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ABSTRACT

This booklet is a reference guide intended to serve as an introduction to basic terms, services, and supports regarding people with developmental disabilities. The different sections include: (1) a philosophy statement regarding persons with disabilities by the North Carolina Council on Developmental Disabilities; (2) guidelines on using appropriate language when writing or speaking about developmental disabilities; (3) suggestions for interacting with persons having developmental disabilities; (4) a glossary of key concepts related to developmental disabilities; (5) a listing of common acronyms in the field of developmental disabilities; (6) federal and state laws applicable to individuals with developmental disabilities; (7) a listing of state (North Carolina) government agencies which serve persons with developmental disabilities; and (8) a listing of consumer, advocacy, and professional organizations involved with persons having developmental disabilities. (DB)

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# PEOPLE FIRST

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## A REFERENCE GUIDE REGARDING PERSONS WITH DISABILITIES

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North Carolina Council on Developmental Disabilities



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# PEOPLE FIRST

A REFERENCE GUIDE  
REGARDING PERSONS  
WITH DISABILITIES

# INTRODUCTION

The North Carolina Council on Developmental Disabilities has recognized through its work, a need for a shared vocabulary that both accords dignity to persons with disabilities and promotes an understanding of important concepts and issues. This reference guide will serve as an introduction to basic terms, services, and supports regarding people with developmental disabilities.

The way a society refers to persons with disabilities shapes its belief and ideas about them. Using appropriate terms can foster positive attitudes about persons with disabilities. Positive, everyday communication can become a powerful way to bring about the full acceptance of people with disabilities into our society.

This reference guide contains information which can assist the reader in communicating with, writing about, and referring to persons with developmental disabilities. The different sections include:

- a philosophy statement regarding persons with developmental disabilities;
- guidelines on using appropriate language when writing or speaking with developmental disabilities;
- suggestions for interacting with persons with developmental disabilities;
- a glossary of key concepts related to developmental disabilities;
- a listing of common acronyms in the field of developmental disabilities;
- federal and state laws applicable to individuals with developmental disabilities;
- a listing of state government agencies which serve persons with developmental disabilities; and
- a listing of consumer, advocacy, and professional organizations involved with persons with developmental disabilities.

# **PHILOSOPHY STATEMENT**

## **From The Mental Health Study Commission Comprehensive Plan for Services and Supports for Persons with Developmental Disabilities**

(As adopted by the North Carolina Council on Developmental Disabilities, August 28, 1992)

- A. Persons with or at risk for developmental disabilities have the same needs, hopes, desires, and feelings common to all people. They are entitled to the full benefits of citizenship, opportunities, and responsibilities.
- B. Persons with or at risk for developmental disabilities must:
- be supported and encouraged to achieve their full potential;
  - be afforded the dignity of risk;
  - be able to live, learn, work, play, and retire in environments of their choice;
  - have access to coordinated services and supports, determined by the individual's unique strengths, needs, and choices; and
  - be primary participants in all aspects of the planning, implementation, monitoring, and evaluation of services and supports.
- C. Service and support systems for persons with or at risk for developmental disabilities and their families must:
- emphasize education, research, information and referral, and other services which prevent or lessen the impact of developmental disabilities;
  - provide family-centered prevention services and early intervention services beginning at birth;
  - ensure that individualized education and related services and supports are provided in the most inclusive, most appropriate environment;
  - provide safeguards to ensure freedom from harm, discrimination, and stigma;
  - be developed around the individual's and the family's strengths, capabilities and choices, and rely, whenever possible, on informal or natural supports;

- be provided in as normal an environment as possible;
- employ or develop specialized services only when those used by the general public cannot reasonably accommodate the needs and choices of the individual;
- be coordinated, enabling, affordable, efficient, accountable, fully accessible, and culturally sensitive; and empower consumers and families as the primary decision-makers; and
- be directed by and toward the enhancement of quality of life and the achievement of independence, contribution and inclusion into the community.

# CHOOSING WORDS THE "PEOPLE FIRST" WAY

It is still all too common in our society to come across labels for disabilities that either have negative connotations or are misleading. Using such labels may contribute to negative stereotypes. For this reason, some words, such as the following, should be completely avoided: afflicted, bleeder, crazy, defective, deformed, invalid, lame, maimed, pitiful, spastic, unfortunate, etc. All of these words devalue the person they attempt to describe. Avoid them when speaking to, or about, persons with disabilities.

