas for Medical Sciences [UAMS] provided medical management for many newly injured individuals with spinal cord injuries as well as training many of the neurosurgeons who established practices throughout the state. Leadership afforded by Mr. Russell Baxter, Commissioner for Rehabilitation Services, established an additional grant from R.S.A. to fund a Rehabilitation Medicine program at UAMS under the direction of the then dean for the College of Medicine, Tom Bruce, M.D. Dr. Flanigan was the Director of the early rehabilitation program, working closely with ASCC Case Managers to identify spinal cord clients experiencing problems. He was the first ASCC Medical Director, serving from 1975 to 1985. During the 1970's, a few individuals with complex spinal cord injuries who could not be managed at UAMS, Hot Springs Rehabilitation Center, or other facilities in the state, were

transported to the Texas Institute of Rehabilitation and Research (TIRR) in Houston, the Regional Model System facility.

A part of the 1975 enabling legislation called for the Commission to develop or cause to be developed an Arkansas spinal cord treatment center and system. After efforts by the Commission to establish a 'bricks and mortar' SCI rehabilitation center on the UAMS campus were unsuccessful, the Commission looked to Baptist Medical Center in Little Rock to provide intermediate care and rehabilitation for spinal cord injured patients. The hospital had recently moved to its west Little Rock campus and there was space available in the old hospital building on Marshall Street (near the present Arkansas Childrens Hospital). This effort led by John Gilbreath, then Administrator of Baptist Medical System, and brought about the establishment of the Arkansas Rehabilitation Institute (ARI) in 1975. ASCC provided funding to ARI for the first three years to assist in equipping the rehabilitation unit with Physical, Occupational and Recreation Therapy equipment including mat tables, weights, kitchen and bathroom adaptive equipment tilt tables, wheelchairs and sports equipment. The Commission also paid for the salaries of the therapy staff until the program could get underway. Expert staff was hired including a physiatrist team leader and the SCI program was established. ARI was the only rehabilitation center for spinal cord injuries in Arkansas for many years and the program thrived, with newly injured individuals from around the state coming there for inpatient and outpatient services. An ASCC Case Manager was assigned to the center to assure continuity in discharge planning. The Institute, which had added rehabilitation services for individuals with traumatic brain injuries, strokes, amputations and other physical disabilities over the years, moved to a new free standing facility on the BMC campus in west Little Rock in 1985 under Medical Director J. Patrick Maloney, M.D. He recruited Dr. Shirley McCluer to head up the spinal cord injury service in the new hospital, renamed Baptist Health Rehabilitation Hospital. In 1985 she assumed the role of ASCC Medical Director and served until her retirement in 1996. Upon her retirement, a hand picked successor, Dr. Thomas Kiser, a Board Certified Physiatrist who shared Dr. McCluer's interest in spinal cord injury rehabilitation was named ASCC Medical Director. After a change in state law in 1987 regarding the certificate of need for hospitals, many regional and local hospitals established rehabilitation units and several national rehabilitation companies established rehabilitation hospitals in the state, however only a few provided spinal cord injury rehabilitation. Hot Springs Rehabilitation Center, renamed Arkansas Career Training Institute in 2003 continued to provide spinal cord rehabilitation, particularly to those individuals without insurance coverage, until the medical rehabilitation program there closed in 2012.

In the same manner that the Commission 'seeded' the funding for inpatient rehabilitation, in 1978, the Commission partnered with Arkansas Childrens Hospital to establish a Spina Bifida clinic, allowing families to bring their children with spina bifida to one site where they were seen by medical specialist including physiatrists, neurosurgeons, orthopedists, urologists and developmental pediatricians as well as physical and occupational therapists and have all tests, x-rays and other procedures on one visit, rather than the previous practice of spending several days a month traveling to specialists all over the state. In addition to the multidisciplinary medical care for spina bifida patients, the clinic provides education and training about spina bifida for these patients and their parents. Also since 1978, in collaboration with MedCamps of Arkansas

and Camp Aldersgate, the Spinal Cord Commission sponsors one week of overnight camp for children and adolescents ages 6-16 with spina bifida and other spinal cord disabilities. Over 500 children with spina bifida and other spinal cord injuries have gone to the fully wheelchair accessible camp, promoting their independence and providing an often needed respite for parents.

In 1981, the Arkansas Legislature mandated the ASCC Long Term Attendant Care program, providing reimbursement for personal care services to clients with tetraplegia who met eligibility criteria. In 2013, 26 clients received approximately 4 hours of care per day from attendants assisting in such activities of daily living as hygiene, meals, dressing and transferring in and out of bed. The annual average cost was \$10,900 per client, which is approximately 20% of the cost of maintaining these clients in a nursing home. An innovative program, particularly utilizing the consumer direction model, allowing individuals the ability to select, train, supervise and pay their own attendant to work the hours they choose, the program has been a model for other personal care programs in the state and the nation.

In 1987, the Commission adopted medical criteria to assure that the individuals who received services from the Spinal Cord Commission had sustained medically documented damage to the spinal cord. In addition to this, additional criteria were established to determine the disabling condition resulting from the damage, including a documented impact on motor ability or movement, sensation or ability to feel and lack of normal bladder and bowel function. When the new criteria was approved by the commission, after review by the Arkansas attorney General, the clients on the ASCC registry at that time were 'grandfathered' into eligibility for services, whether or not they met the new criteria. With ASCC's limited resources, this medical criteria assured that the agency would serve those Arkansans who had actually sustained a disability from their spinal cord damage.

