

NOTE: The following are terms used throughout the report that describe functional limitations, service needs, or other concepts used in the developmental disability field.

Adult Basic Education: A program for adults, who have not completed an eighth-grade education, to increase basic reading, writing, computation, and critical thinking skills. The program is offered by community colleges.

Adult day health: Adult day health services are furnished four or more hours per day on a regularly scheduled basis for one or more days per week. Adult day health services are provided in an outpatient setting. They include both health and social services needed to ensure the optimal functioning of the participant.

Adult Developmental and Vocational Program (ADVP): A facility which provides developmental activities for adults with developmental disabilities to prepare the individual to live and work as independently as possible by fostering community integration and increasing age-appropriate actions, images, and appearance of the individual. Services and activities offered include vocational evaluation, vocational training, remunerative employment, personal and community living skill development, adult basic education, and long-term support and follow-up as well as support services for clients' families. (10A NCAC §27G .2301)

Alternative Family Living (AFL): A residential service program where individuals with developmental disabilities reside with a family that is not their own. The family provides supportive services, supervision, and monitoring of daily activities.

Assistive technology (AT): Technology used to help people with disabilities meet daily needs and to perform functions in all areas of life, including education, employment, transportation, and community living.

Assistive technology device: Any item, piece of equipment, or product system, whether acquired commercially, modified, or customized, that is used to increase, maintain, or improve functional capabilities of individuals with disabilities (29 USC 3001 et seq.) Examples include wheelchairs, adapted communication devices, modified household objects or systems, and voice translation into writing.

Augmentative communication devices:^a Augmentative communication devices are used when a person is unable to communicate with normal speech and when a person's physical impairments make it difficult or impossible to use a gestural system to communicate. Augmentative communication devices include, but are not limited to, communication boards, computer driven devices, or voice synthesizers. Community Alternatives Program for Persons with Mental Retardation/Developmental Disabilities will only pay for up to \$10,000 per year for augmentative communication devices.

Capacity for independent living: The ability of an individual to live in the community and maintain control over their daily lives without intensive medical or other supports and services. The capacity for independent living includes the ability to develop relationships, work, and receive an education. A person displays a significant functional limitation in this area when he/she requires assistance, supervision, or the presence of a second person more than half of the time.

^a Denotes a Community Alternatives Program for People with Mental Retardation/Developmental Disabilities (CAP-MR/DD) Waiver definition.

Community Alternatives Program for Children (CAP/C): A Medicaid home and community-based waiver that offers home and community supports and services for medically fragile children (age 0-18) at risk of having to live in an institution.

Community Alternatives Program for Disabled Adults (CAP/DA): A Medicaid waiver that offers home and community-based services to adults who would otherwise meet the level of need necessary to qualify for care in a skilled nursing facility.

Community Alternatives Program for Persons with Mental Retardation/Developmental Disabilities (CAP-MR/DD):^a A Medicaid waiver that offers home and community services and supports for individuals with developmental disabilities who need the level of care offered in an Intermediate Care Facilities for Persons with Mental Retardation. The services and supports allow individuals with developmental disabilities to live in the community instead of living in a large congregate care setting.

Community inclusion: Full participation by a person in chosen community activities, organizations, and/or groups.

Community rehabilitation program: A program providing supervised work, vocational and basic education, and/or personal care training with the purpose of assisting individuals with intellectual and other developmental disabilities to acquire employment in the community or in the program.

Compensatory education: A community college program designed to help adults with intellectual and other developmental disabilities develop life skills they might not have received because their prior education was inadequate.

Competitive employment: Competitive employment is part-time or full-time work, in an integrated setting, which pays at or above minimum wage. The wages should not be less than wages paid to people without developmental disabilities that perform the same or similar work.

Consumer-directed budgeting: Consumer-directed budgeting means giving the person with a developmental disability control over his or her individual budget. The person with intellectual and other developmental disabilities can use funds allocated in his or her individual budget to purchase services and supports from specific agencies or funds can be used to hire family or friends to provide services and supports.

