

## Glossary of Terms

**Advocacy** is any action that speaks in favor of, recommends, argues for a cause, supports or defends, or pleads on behalf of others.

\*Reference: [www.allianceforjustice.org](http://www.allianceforjustice.org)

**Advance Directive** is an order given by a competent adult that addresses directions or appoints another individual to make decisions on their behalf in the event the individual is unable to participate in those decisions.

**Appeal** is a request for review of a decision.

**Assessment** is the ongoing procedures used by personnel to identify a child's strengths and needs and the services appropriate to meet those needs.

**Behavioral Health Services** promote mental/emotional wellbeing and wellness through treatment and intervention of behavioral health problems including "substance use disorders; alcohol and drug addiction; and serious psychological distress, suicide, and mental disorders" as well as services that "encompass prevention and promotion of emotional health; prevention of mental and substance use disorders, substance use, and related problems; treatments and services for mental and substance use disorders, and recovery support."

\*Reference: <https://www.alliancebhc.org/wp-content/uploads/Individual-and-Family-Handbook.pdf>

**Case Management** is the service of a nurse or social worker to help oversee and coordinate services for an individual.

**Care coordination** services promote the effective (useful) and efficient organization and utilization (use) of resources among all health providers and services to ensure access to necessary comprehensive (broad) services for children with special health care needs and their families.

**Care Coordination for Children (CC4C)** offers community-based services to families with children (birth to 5) that are high risk for developmental delays or disability, have long term medical conditions and/or are dealing with challenging levels of stress.

**Children and Youth with Special Health Care Needs (CYSHCN)** are children that have or are at an increased risk for chronic physical, developmental, behavioral or emotional conditions and who require health and related services of a type or amount beyond that require by children generally.

**Child Protective Services (CPS)**

**Community Alternatives Program for Children (CAP/C)** provides home and community-based services to medically fragile children (through age 20) who are at risk for long-term hospital care or nursing facility care.

**Community Alternatives Program for Disabled Adults (CAP/DA)** provides in home and community-based care for adult Medicaid recipients (ages 18 and up) as an alternative to nursing home placement.

**Community Guide** helps recipients of the Innovation Waiver with resources in their community.

**Community Support Services** are medical and non-medical services received in the community setting or outside of your medical home.

**Department of Health and Human Services (DHHS)** manages the delivery of health and human-related services for all North Carolinians, especially our most vulnerable citizens – children, elderly, disabled and low-income families.

**Department of Public Instruction (DPI)** implements NC's school laws and State Board of Education's policies governing pre-kindergarten through 12<sup>th</sup> grade public education.

**Department of Social Services (DSS)** refers to the county level department of social services. Agency administer child welfare, child support, food and nutrition, work first, and Medicaid/Health Choice services.

**Disclosure** is to permit access to or the release, transfer of records.

**Division of Mental Health, Developmental Disability, Substance Abuse (MH/DD/SA)** provide quality support to individuals with intellectual and or developmental disabilities and quality services to promote treatment and recovery for individuals with mental illness and substance use disorders.

**Division of Public Health (DPH)** promotes disease prevention, health services and health promotion programs that protect communities from communicable diseases, epidemics and contaminated food and water.

**Dual Diagnosis** also referred to as co-occurring disorders is a term used when an individual experiences a mental illness and a substance use disorder simultaneously.

\*Reference: <https://www.nami.org/Learn-More/Mental-Health-Conditions/Related-Conditions/Dual-Diagnosis>

**Early Intervention/Infant Toddler Program** is part of the N.C. Division of Public Health and is the lead agency for the Infant Toddler Program. The Infant-Toddler Program provides supports and services for families and their children, birth to three who have special needs. Sixteen Children's Developmental Services Agencies (CDSAs) across North Carolina work with local service providers to help families help their children succeed.

**Early Periodic Screening Diagnosis Treatment (EPSDT)** is the federal law that says Medicaid must provide all medically necessary health care services to Medicaid-eligible children. Even if a

service is not covered under the NC Medicaid State Plan, it can be covered for recipients under 21 years of age if the service is listed at 1905(a) of the Social Security Act and if all EPSDT criteria are met. Health Check and EPSDT provide for the complete care of children and youth in Medicaid.

