

VISION PLANNING ROADMAP FOR MY CHILD WITH DISABILITY

A Phase by Phase Guide for Families as Your Child Grows



As parents we all have hopes and dreams for our beloved children...

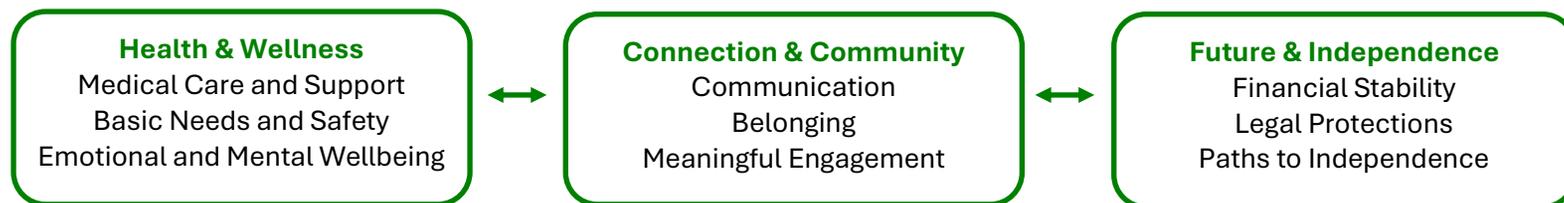
We want them to live lives that are stable, joyful, dignified, and meaningful. Still, raising a child with a disability can be a lot to manage, and it's okay to need guidance along the way.

This roadmap is designed to guide families through each stage of your child's growth, helping you think strategically about your future while honoring your family's unique values and vision. It is organized by phases, highlighting key areas of focus, decisions, and opportunities for growth at each stage. It can help you feel informed, empowered, and less alone.

At the heart of this guide are three core questions to consider:

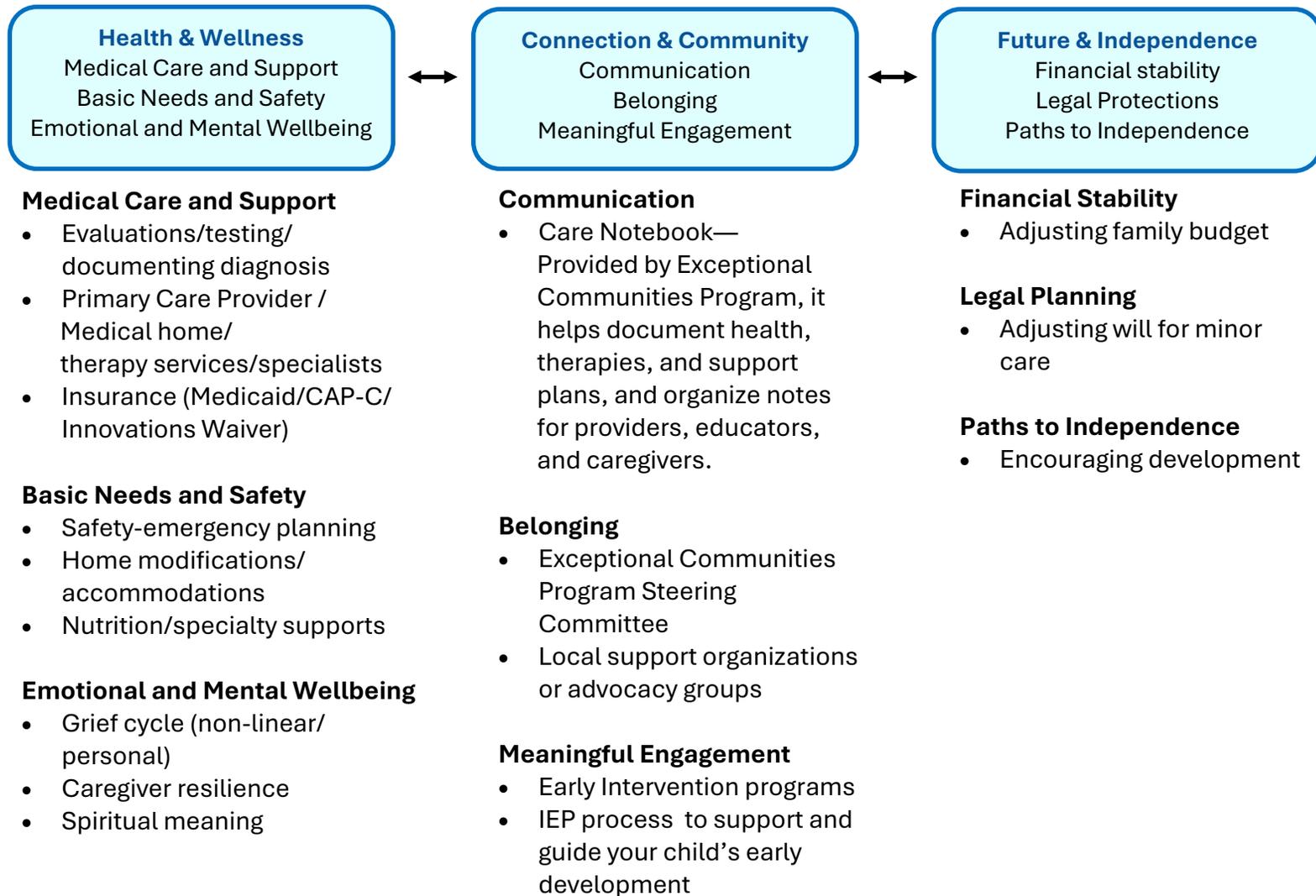
- **What are our goals for our child's life?**
- **What does a stable, joyful life look like for us?**
- **What does a dignified, meaningful life look like for us?**