As more people with disabilities become active participants in community life, our shared vocabulary will continue to change. For example, there are persons with disabilities who advocate not using words like "special", "handicapped", "mental retardation" and even the word "disability" itself. When in doubt about the correct word to use, simply ask the person, or their friends and family, what they prefer. Remember that it's best to focus on getting to know a person, not a disability.

Generally, in choosing words about people with disabilities, the guiding principle is to refer to the *person*, *first*, not the disability. Instead of saying "the disabled", it is more acceptable to say "persons with disabilities." Putting the word "people" first says that people with disabilities are like everyone else. Their disability, like anyone's limitations, is not the most important part of who they are.

**AVOID:** "afflicted with" blindness, deafness, etc.

**USE:** *"person with" blindness, deafness, a hearing loss, etc.*

**AVOID:** crippled, "confined to" a wheelchair

**USE:** *person with a physical disability, person who uses a wheelchair*

**AVOID:** deaf and dumb, deaf mute

**USE:** *person who is unable to speak, person who is nonverbal*

**AVOID:** epileptic

**USE:** *person with epilepsy, person with a seizure disorder*



**AVOID:** cerebral palsied

**USE:** *person with cerebral palsy*

**AVOID:** stricken with ..., a victim of ..., suffering from ...

**USE:** *person with ...*

**AVOID:** mongoloid

**USE:** *person with Down Syndrome*

**AVOID:** handicapped person

**USE:** *person with a disability*

## **SUGGESTIONS FOR INTERACTING WITH PERSONS WITH DISABILITIES**

- Talk directly to the person with the disability, maintaining eye contact, even if he/she is using an interpreter or personal assistant. Encourage the person with the disability to express his/her own opinions, even when parents or friends feel they can speak for the individual.
- Ask if assistance is needed, rather than assuming it is.
- Use a normal tone of voice. If the person cannot hear or understand you, he/she will let you know. Raising your voice may cause more confusion.
- When talking with a person with a cognitive disability, speak in simple, clear sentences. Remember that simple language does not mean childish language.
- If appropriate, sign or gesture to make yourself understood.
- If you do not understand what the person with the disability is saying, you should say so. Ask the person to repeat if necessary.
- When interacting with a person with a speech or language disability, be patient. Give the person ample time to respond to your question. Do not try to finish a statement for him/her. Keep your manner encouraging, rather than correcting.

- Be careful not to assume that a person with one disability also has other disabilities. A person with a physical disability does not necessarily have a cognitive disability, nor is a person with blindness particularly likely to have a hearing loss.
- When talking with an adult who uses a wheelchair, try to sit across from the person at eye level. If no chair is available, stand. Kneeling may convey a demeaning attitude toward the individual.
- Discuss the same topics and use the same terms with persons who have disabilities as you would with anyone else. For example, do not avoid using "look" or "see" with a person with a visual loss. Likewise, do not hesitate to say, "Let's walk over ..." to a person using a wheelchair.
- In social settings, treat people with disabilities just as you would anyone else. Avoiding contact or being overly attentive calls attention to the disability at the person's expense.
- Be aware that an assistance animal, e.g., a guide dog helping an individual with blindness, is on duty. Petting or otherwise distracting the animal should be discouraged, unless first approved by the owner.
- Encourage children and adults to learn about people with disabilities. Open, informed communication helps overcome fear and misleading attitudes. People with disabilities themselves are their best spokespersons.

# GLOSSARY

**ACCESSIBLE:** Buildings, structures, programs, transportation services, public services, etc., which are designed or modified to enable persons with disabilities (physical and/or cognitive) to utilize them without undue difficulty. This term includes accommodations or practices such as ramps to enter and exit buildings, TDD relay services for telephone use, lifts on public transportation, the provision of personal assistance, the provision of braille print or otherwise adapted documents, and other accommodations consistent with the requirements of the Americans with Disabilities Act (ADA).

**ADULT BASIC EDUCATION:** A program offered by community colleges for adults who have not completed an eighth grade education in the public schools. The major objective of the program is to increase basic skills in reading, writing, and computation, with an emphasis in developing critical thinking skills.

**ADULT DEVELOPMENTAL ACTIVITY PROGRAM (ADAP):** A service providing vocational training and developmental activities for adults with developmental disabilities, preparing them to live and work as independently as possible. Training and activities are designed to enhance the independence, productivity and community integration of individuals with developmental disabilities.