Crisis respite:^a A short-term service designed for participants experiencing a crisis for which a period of structured support and/or programming is required. Crisis respite may be used when a participant cannot be safely supported in his/her home due to behaviors exhibited, when implementation of formal behavior interventions have failed to stabilize the behaviors, and/or when all other approaches to insure health and safety have failed. In addition the service may be used as a planned respite stay for participants who are unable to access regular respite due to the nature of behaviors they exhibit. The service is provided in a licensed respite facility.

Crisis services:^a Crisis services provide one additional specially-trained staff person to provide services during an acute crisis so that the person can continue his/her daily routine and/or residential setting without interruption. The staff person is specially trained in behavior techniques. Crisis services are available 24 hours per day, seven days per week to support other direct care staff, family members, or primary caregivers. The goal is to avoid imminent institutional admission and to protect the person from harming him/herself or others.

Day programming: Programs, services, and supports provided to individuals with intellectual and other developmental disabilities during the day.

Day supports:^a Day supports provide assistance to help an individual acquire, retain, or improve self-help, socialization, and adaptive skills. Day supports are provided in a nonresidential setting, outside of the home or

facility in which the individual resides. Day supports focus on enabling the person to attain or maintain his or her maximum functional level. The services are coordinated with any physical, occupational, or speech therapies listed in the Person Centered Plan. Day supports may include prevocational activities (e.g. activities directed at underlying habilitative goals such as attention span, motor skills, attendance, and task completion), but may not be used for the provision of vocation services.

Developmental center: In North Carolina, a state-run Intermediate Care Facility for Persons with Mental Retardation. There are three state developmental centers in North Carolina, including J. Iverson Riddle Developmental Center (Morganton, NC), Murdoch Developmental Center (Butner, NC), and Caswell Developmental Center (Kinston, NC).^b These developmental centers provide comprehensive, all-inclusive residential services for people diagnosed with severe intellectual and other developmental disabilities. In addition to room and board, these centers provide health-related services (including medical, dental, behavioral health, and special therapies), educational and vocational training, recreational supports, and assistance with activities of daily living.

Developmental disability: Under North Carolina law, developmental disability is defined as “A severe, chronic disability of a person which:

- a. Is attributable to a mental or physical impairment or combination of mental and physical impairments;
- b. Is manifested before the person attains age 22, unless the disability is caused by a traumatic head injury and is manifested after age 22;
- c. Is likely to continue indefinitely;
- d. Results in substantial functional limitations in three or more of the following areas of major life activity: self-care, receptive and expressive language, capacity for independent living, learning, mobility, self-direction and economic self-sufficiency; and
- e. Reflects the person's need for a combination and sequence of special interdisciplinary, or generic care, treatment, or other services which are of a lifelong or extended duration and are individually planned and coordinated; or
- f. When applied to children from birth through four years of age, may be evidenced as a developmental delay.” (NCGS §122C-3(12a))

Developmental therapy: A service for individuals with intellectual and other developmental disabilities that provides assessment, habilitation and instruction in regards to the acquisition of activities of daily living skills.

Economic self-sufficiency: The ability to earn an income at a level that enables a person to support himself or herself without other monetary assistance.

Family centered: A family focused approach to planning and implementing services, which incorporates family members as key participants in developing and determining services and supports and in determining when, where, and how often these services will be provided.

^b Beginning in 2006, O’Berry Developmental Center was renamed O’Berry Neuro-Medical Treatment Center and has begun a several year conversion to a skilled nursing facility. O’Berry is still Intermediate Care Facility for Persons with Mental Retardation (ICF-MR) certified and continues to care for individuals with intellectual and other developmental disabilities. As such, the center continues to receive Medicaid ICF-MR funding. However, O’Berry no longer admits individuals who would be accepted to state developmental centers. Instead, O’Berry accepts individuals who need highly specialized residential services, targeting individuals with specific coexisting conditions whose needs exceed the level of care provided in traditional community placements.