By exploring these questions and shaping them within the three guiding goals below, along with practical steps for each phase, this roadmap can help you navigate your child's journey with clarity, confidence, and hope.



PHASE 1: Early Childhood (Birth to Age 5) or New Diagnosis

What does my child need right now to be safe, supported, and understood?



Potential Supports and Resources
PHASE 1: Early Childhood (Birth to Age 5) or New Diagnosis

Caregiving Kinetics		A framework that helps caregivers navigate changing care needs by strengthening resilience , coping skills, and stress management.
Care Solutions Mobility Center	866-352-2273	Offers high-quality mobility medical equipment with personalized service to enhance comfort, health, and independence for every client.
Children’s Developmental Services Agency (CDSA)- Infant Toddler Program	828-250-3400	Provides early intervention and family-centered support for children birth to three, helping families access services and guide their child’s development.
Community Care of NC	877-566-0943	Coordinates care among doctors, hospitals, and community organizations to improve health outcomes for Medicaid and underserved populations in NC.
Easter Seals of NC	800-662-7119	Provides services and residential support to people with disabilities, including recreation, mental health, daily living skills, and employment assistance.
Exceptional Communities Program	828-694-6450	Provides a free Care Notebook to help families track health, therapies, and support plans, and to organize notes for providers, and caregivers.
Family Support Network of WNC	800-852-0042	Offers information, support, and resources to help families of children with special needs navigate services and connect with community support.
First WNC (Western North Carolina)	828-277-1321	Empowers people with disabilities by providing tools, support and resources to overcome challenges and engage more fully in their community.
Footprints Case Management	704- 412-2144	Provides case management and community-based services for medically fragile children to improve quality of life and reduce institutional care.

