SIBLING LEADERSHIP NETWORK

Why are Siblings of Individuals with Disabilities Important?

• Siblings often have the longest-lasting familial relationships.

• Many of the estimated 4.9 million individuals with developmental disabilities (I/DD) in the United States have brothers and sisters.

• Siblings often become the next generation of caregivers when parents are unable to provide care. Frequently, the oldest female sibling becomes the caregiver.

• Most siblings anticipate fulfilling greater supportive and caregiving roles.

• The peer nature of the relationship makes siblings uniquely positioned to support their brothers and sisters with disabilities to lead self-determined lives. This support can include many areas such as employment, voting, transportation, relationships and sexuality, healthcare, housing supports, and more.

• Even though siblings have unique roles and are likely future caregivers, the needs and perspectives of siblings are often overlooked. By addressing the needs of siblings, their brothers and sisters with disabilities will have better outcomes.

• Adult siblings are called the "club sandwich generation" because they often juggle the caregiving of their aging parents, their own children, as well as their brothers and sisters with disabilities.

• While support programs and services have been developed for individuals with I/DD and their parents, supports for siblings have been limited.

• There is a specific need for information on future planning. Future planning programs should include both the siblings with and without disabilities in the entire process.

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