Role of the Spina Bifida Association of Northeastern New York in the Community

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The Spina Bifida Association of Northeastern New York (SBANENY) is a not-for-profit affiliate of the National Spina Bifida Association formed in 1993 by a small group of parents whose children were born with Spina Bifida. What started as a group of volunteers serving a handful of local families has evolved into a nationally recognized organization with one and a half staff, 6 part-time interns, and 100+ volunteers serving over 350 families and individuals impacted by Spina Bifida in the state of New York. The current Board of Directors includes founding members of the organization, adults living with Spina Bifida, and parents of children with Spina Bifida, effectively rooting the organization as a family-focused foundation.

When the Spina Bifida Association of Northeastern New York was established, various other affiliate chapters existed in New York City, Long Island, the Capital Region, and Western New York. Due to funding and staffing challenges, these chapters have all dissolved, leaving SBANENY as the sole remaining affiliate chapter in New York State. As detailed in the chapter website, sbaneny.org, the agency's official service area is Northeastern New York, but SBANENY is committed to responding to service requests from the estimated 10,000 individuals living with Spina Bifida in every region across New York State.

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As reported by the CDC, about 1,427 babies are born with Spina Bifida nationally each year. [1] Individuals living with Spina Bifida often experience paralysis, bladder and bowel incontinence, gastrointestinal disorders, learning disabilities, and executive dysfunction which impacts their ability to function independently in society. Individuals with Spina Bifida are also more likely to experience numerous other physical and psychosocial diagnoses that can include hydrocephalus, anxiety, depression, latex allergy, and obesity.[2] The estimated lifetime cost for an individual living with Spina Bifida is $791,000.[3] Financially, healthcare needs greatly impact families and individuals as a variety of care is necessary across the lifespan. Often the accompanying conditions that develop with Spina Bifida warrant an even greater lifetime expenditure. When analyzing the healthcare needs of a person with Spina Bifida, the data surrounding the financial encumbrance illustrates the intensity of the condition. As detailed by the

National Institute of Neurological Disorders and Stroke, factors that impact the severity of these challenges include the type of Spina Bifida an individual is diagnosed with, the location and size of the spinal opening, as well as in-utero experiences.[4] Ultimately, Spina Bifida is a complex, chronic medical condition with unique challenges that affect everyone differently.

Although Spina Bifida is the most common permanently disabling birth defect in the United States, SBANENY has recognized that many people still have not heard of the condition.[5] This lack of awareness contributes to the inaccessibility individuals with Spina Bifida face in all facets of life, including but not limited to access to quality services, equal education opportunities, employment, accessible housing, transportation, and opportunities to promote autonomy and overall well-being.[6]The Spina Bifida community disproportionately faces unemployment or underemployment.[7] The limitations in these areas of life inhibit individuals with Spina Bifida from living independently as contributing members of society. Although data of the exact employment rate of individuals living with Spina Bifida is unknown, the 2020 U.S. Bureau of Labor Statistics data reported only 17.9% of persons with a disability were employed, down from 19.3% in 2019.[8] Mukherjee reported employment rates of 25-54% in 2007 with many young adults living with their parents and few being married.[9] The same problems occur in Europe despite many programs designed to increase employment for persons with disability.[10] As a part of the disability community, this data is representative of individuals with Spina Bifida. Providing training in advocacy and self-determination skills increases the rate of finding and succeeding in employment for disabled students.[11]

SBANENY serves as the hub of Spina Bifida support and expertise for consumers and is a connecting link between individuals living with Spina Bifida and the medical professionals caring for that community in New York State. The mission of the organization is to build a better and brighter future for all those impacted by Spina Bifida, the goal being that individual life choices of people with Spina Bifida are not hindered by their condition, and each can live a personally rich and fulfilling life amidst a barrier-free society. To pursue this vision, SBANENY responds to requests for information, referral, advocacy, systems navigation, and programming. These services are available at no cost and are utilized by individuals with Spina Bifida across the lifespan.

Image 1. Dance 2019

In addition to the aforementioned services, SBANENY conducts monthly peer support programs along with events throughout the year featuring relevant financial, healthcare, or parenting topics. SBANENY also provides an employment training program for young adults living with Spina Bifida to participate in paid, part-time internships. Another notable program is the equipment exchange program for consumers to access donated equipment when insurance denies them coverage.[12] SBANENY has also led multiple awareness campaigns on topics including neural tube defect prevention, adaptive clothing, and self-advocacy for people with disabilities. These programs are promoted through their social media platforms which engages not only the consumers they serve, but also people beyond the Spina Bifida community. The information provided to these individuals and families fosters a community-oriented space for engaging with each other which, in turn, sustains the organization through continued consumer participation, learning, and resource acquisition.

Image 2. Swimming 2020

The hardships faced by the Spina Bifida community in New York State are distinct to the condition and have been partially alleviated by means of self-advocacy and support facilitated through SBANENY. Many of the programs offered are enhanced when individuals receiving services also act in support of each other. This practice is demonstrated through the SBANENY Peer Support Network. A staff member will field a request for peer support through a phone call or email. This could pertain to a range of topics such as grieving the loss of a child with Spina Bifida, to advice on self-catheterization, to finding trusted medical providers. Those with expertise or advice can respond to the request, and a list of available peers and their contact information is distributed to the individual who sought support. This network exemplifies how the Spina Bifida community utilizes self-advocacy and internal support as a primary means of navigating systemic barriers that could diminish their quality of life. SBANENY actively uses this tool to authentically aid the Spina Bifida community. Such internal community support exhibits resiliency within the Spina Bifida community and strengthens individuals when solutions are achieved in this manner. SBANENY celebrates this fortitude through the design of their programs and facilitates this strength in ways many other not-for-profits do not have the ability to do.

SBANENY is funded via grants, donations, and fundraising events. The organization has a three-pronged fundraising approach: a Walk-N-Roll event in May, a celebration gala in November, and an ongoing direct mail campaign. [13, 14] The organization details their financial reports on their chapter website. The agency donor base supports programs and services through memorials and honorariums. Additionally, SBANENY receives an assortment of small community-based grants. After 3 years of meeting with the New York State Legislature and Executive Branch, funding for the Spina Bifida

Association was included in the New York State budget in 2020 to hire a staff person dedicated to individual and family services. Funding for SBANENY was also included in the 2021 budget, and the organization is currently advocating to be included for the year 2022.

With additional funding, SBANENY looks forward to enhancing case management services, expanding the reach of their platform, initiating new projects to benefit the Spina Bifida community, and collecting data on which programs are effective in improving the lives of these families. To learn more about SBANENY's finances and services, visit www.sbaneny.org to view the 2020 Annual Report. You can also learn more about Spina Bifida and SBANENY by following their social media accounts www.facebook.com/SBANENY, or www.instagram.com/sbaneny1.

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