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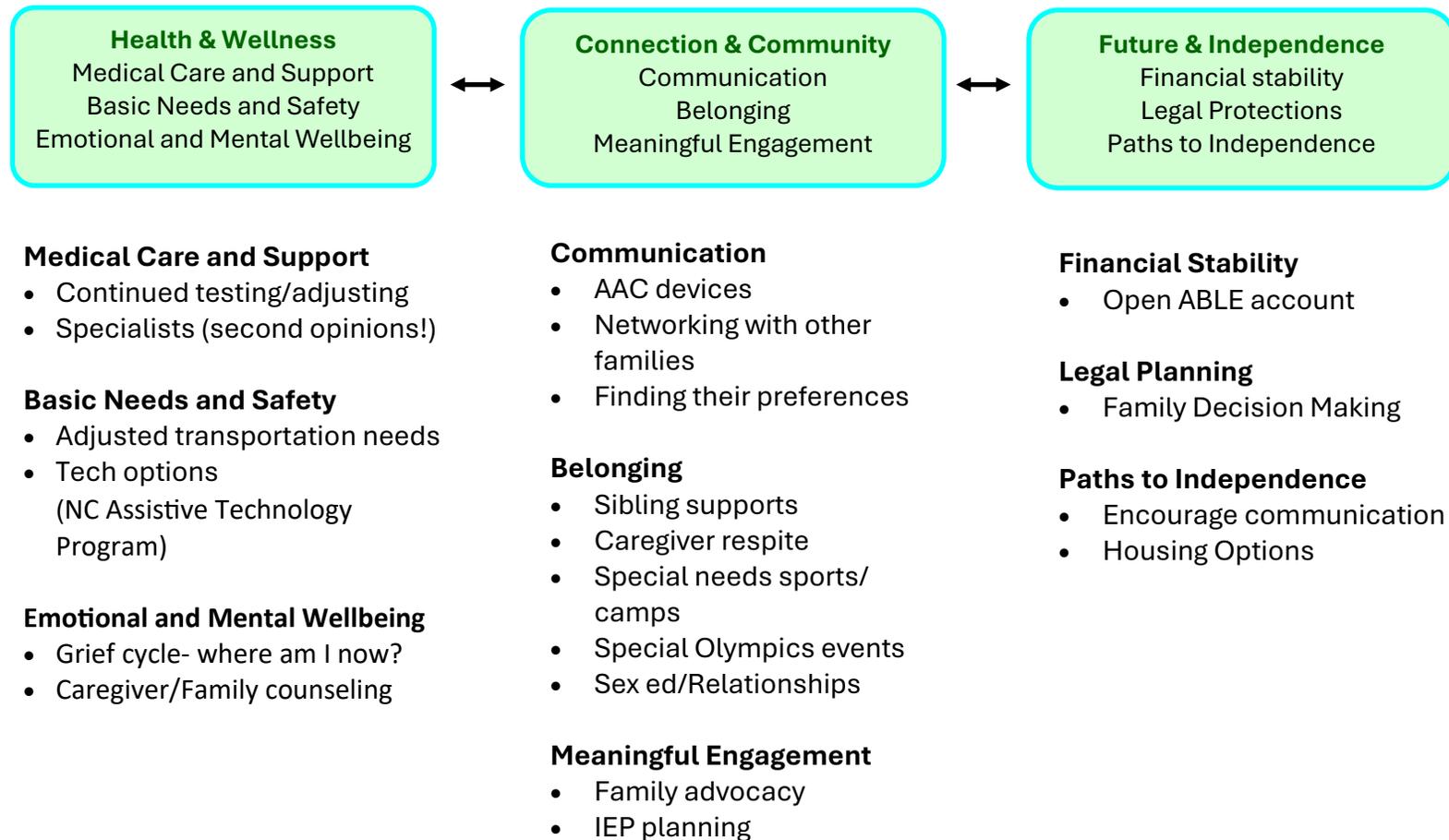
Potential Supports and Resources
PHASE 1: Early Childhood (Birth to Age 5) or New Diagnosis

Helpline and Emergency Checklist (Children with Special Health Care Needs)	800-737-3028	Free service offering information and referrals for caregivers and professionals supporting children with health, developmental, or behavioral challenges.
Henderson County Public Schools—Exceptional Children’s Program	828-697-4733	Provides free, specially designed instruction for children ages 3–21 with disabilities, tailored to each student’s Individualized Education Plan (IEP).
Jett Foundation	781-585-5566	Supports people and families affected by Duchenne muscular dystrophy through education, programs, and ongoing resources across all stages.
Mosaic Pediatric Therapy— (Autism Diagnostic Services)	828-382-3262	Provides play-based, evidence-based therapy for children, combining clinical expertise with personalized support to promote development and growth.
NSM (National Seating & Mobility)	828-277-2577	Provides personalized mobility solutions to enhance independence and support for families and caregivers.
St. Gerard Center for Autism	828-693-4223	Supports individuals with autism and their families through therapies, programs, and advocacy for better outcomes and well-being.
Vaya Health	800-962-9003	Provides free care management connecting members to Medicaid services, identifying needs, and creating personalized care plans.
WNC Source	828-884-2255	Supports self-reliance and healthier living through programs in early childhood education, transportation, housing, and older adult services in WNC.