Family-support services: Services and supports provided to families of individuals with disabilities as a means of supporting the family as the primary caregiver, preventing inappropriate out-of-home placement, and maintaining family relationships.

Group home: A 24-hour, licensed residential setting for people with disabilities. The number of residents and supports and services provided differ between homes, but the state dictates how services are provided and the methods of accountability for providing those services.

Habilitation: Teaching, training, services, and specialized therapies provided to people with developmental disabilities to maintain or increase functioning in a developmental skill area, such as self-help, fine and gross motor skills, language and communication, and cognitive and social skills. The purpose of habilitation is to maintain or increase a person's skills to maximize independent living. (NCGS §122C-3(16))

Home and community supports:^a Home and community supports helps an individual acquire and maintain skills that will allow him or her to function with greater independence in the community. Home and community supports provide habilitation, training, instruction, and support. This service is different from personal care services, as this service includes training activities in combination with support, supervision, and monitoring as described in the Person Centered Plan. This service can be provided in a person's home or in a variety of community settings that the individual chooses to attend.

Home modifications:^a Home modifications include equipment and physical modifications to a person's home to ensure the health, safety, and welfare of the individual and enable the person to function with greater independence in the home. Home modifications include, but are not limited to:

- Installation, maintenance, and repairs of ramps, grab bars, and handrails as well as portable ramps.
- Widening of doorways/passageways for handicap accessibility.
- Modification of bathroom facilities.
- Bedroom modifications to accommodate hospital beds and/or wheelchairs.
- Alarm systems/alert systems including auditory, vibratory, and visual to ensure the health, safety, and welfare of the participant (includes signaling devices for persons with hearing and vision loss).
- Hydraulic, manual, or electronic lifts, including portable lifts or lift systems that could be removed and taken to a new location that are used inside the participant's home.
- Fire safety adaptations.

Home supports:^a Home supports are available to adults who live and receive supports from their family. Home supports includes assistance to help an individual acquire and retain skills related to activities of daily living, including personal grooming and cleanliness, household chores, eating and the preparation of food, and the social and adaptive skills needed to enable the participant to reside in a noninstitutional setting. Home supports are similar to residential supports.

Inclusion (often referred to as full inclusion): Integration of people with disabilities into the community so they can fully participate with those who do not have disabilities. The term inclusion also refers to the support services necessary to realize the goal of integration.

Independent living: The ability to live in the community in the residential setting of one's choice, participate in community activities, manage one's affairs, have and sustain relationships, and possibly maintain employment. Independent living also includes learning skills needed to enable people with intellectual and other developmental disabilities achieve these abilities.

Individual budget: An amount of funds that is under the control and direction of the person with intellectual and other developmental disabilities. The amount allocated to support an individual (the individual budget) would be based on results from standardized assessment instruments, other professional assessments, and the Person Centered Plan.

Individual/caregiver training and education:^a Individual and caregiver training and education includes training and counseling services for an individual with intellectual and other developmental disabilities and his or her family members. The intent is to enhance the decision-making capacity of the family unit. The training and education includes information on community integration options and strategies, intervention strategies, and use of specialized equipment and supplies.

Individualized Education Program (IEP): A plan written for children with disabilities in the public school system, describing the child's present levels of performance, measurable annual goals, how progress is to be measured, services to be provided to the child, and the frequency and duration of the services. This plan is required for all students receiving services under the Individuals with Disabilities Education Act (IDEA).

Individual goods and services:^a Individual goods and services are services, equipment, or supplies that would not otherwise be covered as part of the Community Alternatives Program for Persons with Mental Retardation/Developmental Disabilities waiver or through the Medicaid State Plan. Individual goods and services may be covered for specific individuals if it meets certain requirements. The need for the goods and services must have been identified in the Person Centered Plan, and the person cannot have the funds to purchase the goods or services himself or herself. In addition, the item or service must be able to decrease the need for other Medicaid services, promote inclusion in the community, and/or increase the person's safety in the home environment. Individual goods and services are purchased from the individual's self-directed budget.

