



Living with Spina Bifida: A Public Health Challenge

Spina Bifida

- Spina bifida (SB) is a birth defect affecting the spine that is usually detected before birth. SB occurs when a portion of the backbone, as well as the spinal cord beneath, do not form correctly during pregnancy. This typically results in damage to the spinal cord and nerves.
- SB can cause physical and intellectual disabilities that range from mild to severe.
- Each year in the United States about 1,500 babies are born with SB. The Centers for Disease Control and Prevention (CDC) is committed to helping every person with SB reach his or her full potential.

Public Health Need

- **Addressing opportunities for intervention.** SB is a complex condition, impacting several different organs in the body. SB typically requires care from many specialists. Reviewing how and what patient care is delivered at different SB clinics can help determine what treatments work best.
- **Using research to build evidence.** Currently, there is little evidence on the effectiveness of different types of care provided to people with SB. Healthcare professionals often rely on their own experiences when deciding how to care for their patients. Adding evidence-based research findings from scientific literature to this clinical experience can help improve care outcomes for people with SB.
- **Standardizing best practices.** People with SB receive different care depending on where they seek treatment. Once identified, evidence-based best practices need to be shared with all healthcare professionals, ensuring that everyone with SB has the opportunity to receive the same high-quality care. This standardization can improve the lives of SB patients and their families and caregivers, and lessen the impact of SB on the healthcare system.

What is CDC Doing?

Scientists at CDC are partnering with healthcare professionals at SB clinics across the country. Together they are studying the treatments delivered at each clinic and comparing patient outcomes over time. As researchers identify what types of care lead to the best outcomes for patients, this information will be shared with people living with SB, their families, and the healthcare professionals who treat them. Collectively, this work can improve the health of all people living with SB so they can reach their full potential.

What is CDC Doing (continued)

- **Putting research to work.** CDC is the first organization to look at national data comparing people with SB who developed end stage renal disease (ESRD) with people without SB who developed ESRD. Findings indicated that urological issues were the main cause of ESRD among those with SB.
 - » Additionally, CDC has developed a urologic protocol, or a series of care and tests for newborns with SB. This protocol will determine the right care at the right time for young children with SB. The protocol will minimize urological issues, preserve renal function, and ultimately reducing ESRD among people with SB.
- **Building evidence by monitoring public health data.** CDC funds and manages the National Spina Bifida Patient Registry. Staff at spina bifida clinics participating in the Registry collect data annually from children and adults receiving care at their clinics. These data will provide the evidence needed to identify the best care for people with SB. CDC is the only organization in the United States conducting this type of research based on information from multiple SB clinics.
- **Collaborating with partners.** Through a collaboration with the Spina Bifida Association, CDC is building the infrastructure to support a formal network of SB clinics across the country. Healthcare professionals will be able to share resources through this network, including the latest research from the Registry. This network will help people with SB and their families find specialists at their local clinic, and help clinic staff connect patients to services that are not available locally.

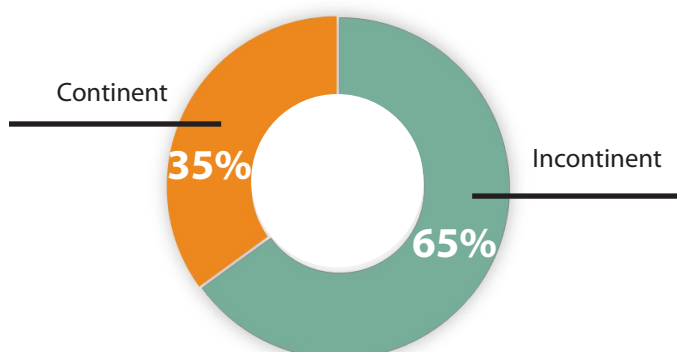
FUTURE OPPORTUNITIES

Although much has been accomplished, important challenges remain to make sure people living with SB reach their full potential.

- **Additional data are important.** To obtain a complete picture of what care works best for SB, researchers need information on more people living with SB, especially those who are 18 years or older. Researchers need innovative ways to collect information on older people with SB because most SB clinics are part of children's hospitals. Many of these children's hospitals have policies that only allow treatment for patients up to 18 years.
- **Addressing an important quality of life and health challenge.** Bladder and bowel continence (ability to control urination and passing stool) are two of the most significant challenges faced by people with SB. Damage to the spinal cord means that many people with SB have no feeling or control in the lower part of their bodies. Determining the correct care, education, and training to help people with SB achieve continence leads to better physical health and social well-being.
- **Support for a transition to adulthood.** People with SB need support to successfully transition to adulthood. Education, employment, housing, transportation, adult health care, and social needs are all areas where providing support early can lead to independence. Currently, there are few healthcare professionals who treat adults with SB, and efforts to help adults with SB live and work independently are inconsistent. There is an opportunity to better address the needs of young adults with SB as they transition to adulthood, specifically by improving how SB clinics prepare adolescents to live independently as adults, and by increasing the number of specialists trained to treat adults with SB.

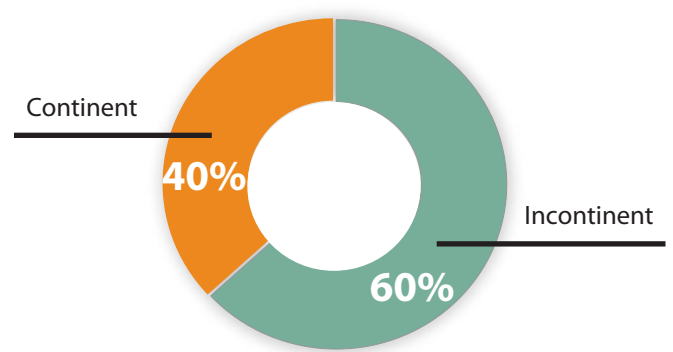
Data from CDC's National Spina Bifida Patient Registry

Urinary continence



These numbers are based on 3707 SB registry participants, age 5 years and older with impaired bladder function.

Bowel Continence



These numbers are based on 3728 SB registry participants, age 5 years and older with impaired bowel function.