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PHASE 2: School-Age or Middle-Childhood Until about Age 17

How do we help our child grow, learn, connect, and participate fully?



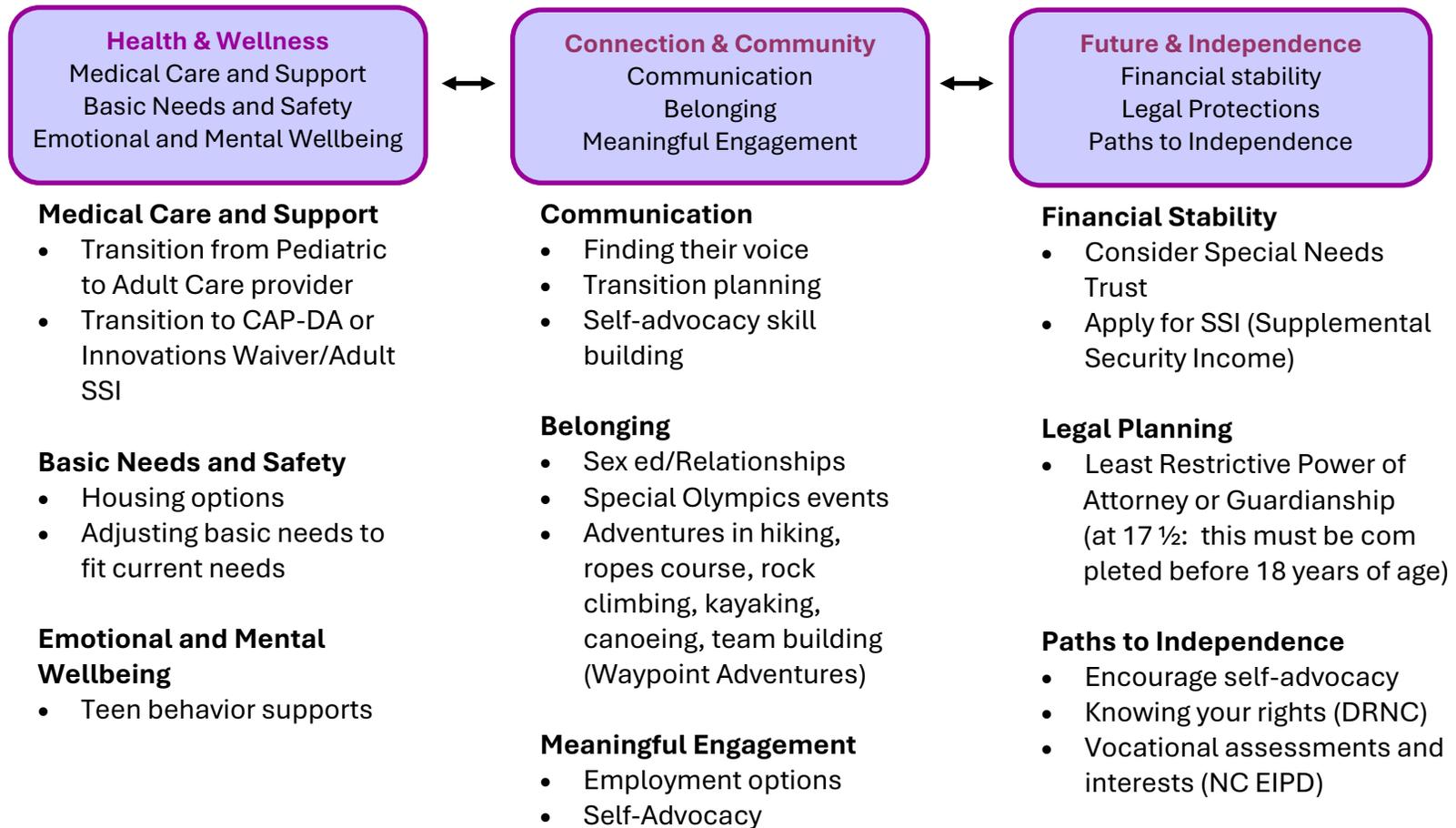
Potential Supports and Resources
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Abilities Tennis Association of NC	828-697-4884	Henderson County chapter that offers tennis programs to individuals with special needs.
ADA Paratransit Services Program	828-698-8571	Apple Country Public Transit (Henderson County) shared-ride service for eligible individuals with disabilities near fixed routes.
Children and Family Resource Center	828-698-0674	Supports children and families with education, resources, and programs to promote school readiness and family well-being.
First in Families	919-251-8368	Helps families in North Carolina access resources, assistive technology, and community support to meet their needs and thrive.
Medicaid (NC Medicaid, Division of Health Benefits)	888-245-0179	NC Medicaid provides health care to eligible low-income adults, children, pregnant women, seniors and people with disabilities.
NC Assistive Technology Program	919-368-5417	Provides a user-friendly platform for finding and borrowing assistive technology devices.
NC Employment & Independence for People with Disabilities	828-692-9184	Vocational rehabilitation: Supports people with disabilities in achieving employment and independent living goals through personalized services.
Sibling Support Project	800-999-6673	Supports siblings of people with special needs through online communities, resources, and workshops.
Special Needs Sports of WNC	828-606-5691	A free WNC program offering sports, social activities, and family-friendly events for individuals with special needs.
Special Olympics	828-551-4222	Offers year-round sports training and competitions for children and adults with intellectual disabilities.
The Arc of Buncombe County	828- 253-1255	Empowers children and adults with intellectual and developmental disabilities through education, support programs, and advocacy for equal rights.