Integration: Exercising the equal right of individuals with developmental disabilities to access and use the same community resources as are used by and available to other individuals. (42 USC §15002)

Intellectual disability: See "Mental retardation." Intellectual disability is the preferred term.

Intermediate Care Facilities for Persons with Mental Retardation (ICFs-MR): Certified residential settings with four or more beds providing active treatment as defined by the Department of Health and Human Services. This includes 24-hour personal care and habilitation, as well as support services to people with developmental disabilities. This does not refer to individuals who are able to maintain independence with minimal assistance.

Job coach: A person who instructs and aids an individual with intellectual and other developmental disabilities to obtain and maintain employment. The job coach provides one-on-one training to help the person with a developmental disability learn to perform job tasks and to learn the necessary interpersonal skills needed for employment.

Learning: The cognitive ability to acquire new skills, behaviors, and information as well as use previous experiences to navigate new experiences. A substantial limitation in learning occurs when special interventions or programs are required to assist a person in learning.

Long-term vocational supports:^a Long-term vocational supports include ongoing and periodic supports to assist working individuals with intellectual and other developmental disabilities with the social or environmental issues that are a part of successful employment. Long-term vocational supports are available to working individuals who no longer need the intense level of support, job coaching, and training available through supported employment services.

Mental retardation: Under North Carolina law: “Significantly sub-average general intellectual functioning existing concurrently with deficits in adaptive behavior and manifested before age 22.”^c “Intellectual disability” is the preferred terminology.

Mobility: The development of gross and fine motor skills as well as the ability to use these skills. A substantial limitation in mobility occurs when assistance, from another person or from a mechanical device, is required.

North Carolina Supports Need Assessment Profile (NC-SNAP): The NC-SNAP is an assessment tool that was developed to measure an individual’s level of support needs for developmental disability services and supports. Currently, everyone who is receiving or waiting to receive developmental disability services and who has a developmental disability diagnosis must have an NC-SNAP administered annually.

Person-centered planning: A service and support planning process focused on identifying the personal goals and needed services and supports of an individual with intellectual and other developmental disabilities. The individual with intellectual and other developmental disabilities is the key participant in developing and determining the goals, the services and supports needed to meet those goals, and where and how these services will be provided.

Personal care services:^a Personal care services generally include the services, supports, and supervision needed to assist people with the activities of daily living, including eating, bathing, dressing, personal hygiene, transferring, ambulation, and other activities of daily living. The types of personal care services that can be provided and the providers who offer the services may vary, depending on whether the services are covered under the Community Alternatives Program for Persons with Mental Retardation/Developmental Disabilities waiver or the regular Medicaid program.

Enhanced personal care services are limited to people who are receiving Community Alternatives Program for Persons with Mental Retardation/Developmental Disabilities services. They are limited to individuals who have intense medical or behavioral needs, who either: 1) require the expertise and/or supervision of a Registered Nurse or Licensed Practical Nurse due to the complexity or critical nature of the activities provided or 2) who have complex or extreme behaviors that require a comprehensive behavioral plan because they are difficult to assess or effectively treat.

Personal Emergency Response System: Personal Emergency Response System (PERS) is an electronic device, which enables individuals at high risk of institutionalization to obtain help in an emergency. The PERS is connected to the person's phone and is programmed to send a signal to a response center when the "help" button is activated. Trained professionals who staff the response center respond to the emergencies.

Receptive and expressive language: The ability to use both verbal and nonverbal communication behaviors to express ideas and information to others and to understand ideas and information from others. These behaviors include reading, writing, listening, speaking, and the cognitive skills needed to use and process language. A substantial limitation occurs when another person or mechanical device is needed to effectively communicate or when a person is unable to articulate thoughts.

^c NCGS §122C-3(22).

Recreational supports: One type of service offered by Intermediate Care Facilities for Persons with Mental Retardation that includes using recreation as a source of therapy, education, or simply an opportunity to have fun.

