

Support Service Provider/ CoNavigator (SSP/CN)

Our Mission: NFADB exists to empower the voices of families with individuals who are Deaf-Blind and

advocate for their unique needs.

What we believe: NFADB believes individuals who are Deaf-Blind are valued members of their communities and should have the same opportunities and choices as others in the community.

<u>Our Position:</u> Support Service Provider/Co-Navigator (SSP/CN) services should be recognized, established, and provided for autonomous Deaf-Blind individuals so they can maintain their independence in the community. SSP/CN services and training should be standardized and expanded to all states.

<u>Definition of Deaf-Blind:</u> Deaf-Blindness involves combined vision and hearing loss to the extent that neither of these senses can compensate for the lack of the other. Deaf-Blindness creates an inability to access both visual and auditory information about people and things in the environment necessary for learning, communication, and overall development. It is a very isolating condition.

A Successful Model: As family and guardians of individuals who are Deaf-Blind, we want our family members to be independent members of society. SSPs/CNs help our family members who are Deaf-Blind lead dignified, independent, and autonomous lives by helping them carry out their decisions instead of making decisions for them. They provide access to information, community services and activities; facilitate communication with others; serve as guides, facilitate transportation, and act "as a connection between someone who has a combined loss of vision and hearing and the surrounding environment" (Deeming et al., 2021, p. 7). SSPs/CNs work with Deaf-Blind individuals in a variety of environments, including their homes.

For example: If our family member who is deaf-blind wants to go to the bank, the SSP/CN will help them complete all the steps needed to travel and reach the bank safely; provide visual and environmental information (e.g.,describing the setting and people in the room); read documents and brochures; and facilitate interactions with a banking professional to complete the transaction. Throughout all of these activities, the SSP/CN is following the directions of the individual who is Deaf-Blind and not making decisions for them.

SSPs/CNs do not teach or instruct, provide personal care, run errands, make decisions or advocate for the person, or serve as a sign language interpreter (Deeming et al., 2021, p. 14). For information about other services for individuals who are deaf-blind, such as interveners and interpreters, see the References and Resources section below.

Where We Are Now:

SSPs/CNs are not listed as "aids and services" under the American with Disabilities Act (U.S. Department of Justice, 2014). Current SSP/CN programs are typically funded and managed by local government or nonprofit agencies.

Although they are an essential service for individuals who are Deaf-Bind, SSP/CN services are not available in all states and localities and funding for the programs is often inconsistent. According to a 2020 survey (Deeming et al, 2021, p. 12),

State funding exists for 25 of the country's 35 SSP programs in the form of legislated appropriations, Medicaid or Medicare funds, vocational rehabilitation funds, or a combination of these sources. Fourteen programs rely on less consistent, less sustainable resources such as volunteers, donations, grants, and local fundraising (some states use multiple sources of funding).

Only 17 programs (in 16 states) have been providing SSP services for 10 or more years.

The same survey found that only 1,276 Deaf-Blind individuals were receiving SSP services in 2020.

SSP/CN programs develop their own recruitment criteria and training programs, but there are no standardized guidelines that apply across states or programs and no national curriculum or certification. This is an area of concern for families because we do not always know whether our family member's SSP/CN clearly understands their role and has been appropriately vetted and trained.

Consequences:

- Our family members who are Deaf-Blind will find it challenging to conduct daily activities and carry out their decisions.
- Our family members who are Deaf-Blind will experience isolation and have limited opportunities to participate in society in a meaningful way.
- Our family members who are Deaf-Blind will have limited to no access to community events, social settings, connections with others, and natural everyday experiences.
- Our family members who are Deaf-Blind will experience reduced to no access to visual and auditory information in their environments.
- Our family members who are Deaf-Blind may be unaware of their surroundings and feel unsafe, insecure, and anxious, making enjoyment of leisure activities and daily living tasks difficult.
- Our family members who are Deaf-Blind will not be able to maintain their independence in the community.

Where We Should be: SSP/CN services should be recognized, established, and provided for autonomous Deaf-Blind individuals so they can maintain their independence in the community. SSP/CN services and training should be standardized and expanded to all states. This will require consistent funding; clear guidelines for recruitment, training, and certification; and support for SSPs/CNs and the Deaf-Blind individuals and their families who will use their services.

Benefits of Having an SSP/CN:

- Our family members who are Deaf-Blind will have the dignity of living an independent and autonomous life of their choice.
- Our family members who are Deaf-Blind will not be dependent on the availability of their family members, friends, or strangers to take them places.
- Our family members who are Deaf-Blind will have stronger relationships with their families, friends, and their communities.
- Our family members who are Deaf-Blind will have increased access to environmental information (e.g., details about settings and people in those settings).
- Our family members who are Deaf-Blind will be independent in carrying out their decisions and day-to-day activities.

References:

Deeming, P., Gabry, K., Gasaway, M., Jordan, B., Pope, R., & Spiers, E. (2021, April). *Deafblind people and support service providers in the 21st century* [White Paper]. https://www.nationaldb.org/media/doc/ssp-white-paper-2021.pdf

U.S. Department of Justice. (2014). *ADA requirements: Effective communication*. https://www.ada.gov/effective-comm.htm

Additional Resources:

What is an SSP? (Helen Keller Services)

YouTube Video Link: SSPs in Action

Report on Support Service Providers (SSPs)/CoNavigators (CNs) - Texas Governor's Committee on People with Disabilities (December 2020)

Interveners, Interpreters, & SSPs (Co-Navigators) (FAVI Deaf-Blind Collaborative)

Interpreters, Interveners, and Support Service Providers (Registry of Interpreters for the Deaf)