



SBA's 2021 Advocacy Priorities

Spina Bifida affects an estimated 166,000 individuals in the U.S., and over half are adults. It is a birth defect for which there is no cure and results in a spinal cord injury before a baby is born.

1. Increase funding for the National Spina Bifida Program at the National Center for Birth Defects and Developmental Disabilities (NCBDDD) at the Centers for Disease Control and Prevention (CDC)
2. Tell Congress to Include the Disability Community in legislation

Fund the National Spina Bifida Program

THE ISSUE: The only place in the federal government specifically studying this complex condition for children and adults is the NCBDDD at the CDC through the National Spina Bifida Patient Registry, the Spina Bifida Collaborative Care Network, and specific research projects.

THE ASK: Support a \$9 million budget for the National Spina Bifida Program. The program is currently funded at \$7 million. With increased funding, we could:

1. Fund research on sudden unexplained death among adults in the Spina Bifida community
2. Develop studies on social determinants of health within the Spina Bifida registry
3. Create a protocol to improve the health outcomes of children who have Spina Bifida with hydrocephalus
4. Research barriers to transition from pediatrics to adult care
5. Analyze potential models for adult care to determine impacts on individual health outcomes
6. Study the effects of adults living with Spina Bifida

Tell Congress to Include the Disability Community in Legislation

THE ISSUE: Congress has passed several bills to respond to the coronavirus pandemic – but they have not addressed the **critical needs** of people with disabilities, their families, and the direct support professional workforce.

THE ASK: Ask Members of Congress to support funding for the following:

1. Fund a temporary Medicaid funding increase to support access to home and community-based services to limit the risk of people with disabilities being put into institutions and to support the workforce that serves them. Congress should pass the *COVID HCBS Relief Act (S. 151 and H.R. 525)*.
2. Pass legislation to make the *Money Follows the Person* program permanent.
3. Support paid leave for caregivers. As more people with disabilities lose their usual sources of care, family caregivers are scrambling and need access to paid leave and sick days to help their loved ones. Congress should include all family caregivers in the emergency paid leave provisions.
4. Allow at-home employment to be continued as an accommodation for disabled employees.
5. Pass economic impact payments for all people with disabilities. Tell Congress to *pass S. 261, the All Dependent Children Count Act*, and ensure that adults with disabilities who are claimed as dependents get their economic impact payments.