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PHASE 3: Transition to Adulthood (about 17-21 years of age)

How do we prepare for adult life – healthcare, work, legal, and where they will live?



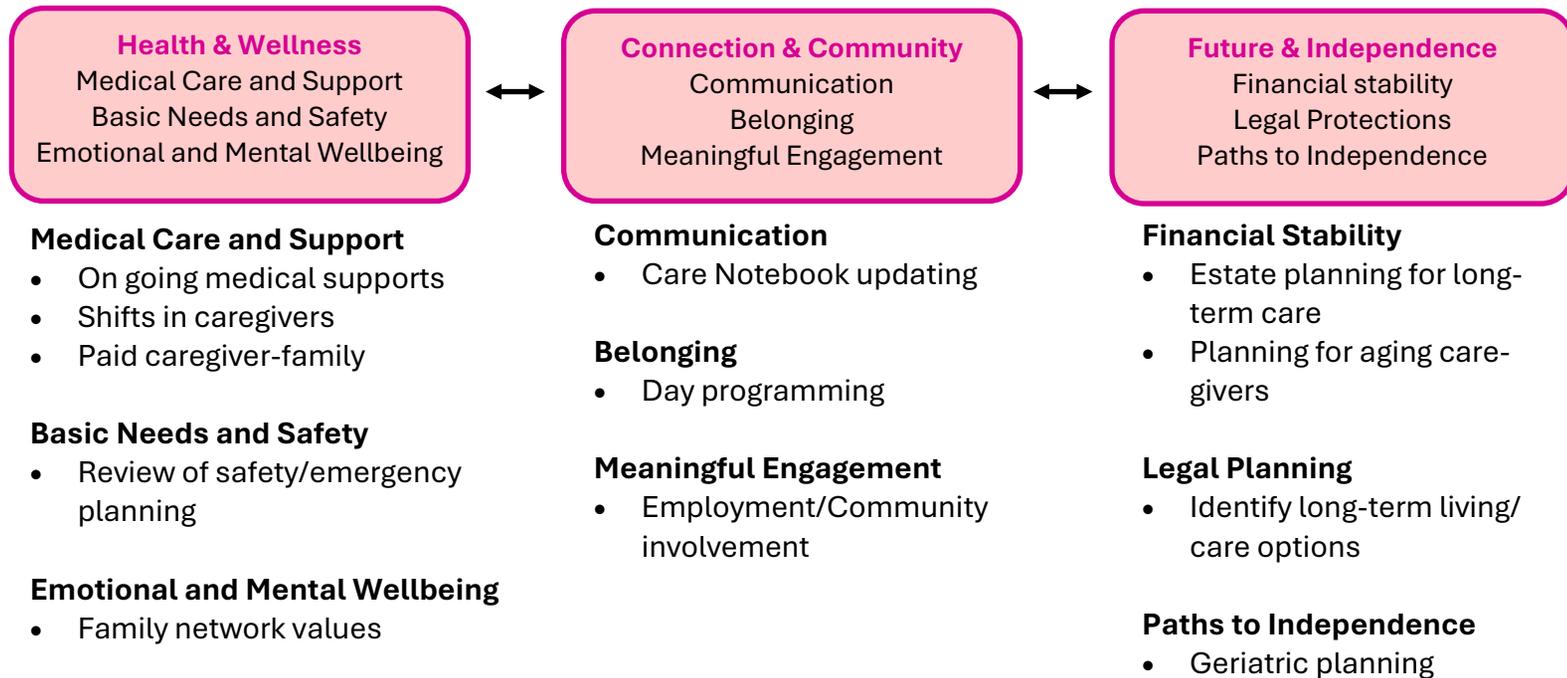
Potential Supports and Resources
PHASE 3: Transition to Adulthood (about 17-21 years of age)