**AMERICANS WITH DISABILITIES ACT (ADA):** See Public Law 101-336 in RELEVANT FEDERAL STATUTES.

**ASSISTIVE TECHNOLOGY:** The systematic application of technology, engineering methodologies, or scientific principles to meet the needs of, and address the barriers confronted by persons with developmental disabilities in areas including education, employment, supported employment, transportation, independent living and other community living activities. (See P.L. 100-407)

**ASSISTIVE TECHNOLOGY DEVICE:** Any item, piece of equipment, or system used to increase, maintain or

improve the functional capabilities of individuals with disabilities. (See P.L. 100-407) Examples of such devices are computerized communication boards, automated readers, augmentative hearing devices, toys with adapted switches, modified household gadgets, wheelchairs, and computer-based devices that give enhanced images to people with vision loss or that translate voice input into writing for people with hearing loss or deafness.

**AT-RISK:** Refers to infants and young children (generally up to 36 months of age) who do not have a developmental disability, but 1) who have a physical or mental condition which usually results in a developmental disability, or 2) for whom there is documented evidence of familial, prenatal, neonatal or post-neonatal factors which are associated with developmental delay or atypical development.

**ATTENTION DEFICIT HYPERACTIVITY DISORDER (ADHD):** A condition characterized by 1) difficulty in focusing one's attention and effort to tasks; 2) difficulties in impulse control or delay of gratification; and 3) increased activity unrelated to the current task or situation.

**AUTISM:** A developmental disability substantially affecting communication and behavior, which typically appears during the first three years of life. This disability significantly affects development of social attachments, acquisition of speech and language skills, and range of interests.

**BARRIER FREE:** Building, facility, or area that is fully accessible to persons with mobility limitations; may be used more generally to refer to programs and services which are readily accessed by persons with any type of disability.

**CASE MANAGEMENT SERVICES:** See Service Coordination.

**CEREBRAL PALSY:** Decreased muscular power and coordination due to an injury to the brain, occurring before, during, or after birth. This developmental

disability results in difficulty in walking, speech difficulties, problem with balance, and/or loss of or decreased control over voluntary movements.

**CHILD DEVELOPMENT CENTER:** A center-based day program providing individualized habilitative services to children with developmental disabilities. Services are designed to build self-help skills, fine and gross motor coordination, language and communication, cognitive and social skills, and to facilitate continued education in a less restrictive environment.

**CLOSED CAPTIONED:** Written words appearing across the bottom of the television screen stating what is being said; requires a built-in or external decoder on the television to receive the closed captioned transmission from the studio.

**COMMUNITY ALTERNATIVES PROGRAM (CAP-MR/DD):** A service providing habilitative and support services in the community to individuals with developmental disabilities of all ages who would otherwise require ICF/MR care. CAP-MR/DD provides services reimbursable under Title XIX, as authorized by the Medicaid Home and Community Based Services (HCB) waiver, and was developed to allow eligible individuals to choose services in their homes and communities.

**COMMUNITY SUPPORTED LIVING ARRANGEMENTS:**

Services and supports designed to assist an individual in activities of daily living which enable that individual to live in the individual's own home, family home, or rental unit. Services may include personal assistance, training and habilitation services, 24-hour emergency assistance, assistive technology and adaptive equipment, and support services necessary to aid an individual to participate in community activities. Services not reimbursable under Medicaid are room and board and the cost of prevocational, vocational, and supported employment services. However, these services may be provided through state, local or private funding. (See P.L. 101-508)

**COMPENSATORY EDUCATION:** A program offered by the community colleges for adults with mental retardation who did not attend public schools, who attended on a limited basis, or who need additional education after

leaving public school. The primary objective of the program is to provide opportunities for students to develop the skills and abilities to participate successfully in society. The course of study includes lessons in language, math, social science, community living, consumer education, health and vocational education.

**CONGENITAL DISABILITY:** A disability present at birth.

**CONSUMERS:** Consumers are persons with disabilities, or those parents or guardians of persons with disabilities, who utilize or have need of services or supports.

**CYSTIC FIBROSIS:** An inherited condition characterized by chronic respiratory and digestive problems due to excessive mucus production.

**DEAFNESS:** Severe or profound hearing loss; unable to hear and understand at the ordinary conversational level with or without hearing aids.