\* Elements of EPSDT:

Early	Assess and identify problems early, starting at birth
Periodic	Check children’s health at periodic, age appropriate intervals in comprehensive well-child visits, including health education
Screening	Provide physical, dental, mental, developmental, hearing, vision and other screening or laboratory tests to detect potential problems
Diagnosis	Perform diagnostic tests and assessments to follow up when a risk is identified during screening and examinations
Treatment	Control, correct or ameliorate any problems that are found

\* Reference: <https://mchb.hrsa.gov/maternal-child-health-initiatives/mchb-programs/early-periodic-screening-diagnosis-and-treatment>

**Fetal Alcohol Spectrum Disorders** is a term used to characterize the full range of prenatal alcohol damage varying from mild to severe and encompassing a broad array of physical defects and cognitive, behavioral, and emotional deficits.

**Guardian** is an individual who is appointed to make decisions and advocate on another person’s behalf.

**Grievance** is any complaint or dispute expressing dissatisfaction with any aspect of the operations, activities, or behavior of a program or provider.

**Health Choice** is a health coverage program for children ages 6-18 who meet eligibility requirements.

**Home Modifications** are items that are provided to maintain safety, mobility and independence in a child’s home. Modifications include wheelchair ramps and widening of doorways for wheelchair access.

**Hospice care (end-of-life care)** helps patients who aren’t expected to live longer than 6 months stay as comfortable as possible. Hospice care can include many different kinds of services — for example, pain management and family counseling.

**Individual/member/enrollee** are the different names used to describe a person that needs services for treatment of a mental health, IDD or substance use condition.

**Individualized Education Plan (IEP)** is a written document used in special education for children ages 3 to 21 that focuses on the educational needs of the child. Sample IEP can be found

at <https://ecac2016.wpengine.com/wp-content/uploads/2016/02/NC-IEP-Forms-revised-9-2012.pdf>

**Individualized Family Service Plan (IFSP)** is a written document for children, birth to three, enrolled in the Infant Toddler Program that focuses on the child, family and the services that a child needs to help them enhance their development. Sample IEP can be found at <https://bearly.nc.gov/index.php/staff/forms>

**Individual Support Plan (ISP)** is a plan that details which services and supports an individual with intellectual disabilities will be eligible to receive.

**Individuals with Disabilities Education Act (IDEA)** ensures that all children with disabilities are entitled to a free appropriate public education to meet their unique needs and prepare them for further education, employment and independent living.

**Innovations Waiver** is a Federally approved 1915 C Medicaid Home and Community-Based Services Waiver (HCBS Waiver) designed to meet the needs of individuals with intellectual or developmental disabilities (I/DD) who prefer to get long-term care services and supports in their home or community, rather than in an institutional setting. The Medicaid Innovations Waiver supports Individuals with I/DD to live the life they choose.

**State Funded: b 3 services** are in addition to the ones the state has chosen to provide for people with mental health disorders, intellectual disabilities/developmental disabilities and substance use disorders. These services are available statewide and are intended to expand supports for individuals with complex needs. Services for children and adults with IDD include: community guide, de-institutionalization service array, in-home skill building, respite, supported employment, psychiatric consultation. NC Innovations Waiver participants are eligible only for (b) (3) Psychiatric Consultation.

**Intellectual and/or Developmental Disabilities (IDD)** are disorders that affect an individual's physical, intellectual, and/or emotional development.

**Intermediate Care Facility (for Individuals with Intellectual Disabilities) ICF or ICF-IID** is an institution that functions primarily for the diagnosis, treatment or rehabilitation of individuals with intellectual disabilities or with a related condition and provides ongoing evaluation, planning, 24-hour supervision, coordination and integration of health or rehabilitative services in a residential setting.

**Legal Aid of North Carolina's Medical-Legal Partnership (MLP)** project brings together physicians, nurses, social workers, attorneys and paralegals to address social and environmental determinants of poor health that may have a legal remedy, including: substandard housing conditions; domestic violence; food, income, and housing insecurity; improper denials of Medicaid and disability benefits; and failure to provide children with the special educational services to which they are entitled.

**Lobbying** is an attempt to influence government action through either written or oral communication.

**Local Health Department (LHD)** work to improve the health of people and communities in NC by promoting health, preventing disease and protecting the environment. To find your local health department click <https://www.ncdhhs.gov/divisions/public-health/county-health-departments>

**Local Management Entity (LME) - Managed Care Organization (MCO)** administrator of Innovation Waiver services.

**Mediation** is the process of bring in a neutral third-party who assist in reaching a mutual agreement when individuals or agencies are in conflict.