Alula (formerly Transylvania Vocational Solutions)	828-884-1517	Provides vocational training, employment, and support services to help individuals with disabilities gain skills, meaningful work, and independence.
College Foundation NC	866-866-2362	A free NC service helping students plan, apply, and pay for college.
Disability Rights of NC	800-735-2962	Provides free services to protect the rights of people with disabilities in North Carolina.
First WNC (supported living)	828-277-1315	Provides guidance and coordination with agencies, schools, and community partners to ensure individuals and families are heard and supported.
Got Transition	202-769-0486	Supports the transition from pediatric to adult health care using evidence-based strategies for youth, families, and health professionals.
Hendersonville Hope AKtion Club (Kiwanis)	803-429-6730	Empowers people with disabilities to build leadership, friendships, and serve their community.
NC Employment & Independence for People with Disabilities	828-692-9184	Vocational rehabilitation: Supports people with disabilities in achieving employment and independent living goals through personalized services.
Think Colleege	617-287-4300	Provides resources, training, and a national listing of college programs for students with intellectual disabilities
Vaya Health	800-962-9003	Provides free care management connecting members to Medicaid services, identifying needs, and creating personalized care plans.
Waypoint Adventures	828-483-3383	Empowers people with disabilities through accessible adventure-based programs that promote personal growth, teamwork, and confidence.
Youth Villages	828-250-3700	Provides safe care, treatment, and support programs to help children and families build skills and achieve long-term success.

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PHASE 4: Adulthood and Transition of Caregivers

How do we support independence, caregiving transitions, and long-term support?



Potential Supports and Resources

PHASE 4: Adulthood and Transition of Caregivers

Disability Rights of NC (DRNC)	800-735-2962	Provides free legal advocacy to protect the rights of people with disabilities in North Carolina.
First WNC (Supported Living Guidebook -and housing options)	828-277-1315	Helps people with intellectual or developmental disabilities live independently with tailored support.
Land of Sky Regional Council -Area Agency on Aging	828-251-6622	Connects older adults and caregivers with services and support to help seniors stay independent, healthy, and active.
Legal Aid of North Carolina	877-579-7562	Provides free civil legal services to low-income North Carolinians to help ensure equal access to justice and fair treatment under the law.
Medicare Special Needs Plans	855-408-1212	provides benefits and services to people with specific severe and chronic diseases, certain health care needs, or who also have Medicaid.
Mountain Aging Partners	828-697-7070	Supports older adults and caregivers with programs and resources that promote independence, connection, and confidence.
Pisgah Legal Services	800-489-6144	Provides free civil legal aid to low-income people, helping with urgent needs like housing, safety, and health care.
Special Needs Alliance		A national alliance of attorneys who help people with special needs plan to protect benefits, preserve assets, and ensure lifelong care.
The Hope Center of Hendersonville	828-692-0905	A day program for adults with intellectual and developmental disabilities that provides support, skill-building, and social engagement.
Vaya Health	800-962-9003	Provides free care management connecting members to Medicaid services, identifying needs, and creating personalized care plans.

