

# Spinal Cord Disability Registry

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The Arkansas Legislature established the Arkansas Spinal Cord Disability Registry in 1977 (ACA 20-8-206). It was the first state-mandated spinal cord disability (SCD) registry in the United States. It remains one of the most comprehensive registries in the country in the number of elements of information it collects and the volume of cases. Over 6,700 records of Arkansans with spinal cord disabilities have been entered into the registry.

Act 330 of 1977 (ACA 20-80-206) mandates that:

“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 total, or total disability shall be reported to the commission immediately upon identification.

(2) The report shall contain the name, age, residence, and type of disability of the individual and such additional information as may be deemed necessary by the commission.

(B)(1) Within fifteen (15) days of the report and identification of a spinal cord disabled person, the commission shall notify the spinal cord disabled person or the most immediate family members of their right to assistance from the state, the services available, and the eligibility requirements.”

When an individual is referred to the Commission, as part of the initial assessment, the ASCC Case Manager will complete a survey (often called the ‘surveillance form’) to collect data for the registry. In addition to basic demographics such as date of birth, gender, race and address, additional elements about the individual’s educational, work and health history are collected. For those who have sustained traumatic injuries, details about the etiology (cause) of the injury and hospitalizations are collected.

The data in the registry is used primarily to drive ASCC programs, including the assignment of client cases to the appropriate case manager and to maintain the status of each case (i.e. open or closed, monitoring status, reason for closure). The dynamic nature of the registry allows ASCC to maintain up to date information on clients’ contact information in order to provide them with useful resources including the quarterly Spinal Connection and other resources.

The Registry is also used to establish trends, including the incidence and prevalence of spinal cord disabilities in Arkansas. These reports are used to determine how resources will be used at the Commission and in requesting funding for Commission services. They are also used in creating legislation (i.e. the primary seatbelt law), and to help target injury prevention efforts as well as other statewide services. Arkansas data is also compared to national data on spinal cord disabilities. The Commission prepares reports in response to queries from Legislators, other state

agencies, disability organizations and others interested in the spinal cord population. When requested, the data (without personal identifiers has been shared with the national Centers of Disease Control and Prevention. Over the years ASCC has worked closely with CDC on the data collection methods and analysis of data.

Finally registry data has been utilized in clinical and public health research in collaboration with CDC and esteemed research faculty at UAMS and other universities around the state and Country. Statistics and generalizations made from analysis of the data are made on groups and do not identify any one individual.

All registry information is confidential and safeguarded by ASCC using the latest technology. It is maintained in a secure database and protected under the Health Insurance Portability and Accountability Act (HIPAA). No information with personal identifiers is ever released to anyone outside ASCC without an individual's written permission.

If you have questions about the AR Spinal Cord Disability Registry, contact the ASCC Information Technology Manager at **501-296-1785 or 1-800-459-1517.**