**Medicaid for Infants and Children** is a health coverage program for children ages 0-20 who meet eligibility requirements.

**Medical home** is a model of care where each patient has an ongoing relationship with a personal physician who leads a team that takes collective responsibility for patient care. The physician-led care team is responsible for providing all the patient's health care needs and, when needed, arranges for appropriate care with other qualified physicians.

**NC Achieving a Better Life Experience (ABLE) Program** is a program that allows individuals with disabilities the opportunity to save money in a tax-advantaged NC ABLE account, while maintaining Medicaid, SSI and other supports. Individuals with disabilities or their parent/guardian may open a NC ABLE account. Savings up to \$100,000, are not counted toward a person's eligibility for SSI, and Medicaid eligibility is maintained with savings up to \$450,000. A total of \$15,000 a year can be contributed to the NC ABLE account in 2018, from various sources such as friends, family and employment earnings.

**NC Medicaid/Health Choice** are publicly funded children's health insurance programs open to North Carolina residents who meet income, age and immigration guidelines. A child may qualify for healthcare coverage through Medicaid or Health Choice, NC's CHIP grant program -- both offer free or low cost health insurance for children and teens.

**NC Medicaid Division of Health Benefits** helps low-income parents, children, seniors and people with disabilities receive physical and behavioral care and services to improve their health and well-being.

**NC Systemic, Therapeutic, Assessment, Resources and Treatment (NC START)** is a statewide community crisis prevention and intervention program for individuals age 6 and up with intellectual/developmental disability and co-occurring complex behavioral and/or mental health needs.

**Nutrition** is the intake of food in relation to the body's dietary needs. Good nutrition improves children's health, learning potential and school attendance and schools are vitally important settings through which to promote good nutrition and provide nutrition interventions. Healthy

nutrition contributes to decreasing the risks of today's leading health problems: Obesity, Cardiovascular Diseases, Cancer, and Eating Disorders.

**Palliative care** is care that focuses on improving quality of life for patients with progressive, incurable illness (life limiting conditions that cannot be cured).

**Person-Centered Plan (PCP)** is a document that includes important information about the participant, his or her life goals and the steps that he or she and the planning team need to take to get there. It also identifies support needs and includes a combination of paid supports, natural supports from family and friends and community supports.

**Registry of Unmet Needs** is a registry that contains a list of individuals who are waiting for NC Innovations funding for services.

**Residential care facilities** are facilities that provide custodial care to persons who, because of physical, mental, or emotional disorders, are not able to live independently.

**Psychiatric Residential Treatment Facility (PRTF)** provides inpatient psychiatric services to individuals under the age of 19.

**Respite care** is temporary, short-term relief from caring for a child or adult with disabilities for a family caregiver. Respite care may be provided by another family member, a friend or a paid employee.

**Respite Centers** provides planned short-term and time-limited breaks for families and other unpaid care givers of children/adults with a developmental delay.

**Social Security Administration (SSA)** is an independent agency of the federal government that administers Social Security, retirement, disability and survivor's benefits.

**Social Security Disability Insurance (SSDI)** is a program that is financed through Social Security taxes that are paid by workers, employers and self-employed individuals. SSDI is only available for disabled adults who have been in the workforce.

**Social Security Supplemental Income (SSI)** is a federal program offered through Social Security Administration that offers assistance to help pay for a child under 18 with a documented disability or medical need. In NC individuals who qualify for SSI automatically are eligible for Medicaid.

**Special Needs Trust** is a legal arrangement that allows an individual with a physical or mental disability to receive income without reducing their eligibility for disability benefits.

**Traumatic Brain Injury** is an injury to the brain that is caused by an external physical force.

**Transition to Adult Healthcare** refers to the process of preparing youth with special health care needs (YSHCN) for the eventual move to adult-focused health systems. Processes begin in early

adolescence and involves individualized planning and ongoing skills development. A major goal of transition preparation is to improve self-management skills in anticipation of eventual transfer of care. YSHCN that receive care from some medical specialists, such as internal medicine–pediatrics (med-peds) and family medicine, may not require the actual transfer of their primary care to another provider.

**Transition readiness assessment** aims at figuring out how a youth or family feels a youth is doing with having certain skills and information about how to care their health and manage their special needs on their own or with help. The tool helps a health care provider, youth and family to plan on what to work on or have a process to help the youth learn a skill or have someone else learn that skill to help the youth.