Residential supports:^a Residential supports are available to adults who live and receive supports from their family. Residential supports include assistance to help an individual acquire and retain skills related to activities of daily living, including personal grooming and cleanliness, household chores, eating and the preparation of food, and the social and adaptive skills needed to enable the participant to reside in a licensed community residential setting, foster home, or an unlicensed alternative family living home that serves one adult. Residential support also includes assistance to all individuals to participate in home or community activities and covers home and vehicle modifications. Residential support is similar to home support for people living in their family home.

Respite services:^a Respite services provide periodic relief for the family or the primary caregiver who lives with an individual with intellectual and/or other developmental disability. There are different levels of respite services, which may be provided in the person's home or in an out-of-home setting. Respite services include:

- Enhanced level of respite for individuals who have behavioral or medical needs that require specially trained staff to provide personal care or behavioral services.
- Nursing level of respite for individuals who have medical needs that require nursing staff to conduct personal care services.
- Respite care institutional is respite provided in a state developmental center. Respite care institutional is used when community-based services are not available to care for the person.

Self-care: "Daily activities that enable a person to meet basic life needs for eating, hygiene, grooming, health and personal safety. A substantial limitation occurs when a person needs assistance at least one-half the time for one activity, or needs some assistance in more than one-half of all activities normally required for self-care. Assistance is usually in the form of the intervention of another person directly or indirectly by prompts, reminding and/or supervising someone."

Self-determination: As used in this report, self-determination means involving individuals with intellectual and other developmental disabilities in all aspects of decision making about their lives. Self-determination is often used interchangeably with the ability to control how public funds are allocated for a person's services and supports. However, in this document, the ability to control how public funds allocated for a person's services and supports are spent is called consumer-directed budgeting.

Self-direction: The ability of a person to make independent decisions regarding his or her own life, manage one's social activities, handle personal finances, and protect one's own self interest. A substantial limitation in this area occurs when a person requires direct or indirect assistance or supervision to successfully use these skills.

Services and supports: Programs, training, technologies, and other assistance for people with intellectual and other developmental disabilities that promote health, independence, productivity, integration, and inclusion in the community. Services and supports include, but are not limited to, medical, dental, behavioral health and special therapies; educational and vocational training; assistive technologies and other specialized equipment and supplies; home and vehicle modifications; recreational supports; assistance with activities of daily living; and residential programs.

Specialized consultative services: Specialized consultative services are specialized training and technical assistance for family members, caregivers, or other direct support workers. Family members and other paid/unpaid caregivers are trained by a licensed professional to carry out therapeutic interventions in particular specialty areas (e.g.

therapeutic recreation, speech therapy, occupational therapy, physical therapy, or nutrition) needed to support individuals who have long-term habilitative treatment needs.

Specialized equipment and supplies:^a Specialized equipment and supplies include devices, controls, or appliances specified in a participant's Person Centered Plan to assist the person in performing activities of daily living, or in perceiving, controlling, or communicating with their external environment. Specialized equipment and supplies may include, but are not limited to, adaptive positioning devices (e.g. prone boards and attachments, positioning chairs and sitters), mobility aides to improve the individual's gross motor skills, or aids for daily living (e.g. adaptive eating equipment, adaptive switches and attachments, adaptive toileting chairs and bath chairs, adaptive clothing, bed rails, assistive listening devices for participants with hearing and vision loss).

Supervised living: A residential facility providing 24-hour residential services and supports to people living in a home environment. The services and supports provided are for the purpose of habilitation or rehabilitation of people with a mental illness, intellectual or other developmental disability, or substance abuse disorder requiring supervision.

Supported employment:^a Supported employment services include services designed to help individuals choose, obtain, and maintain competitive jobs. Services include pre-job training or education to prepare an individual to engage in meaningful work-related activities (e.g. career/educational counseling, job shadowing, training in resume preparation, job interview skills), assistance in learning job skills necessary for job retention (e.g. work-related training, job coaching, monitoring and assistance in job tasks), transportation, and employer consultation to identify any work-related problems or needs and proactively work with the individual to address the problems. Supported employment also includes assisting an individual to operate a micro-enterprise.

