

Thank you, Senator Fahy, Senator Ramos, and members of the Senate Disabilities and Senate Labor committees for your time and attention to the persistent challenges experienced by people with disabilities regarding employment.

My name is Julia Duff, and I am the Executive Director of the Spina Bifida Association of New York State (SBANYS). Since 1993, our organization has served individuals living with Spina Bifida, their immediate family and professional care network.

Spina Bifida is a neural tube defect that occurs in the first month of pregnancy when the spinal column does not close or form properly, leaving nerves exposed and resulting in damage to the spinal cord. Individuals born with Spina Bifida often face a range of health challenges throughout their lives, particularly as they age. These challenges can be physical and include paralysis or orthopedic disabilities, incontinence, gastrointestinal disorders, skin breakdown, and obesity. Some individuals also experience intellectual disabilities, processing issues, and mental health diagnoses such as anxiety, depression, and post-traumatic stress disorder. We describe Spina Bifida as a “snowflake condition” as each person is impacted uniquely.

As identified on the hearing notice, fragmented services, limited transition support, and structural barriers are huge issues that continue to affect people with Spina Bifida in securing employment. Here are some specific examples of barriers to employment for those impacted by Spina Bifida:

- Teenagers living with Spina Bifida and their families are not equitably approached or informed about ACCES-VR and opportunities for higher education, training, or employment.
- Because Spina Bifida presents health challenges including paralysis and incontinence, job opportunities are significantly narrowed down based on scheduling, transportation, and the type of job duties required. This limits opportunities for vocational training and soft skill development.
- Many individuals living with Spina Bifida rely on SSI or SSDI for financial stability and insurance coverage. Out of fear of losing said benefits, many individuals will not pursue employment.

Here are some potential solutions to improve outcomes for people with Spina Bifida:

- Improve transparency and consistency in sharing opportunities for higher education, skills training, and employment for the Spina Bifida community starting at 14 years of age.
- Reduce the need for reasonable accommodation by incentivizing employers who provide job opportunities that can be done remotely and/or with flexible hours. These are also benefits for said employees and increase the hiring pool for the employer.
- Improve employment training and job coaching services by providing education to enhance awareness of resources, support, and opportunities.
- Increase awareness of support for employees with disabilities including benefits advisement and services through NYESS.
- Identify a representative from the disability community to serve as an advisor for the Senate Labor committee

Thank you again for your time and consideration of the Spina Bifida community as it relates to disability and employment.

Sincerely,

Julia Duff, Executive Director