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Glossary

AAC devices	Augmentative and Alternative Communication Devices are tools or technology that help individuals with speech or communication difficulties express themselves, such as communication boards, speech-generating devices, or apps.
ABLE Account	Achieving a Better Life Experience Account is a tax-advantaged savings account that lets individuals with disabilities and their families save money for qualified disability expenses without affecting eligibility for benefits like Social Security or Medicaid.
CAP-C	Community Alternatives Program for Children is a North Carolina Medicaid program that provides in-home and community supports to help children with significant medical or developmental needs live at home instead of in an institution.
CAP-DA	Community Alternatives Program for Disabled Adults is a North Carolina Medicaid waiver that helps adults (18+) with serious health conditions live at home by providing in-home, community-based services to eligible low-income individuals at risk of nursing home placement.
Care Notebook	A binder created for families to record their child’s story, preferences, schedules, and important information about services, helping organize and simplify record keeping.
Caregiver Resilience	Resilience is the ability to adapt to difficult situations. Resilient caregivers find the strength to continue to help others, even in the face of adversity.
DRNC	Disability Rights of North Carolina is an organization to help people with disabilities protect their civil rights.
Exceptional Communities	A steering committee of parents, service providers, and community members who collaborate to improve the lives of individuals with disabilities or special needs.
Geriatric Planning	A process of coordinating medical, financial, legal, and personal care decisions to support an older adult’s health, safety, and quality of life as they age.
Grief Cycle	The stages people often experience after a loss, typically including denial, anger, bargaining, depression, and acceptance. www.health.clevelandclinic.org/5-stages-of-grief
Guardianship	A legal arrangement in which a court appoints a person to make decisions for another individual who is unable to make certain decisions for themselves.
HCPS	Henderson County Public Schools—Exceptional Children’s (EC) Program provides free, specially designed instruction for children ages 3–21 who qualify for special education services to meet their unique learning needs.

Glossary

IEP	Individualized Education Program is a written plan developed for a student with a disability that outlines special education goals, services, and supports to meet their unique learning needs.
Innovations Waiver	A North Carolina Medicaid program that provides home- and community-based services to support adults with intellectual or developmental disabilities so they can live in the community rather than in an institution.
NC EIPD	North Carolina Employment and Independence for People with Disabilities (Department of Health and Human Services)
Least Restrictive Power of Attorney	A legal document that gives someone limited authority to act on another person's behalf while preserving as much of that person's independence as possible.
Power of Attorney	A legal document that allows one person to authorize another to make financial, legal, or healthcare decisions on their behalf.
Respite	Short-term care or relief provided to caregivers of individuals with disabilities or special needs, giving them a break from daily caregiving responsibilities.
SNP	A Special Needs Plan (SNP) is a type of Medicare Advantage plan designed to provide coordinated care and tailored benefits for people with specific health conditions or circumstances.
Special Needs Trust	A legal arrangement that holds assets for a person with disabilities so they can receive financial support without losing eligibility for benefits like Medicaid or SSI (Supplemental Security Income). It is managed by a trustee and used for supplemental, non-essential needs.
SSI	Supplemental Security Income is a U.S. federal program that provides monthly financial assistance to people with low income who are age 65 or older, blind, or disabled.
Vaya	Vaya Health is a managed care organization that provides mental health, developmental disability, and substance use services to eligible individuals in counties in Western North Carolina.
Vocational interests	A person's preferences, strengths, and likes related to work or career activities, used to help guide career planning and job choices.