**DEINSTITUTIONALIZATION:** The reduction of the number of individuals residing in institutions. Deinstitutionalization may be effected by enhancing the abilities of families and/or communities to provide appropriate services and supports for individuals who have been institutionalized, or by "institutional avoidance", i.e., the initial provision of those services and supports necessary to maintain an individual in the community.

**DEVELOPMENTAL DISABILITY:** A severe, chronic disability of a person five years of age and older which: (1) is attributable to a mental or physical impairment or a combination of mental and physical impairments; (2) is manifested before the person attains age twenty-two; (3) is likely to continue indefinitely; (4) results in substantial functional limitations in three or more of the following areas of life activity: (a) self-care, (b) receptive and expressive language, (c) learning, (d) mobility, (e) self-direction, (f) capacity for independent living, (g) economic self-sufficiency; and (5) reflects the person's need for a combination and sequence of special, interdisciplinary, or generic care, treatment, or other services which are of lifelong or

extended duration and are individually planned and coordinated. Developmental disabilities also apply to infants and young children from birth to age five, inclusive, who have substantial developmental delay or specific congenital or acquired conditions with a high probability of resulting in developmental disabilities if services are not provided. (See P.L. 101-496) In North Carolina, persons with severe head injuries occurring after age 22 are considered to have developmental disabilities if they meet the remaining criteria set forth in the definition. (See G.S. 143B-177)

**DEVELOPMENTAL EVALUATION CENTER:** A center staffed by a multidisciplinary team that provides examination and evaluation of a child or adult suspected of having a developmental disability. Prescriptive habilitation and treatment plans are usually developed and follow-up is provided.

**DOWN SYNDROME:** A condition caused by an extra chromosome which results in mental retardation.

**DUAL DIAGNOSIS:** Both mental retardation and mental illness are present at the same time; often refers to a person with mental retardation who also has significant behavioral and/or emotional problems.

**EARLY CHILDHOOD INTERVENTION:** A periodic, regularly scheduled service, usually home-based, designed to promote the developmental growth of children with developmental disabilities, developmental delays, or atypical development. Services may include providing families with training, support and information on child development; coordination of services; and enabling families to access resources for them and their child.

**EMPOWERMENT:** The act of enabling individuals with disabilities and the families of children with disabilities to exercise control in their lives by becoming the primary participants in decision-making about the services and supports they are to receive, where they will live, where they will work or go to school, etc.

**EPILEPSY:** A group of neurological conditions characterized by unusual electrical-chemical patterns in the brain. These patterns are manifested in various forms of physical activity called seizures.

**FAMILY-CENTERED:** Approach to planning and implementing services for children with disabilities and their families which makes the family the focus of intervention. Family-centered services strengthen and support families in ways that make them more capable of meeting their needs and those of their children. This approach empowers family members, making them key participants in choosing services and supports and in deciding when, where, and how often these will be provided.

**FAMILY SUPPORT SERVICES:** Services, supports and other assistance provided to families of individuals with disabilities. Such services are designed to strengthen the family's role as primary caregiver, prevent inappropriate out-of-home placement, maintain family unity, and reunite families with members who have been placed out of the home. (See P.L. 101-496)

**FETAL ALCOHOL SYNDROME:** An identifiable pattern of atypical physical, cognitive and behavioral characteristics displayed by children of women who consumed substantial amounts of alcoholic beverages during pregnancy.

**GENERIC SERVICES:** Services, businesses, organizations or agencies which serve the general population rather than a select disability group. The use of generic resources and their reasonable accomodation to the needs of persons with developmental disabilities can encourage social integration more readily than the sole reliance on specialized services.

**GROUP HOME:** A small community-based residential facility. When serving persons with developmental disabilities, group home programs may assist in the development of the individual's personal, social, and community survival skills, encouraging independence and inclusion in and contribution to the community.



**HABILITATION:** Training, care, and specialized therapies undertaken to assist a person with a developmental disability in achieving or maintaining progress in a developmental skill area.

**HANDICAP:** A condition placed on individuals with disabilities through physical and social barriers to full participation in society. A person with a disability is not handicapped but must face handicaps placed before him/her by individuals and society.

**HEAD INJURY:** Any level of injury to the brain caused by an impact with the skull. Mild symptoms include persistent headaches, mood changes, dizziness and memory difficulties. Severe head injury symptoms are more obvious: loss of consciousness; loss of physical coordination, speech and many thinking skills; and significant changes in personality.