Supports Waiver: The Supports Waiver is a Medicaid home and community-based waiver that is available to certain people with intellectual and other developmental disabilities who would otherwise meet the Intermediate Care Facilities for Persons with Mental Retardation level of care. The Supports Waiver is targeted to people who are receiving significant levels of unpaid support from family caregivers. The Supports Waiver has a relatively low dollar cap that can be authorized for the individual, but offers flexibility in the selection of services within that dollar limit. The Supports Waiver is distinguished from the more comprehensive Community Alternatives Program for Persons with Mental Retardation/Developmental Disabilities waiver that provides more extensive services for people who lack the same level of natural supports.

Transportation: Transportation can be provided to enable individual's access to Community Alternatives Program for Persons with Mental Retardation/Developmental Disabilities waiver services and other community services, activities, and resources specified by the Person Centered Plan. In addition, individuals eligible for Medicaid (and not Community Alternatives Program for Persons with Mental Retardation/Developmental Disabilities) can obtain transportation to help access medically necessary services. Subsidized transportation services are only available when the individual is unable to obtain transportation from family, neighbors, friends, or community agencies without charge.

Traumatic brain injury (TBI): An externally inflicted trauma causing mild to severe injury to the brain.

Vehicle adaptations:^a Vehicle adaptations include devices, controls, or services that enable individuals to increase their independence and/or physical safety. They include, but are not limited to, door modifications; raising the roof to improve head clearance; lifting devices; devices for securing or transporting wheelchairs or scooters; adapted steering, acceleration, signaling, and braking devices; and seating modifications. Vehicle modifications will only be covered under the Community Alternatives Program for Persons with Mental Retardation/Developmental Disabilities waiver when it is cost effective as compared to alternative transportation services.

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ABE	Adult Basic Education
AHEC	Area Health Education Center
AFL	Alternative Family Living arrangement
AT	Assistive Technology
CAP/C	Community Alternatives Program for Medically Fragile Children
CAP/DA	Community Alternatives Program for Disabled Adults
CAP-MR/DD	Community Alternatives Program for Persons with Mental Retardation/Developmental Disabilities
CCNC	Community Care of North Carolina
CDS	College of Direct Supports
CED	Compensatory Education Program
CMS	United State Centers for Medicare and Medicaid Services
CY	Calendar Year
DHHS	North Carolina Department of Health and Human Services
DHSR	Division of Health Service Regulation
DMA	Division of Medical Assistance
DMHDDSAS	Division of Mental Health, Developmental Disabilities and Substance Abuse Services
DPI	Department of Public Instruction
DSW	Direct Support Worker
DVR	Division of Vocational Rehabilitation
ECS	Extended Content Standards
EHR	Electronic Health Record
FAPE	Free and Appropriate Public Education
GED	General Educational Development
ICF-MR	Intermediate Care Facility for Persons with Mental Retardation
ID	Intellectual Disability
I/DD	Intellectual and other Developmental Disabilities
IDEA	Individuals with Disabilities Education Act
IEP	Individualized Education Program
LEA	Local Education Authority
LIHTC	Low Income Housing Tax Credit
LME	Local Management Entity
NADSP	National Alliance for Direct Support Professionals
NCATP	North Carolina Assistive Technology Program

NCCCS	North Carolina Community College System
NCCDD	North Carolina Council on Developmental Disabilities
NCGA	North Carolina General Assembly
NCHFA	North Carolina Housing Finance Agency
NCI	National Core Indicators
NC-SNAP	North Carolina Supports Need Assessment Profile
NSTTAC	National Secondary Transition Technical Assistance Center
OCS	Occupational Course of Study
PASARR	Preadmission Screening and Annual Resident Review
PCP	Person Centered Plan
PMPM	Per Member Per Month
QDDP	Qualified Developmental Disabilities Professional
SBE	State Board of Education
SFY	State Fiscal Year
SIS	Supports Intensity Scale™
SPP	State Performance Plan
SSI	Supplemental Security Income
START	Systemic, Therapeutic Assessment, Respite and Treatment