Over the years, the spectrum of services provided by the Spinal Cord Commission has continues to grow. Using a case management program designed in the client centered insurance case management model, Case Managers are assigned to 10 regional offices and are responsible for services to clients who reside in the counties assigned to the region. In 2013, 14 regional Case Managers and one Intake Coordinator provided services to over 2,600 clients throughout the state. In 2012, ASCC Case Managers made 6,072 client contacts to 2,624 clients in 75 counties. Clients who meet medical and financial eligibility criteria may often obtain purchased services through the Spinal Cord Commission when similar benefits through insurance coverage have been exhausted. This includes medically prescribed equipment such as wheelchairs, braces, wheelchair cushions, adaptive bathroom equipment, medical supplies, medications, and home modification such as ramps, outpatient clinic and therapy visits, and short-term attendant care.

Beyond improving care for individuals with spinal cord injury, the Spinal Cord Commission has taken a role in preventing spinal cord injuries and spina bifida. Beginning in 1987, the Commission joined the 'Think First' movement, promoting safe diving as well as seatbelt use, and prevention of drinking and driving and other risky behaviors that result in spinal cord injuries. These efforts, in cooperation with the National Highway and Transportation Safety Administration (NHTSA), Arkansas Highway Commission, Arkansas Department of Health and

Centers for Disease Control and Prevention (CDC) included school-based program, recreational programs, posting of signage and public service announcements among other promotions. The Commission staff and clients were vocal advocates of the primary seat belt law and other injury prevention measures. In the early 1990s when Centers for Disease Control and Prevention determined the effects of folic acid in the incidence of spina bifida, the Commission joined efforts with the Arkansas Department of Health, March of Dimes and other organizations to promote folic acid supplements for women of childbearing age.

Since 1988, working through cooperative agreements with the Center for Disease Control and Prevention Disability and Wellness Center, the Spinal Cord Commission has been involved in research and demonstration projects to prevent secondary conditions in individuals with spinal cord disabilities. Projects to identify and reduce the incidence of pressure sores in spinal cord injured individuals in Arkansas won national acclaim and have been replicated in the United States and Canada. Other prevention education efforts have demonstrated the impact that support and follow up can have in preventing secondary conditions.

The Arkansas Education and Resource Center on Spinal Cord Injury was established in collaboration with a grant from Paralyzed Veterans of America in 1990 and provides information on spinal cord injury causes, treatments and resources. It contains 900 references including books, articles, videotapes, films and catalogues, including fact sheets on specific topics that were written for clients and families. These fact sheets have been reprinted in numerous publications and resource centers on the country. Satellite resource centers have been established in regional field offices as well to allow ready access of information in the local communities. ASCC established an educational website in 2003 to provide reliable information about ASCC services and other spinal cord disability related topics. The website was expanded in 2013.

Another educational effort to assist Arkansans with spinal cord disabilities in learning about their disabilities and the resources available was the establishment of the “Spinal Courier” quarterly newsletter (renamed the Spinal Connection in 2012), which is distributed to all clients on the registry and interested health care professionals.

Since 1990, the Spinal Cord Commission has sponsored educational conferences and workshops, both large statewide conferences held in Little rock featuring national speakers as well as regional ‘mini conferences’ in rural and distant areas of the state for Arkansans who may not be able to travel to Little Rock. These day long education programs provide clients, families, and health care professionals on spinal cord disabilities, independent living and accessibility among other topics and include an exhibit hall to allow attendees to see the latest technology in durable medical equipment and supplies as well as adaptive service providers.

In 2009, the Arkansas Trauma System was established by the Legislature and the Arkansas Spinal Cord Commission was mandated to appoint a member to serve on the Trauma Advisory Council (TAC). Dr. Lorrie George was the first ASCC representative, followed by Mr. Jon Wilkerson in 2011. The Commission has worked closely with the Arkansas Department of Health, the TAC and rehabilitation providers around the state to assure rehabilitation is an integral part of the continuum of care in the state trauma system. In 2011, the Commission

conducted a study of rehabilitation hospitals in the state and upon presenting that report to the TAC was asked to enter an agreement to assume the lead role for trauma rehabilitation, including a funding stream to carry out the activities. In 2012, the Commission lead efforts to establish state trauma rehabilitation strategic plan and continue to move forward to make changes to improve the rehabilitation care and treatment of individuals with traumatic injuries, including spinal cord injuries.

While the initial goal of the original Arkansas Spinal Cord Commission to become part of the federal Spinal Cord Injury Model Systems of Care has never been met, the Commission continues to improve the care and services to Arkansans with spinal cord disabilities.

Through the vision and hard work Jane Smith, Steve Flanigan and Shirley McCluer and the many dedicated Commission members and staff that have succeeded them, Arkansans who have sustained spinal cord injuries and other disabilities live as independently as they choose.

References

Acton, PA, Farley T: Traumatic Spinal Cord Injury in Arkansas, 1980 to 1980, Arch phys Med Rehabil Vol 74, 1993.

Brown, Pamela: The Arkansas Spinal Cord Commission, Journal of the Arkansas Medical Society, Vol. 91, no.3, August 1994.

Arkansas Spinal Cord Commission Annual Reports, 1990 – 2013.

Personal interviews, correspondence and recollections from:

Mrs. Maurice (Jane) Smith

Dr. Stevenson Flanigan

Dr. Shirley McCluer

George Richardson

Harold Thomas

Russell Baxter

Buddy Carmack

Cheryl Vines

Executive Director of the Arkansas Spinal Cord Commission:

George Thomas 1975 - 1976

Buddy Carmack 1976 - 1978

George Richardson 1978 – 1984

Bruce Thomasson 1984 – 1989

Cheryl Vines 1989 – 2013

Patti Rogers 2013 - 2016

Terra Patrom 2016 - Present