

The Spina Bifida Association of New York State is the sole voluntary health agency and affiliate chapter of the National Spina Bifida Association dedicated to providing individual and family services to those living with and impacted by Spina Bifida in New York State.

Spina Bifida is the most common permanently disabling birth defect compatible with life in the United States, occurring in the first 28 days of pregnancy when the spinal column is forming. Spina Bifida can happen anywhere along the spine if the neural tube does not close all the way. When the neural tube doesn't close all the way, the backbone that protects the spinal cord doesn't form and close as it should. This often results in damage to the spinal cord and nerves. Spina Bifida might cause physical and intellectual disabilities that range from mild to severe. The severity depends on the size and location of the opening in the spine and whether part of the spinal cord and nerves are affected.

Affecting an estimated 4,000+ individuals in New York State, Spina Bifida remains little to unknown. Not only is this true in the general public, but its ambiguity also reaches medical professionals, and disability service providers.

NYS Mental Hygiene Law defines "Developmental disability" as a disability of a person which:

- (a) (1) is attributable to intellectual disability, cerebral palsy, epilepsy, neurological impairment, familial dysautonomia, Prader-Willi syndrome or autism;
- (2) is attributable to any other condition of a person found to be closely related to intellectual disability because such condition results in similar impairment of general intellectual functioning or adaptive behavior to that of intellectually disabled persons or requires treatment and services similar to those required for such person; or
- (3) is attributable to dyslexia resulting from a disability described in subparagraph one or two of this paragraph;

(b) originates before such person attains age twenty-two;

(c) has continued or can be expected to continue indefinitely; and

(d) constitutes a substantial handicap to such person's ability to function normally in society.

You will see, Spina Bifida is not on this list as a qualifying condition, although hitting many markers for eligibility. So, where do people with Spina Bifida go when denied OPWDD services?

When developmental disability services are not accessible, parents and adults are left alone to piecemeal together insurance, benefits, employment - and its services, and without losing benefits, accessible transportation, affordable housing, home modifications, and understanding these services in order to advocate for themselves. There is no coordination of these services with the understanding of how Spina Bifida impacts daily life. Nor is there really an understanding from providers of the physical and hidden challenges associated with Spina Bifida. Additionally, when they do access services, they are often combined with individuals with more significant intellectual disabilities and feel isolated within their own community.

Beyond the systemic challenges a person or family may face, a person with Spina Bifida can see up to nine medical providers, or more. Most individuals we know have a list of surgeries in the double digits and will see providers for developing needs across the lifespan. Managing a complex chronic condition like Spina Bifida could be a full-time job in itself. Imagine, going into a neurosurgeon's office, one of the primary healthcare providers serving patients with Spina Bifida and hearing, "when

did you get Spina Bifida." It is a spinal cord birth defect.

Shunts, a drain placed in the brain to release excess fluid due to hydrocephalus are lifesaving, yet often fail and require replacements. When shunt failure occurs, a person with Spina Bifida is at risk of death. Some major symptoms include fever, headache, and dizziness. What does that sound like to you? We know of many stories of patients being the expert on their bodies, but not considered the expert in the room. The number of misdiagnoses, hospital visits required before being taken seriously, and ruling out of other possible illnesses is a drain of resources on NYS.

This only gets more complicated when a person with Spina Bifida encounters comorbid issues like diabetes, multiple sclerosis, cancer, anxiety and depression, PTSD, learning disabilities, sepsis... the list goes on.

Our funding request is small, but critical to addressing community and provider education, the lack of awareness of our services capable of bridging the gap for individuals and families statewide, programming offering peer support, education, and networking, and raising awareness to promote inclusivity, equity, and access for all people with disabilities. I urge you to not overlook the underdog but help elevate a community in need.