**Self-Advocate and Family**

10/01/2022 – 9/30/2023

**Employment Campaign**

**Proposed Initiative Budget: up to $120,000 Year 1 (of 3)**

**System Gap Addressed**

* North Carolina is undergoing a substantial transformation of Medicaid that provides an unprecedented opportunity to ensure more people with intellectual and developmental disabilities (IDD) are employed throughout the systems that support people with IDD.
* As part of the transition to Medicaid Managed Care, NC Medicaid has designed the Tailored Care Management model. Tailored Care Management will launch in December of 2022 with the implementation of Behavioral Health I/DD Tailored Plans. Under Tailored Care Management, all Tailored Plan members will have access to a dedicated care manager who will work with a multidisciplinary care team to deliver integrated, whole-person care management. Care Extenders can support care managers in delivering Tailored Care Management and fulfilling the member contact requirements. Individuals with IDD and family members can serve as Care Extenders but there are few trainings or directions as to how this will take place.
* North Carolina has made a commitment to increase competitive integrated employment over the next five years and move away from Adult Developmental Vocation Programs (ADVPs).
* The North Carolina Council on Developmental Disabilities (NCCDD) has made significant investments in training individuals with IDD and family members to be leaders within the IDD systems, to serve as peer mentors, and to serve as family navigators.
* North Carolina’s Governor issued an Executive Order making North Carolina an Employment First state. Despite this, only a very limited number of people with IDD and family members work in the systems that serve and support people with IDD.
* There is a growing self-advocacy movement in North Carolina and a growing array of family members of IDD who support the IDD community to navigate the systems.
* The prevalence of DD among US children aged 3 to 17 increased between 2009 and 2017. Families with children who have disabilities face a daunting journey to support and enable their children to live optimal lives, reach their full potential, and achieve the long-held goals of maximizing self-sufficiency and independent living promulgated in the Rehabilitation Act of 1973.
* Families generally provide the nurture, advocacy, and aspirational foundation for children who have disabilities, but families can fulfill this role only when they have the support of other families, service providers, and their communities.
* IDEA services cease at age 22. Too often youth with IDD transition to adulthood without adequate preparation or plans to achieve their full potential in employment and postsecondary education, or to participate fully in their community.

**Initiative Goals and Timeline**

* Introduce evidence-based trainings to North Carolina that enables families and transition aged youth/young adults to live to their fullest potential and work within the IDD systems that serve and support people with IDD. Advocate for developmental disability systems to incorporate such evidence-based trainings and new pilot trainings within conferences and trainings.
* Champion employment and leadership of family members and self-advocates to be employed and leaders within all aspects of developmental disability systems, including care coordination, schools, LME/MCOs, DHHS, and providers
* Spread awareness of competitive integrated employment, inclusive postsecondary education, Employment First in NC, home and community-based services (HCBS), employment of families and peers in care coordination, and assistive technology.
* Empower families and self-advocates with IDD to achieve self-determined goals with maximum independence and community inclusion across their life course.
* Expand self-advocates’ and families’ abilities to build the capacity within this the natural support system that are already in place and that take some of the strain off state funded services.
* Provide family and self-advocate-led and family and self-advocate-centered planning and system-navigation services in local collaborative problem-solving teams to help families get the support they need.
* Establish a network of families and self-advocates with lived experiences to become Care Extenders/Family Navigators/Peer Mentors who will be equipped to mentor additional families and self-advocates.
* Investment by the NCCDD could be up to three years beginning in November 2022.

**Aims and Prospective Outcomes**

* **Employed self-advocates and family members**. More self-advocates and family members would be employed and be leaders in the varied systems that support and serve individuals with IDD.
* **Informed Families and Individuals with IDD**. Informed families and individuals will gain the knowledge and tools to transform their life trajectories and be employed.
* **Implement a transition model.** Self-Advocates, families, and other providers who work with families and self-advocates will implement a transition model to improve adulthood outcomes for individuals with IDD.
* **Raise Awareness.** Raise awareness of competitive integrated employment, postsecondary education, and transition planning, assistive technology, and options for state funded services.
* **Establish Relationships.** Establish relationships with community organizations to share knowledge of other community resources, increased referrals, and participate in a collaborative process to expand integrated services and supports for families with youth who have developmental disabilities.
* **Led by family and peers.** Develop a network of family and peers to help support the transition to employment.
* **On-going forum or network.** Create a forum or network for ongoing discussions to assess needs and develop resources and trainings for families and self-advocates based on movement in the State around competitive integrated employment and changes in benefits.

**Current Models/Resources**

This list is not all inclusive but highlights some of the self-advocates and family models that currently exist:

* The Family Support Network™ of North Carolina (FSN) has developed the successful model of integrated, community-based services and support for unserved and underserved families with children who have developmental disabilities. The focus of family support activities included the formal resources provided through public and private agencies, as well as the informal resources provided through extended family, friends, religious organizations, and other community groups on which families rely.
* Charting the LifeCourse Model is the culmination of state and national efforts led by Dr. Michelle Reynolds of the University of Missouri–Kansas City, Institute for Human Development (UMKC-IHD). The Missouri Family-to-Family Resource Center, a center within UMKC-IHD, began working with statewide stakeholders to develop a framework, based on the principles of life course theory, for providing information and support to families and individuals with IDD about the knowledge and skills needed to achieve a high quality of life.
* The Family Employment Awareness Training (FEAT) is a knowledge-based program designed to help families, including their members with disabilities who have significant support needs, to develop expectations for competitive employment of their family member with a disability and gain knowledge about resources to gain and maintain employment.
* First In Families of North Carolina, FIFNC, helps people with disabilities and their families to believe in their dreams, achieve their goals and give back to others. FIFNC is a grassroots family support initiative founded by families looking for new ways to provide and receive support.

**Expected System Change as a Result**

* More self-advocates and family members would be employed and be leaders in the varied systems that serve and support people with developmental disabilities.
* Develop an awareness campaign to increase employment of self-advocates and family members and for systems to provide the supports and training necessary for them to be successful.
* Train self-advocates and families to use evidenced based tools to create individualized plans, navigate formal service systems, and develop their integrated system of services and natural (informal) supports.
* Convene and sustain a Local Collaboration Team (network) to identify and address gaps in formal services, increase interagency collaboration, and expand informal and community resources for families.
* Implement a self-advocate and family-led planning model and incorporate process evaluation feedback to refine a replicable model.

**Achievements**

**and Outcomes
to Date**

**Description
of Activities**