**HEARING IMPAIRMENT:** Refers to the loss of auditory functioning, ranging from deaf to hard of hearing.

**INCLUSION:** (Often used as FULL INCLUSION.) Full participation by persons with disabilities in settings and activities with persons who do not have disabilities.

**INDEPENDENCE:** As defined by federal law, the extent to which persons with developmental disabilities exert control and choice over their own lives. (See P.L. 101-496)

**INDEPENDENT LIVING:** Control over one's life, based on the choice of options that reduce dependence on others in making decisions and performing everyday activities. Living independently includes managing one's affairs, participating in the day-to-day life of the community in a manner of one's own choosing, fulfilling a range of social roles, including productive work, and making decisions that lead to self-determination.

**INDIVIDUAL HABILITATION PLAN:** A written plan of action developed jointly by the person for whom the plan is established, family members or guardian (when appropriate) and the service coordinator, stating long-range goals and short-term objectives to be achieved by the individual and/or other parties; specifies the

services and supports to be rendered, who will provide them, how they are to be delivered, dates for provision, and procedures for evaluating accomplishments. (See P.L. 101-496)

**INDIVIDUALIZED EDUCATIONAL PROGRAM:** A written plan for students with disabilities in educational settings required by P.L. 94-142 (and its subsequent amendments). This educational plan must be developed by the student (when appropriate), the student's parent(s) or guardian(s), the student's teacher, a representative of the local educational agency, evaluation personnel as needed, and others as requested by the parent(s) or agency. The educational program must include: 1) a statement of the student's present levels of educational performance; 2) a statement of annual goals; 3) a statement of short-term instructional objectives; 4) a statement of specific education and related services to be provided to the student; 5) a description of the extent to which the student will participate in regular education programs and a description of the program to be provided; 6) the projected dates for initiation of services, and 7) appropriate objective criteria and evaluation procedures and schedules for determining, on at least an annual basis, whether the short-term instructional objectives are being achieved. (See P.L. 94-142)

**INDIVIDUALIZED FAMILY SERVICE PLAN:** A written plan as required by P.L. 99-457 (and its subsequent amendments) for providing early intervention services to preschool children with developmental disabilities, preschool children at risk for developmental disabilities, or preschool children experiencing a developmental delay, and to their families. The plan must: 1) be developed jointly by the family and appropriate qualified personnel involved in the provision of early intervention services; 2) be based upon the multidisciplinary evaluation and assessment of the child and the assessment of the child's family; and 3) include services necessary to enhance the development of the child and the capacity of the family to meet the special needs of the child. (See P.L. 99-457)

**INDIVIDUALIZED WRITTEN REHABILITATION PROGRAM:**  
An action-oriented plan developed by the individual with a disability, the vocational rehabilitation

counselor and others as needed, stating long-term goals and short-term objectives that will enable the individual to be successful in preparing for, obtaining, and keeping a job; specifies the types of rehabilitation services to be provided for achieving successful vocational rehabilitation. (See P.L. 102-569)

**INTEGRATION:** As defined by federal law, a) the use by persons with developmental disabilities of the same community resources that are used by and available to other citizens, b) the participation by persons with developmental disabilities in the same community activities and integrated employment in which citizens without disabilities participate, together with regular contact with citizens without disabilities, c) the use of the same community resources by persons with developmental disabilities living, learning, working and enjoying life in regular contact with citizens without disabilities, d) the development of friendships and relationships with citizens without disabilities, and e) the residence by persons with developmental disabilities in homes which are in proximity to community resources, together with regular contact with citizens without disabilities in their communities. (See P.L. 101-496)

**INTERMEDIATE CARE FACILITIES FOR PERSONS WITH MENTAL RETARDATION (ICF/MR):** Residential facilities certified as having met federal requirements which provide 24-hour personal care, habilitation, and developmental and support services to persons with mental retardation or developmental disabilities who may have intermittent recurring needs for nursing services, but who have been certified by a physician as not requiring continuous skilled nursing care. Individuals must receive active treatment (e.g., an aggressive effort to fulfill each person's functional capacity) to be eligible for Medicaid support.

**JOB COACH:** A person who is skilled at training individuals with disabilities, in a one-to-one situation, to successfully engage in a competitive job. Before the person with a disability begins the job, the job coach becomes thoroughly familiar with the job. To do this, he/she will work at the job, list the steps involved in doing it, and assess its physical and social demands. When training begins, the job coach will train and

evaluate the worker's performance. As the worker's performance increases in both speed and quality to a level satisfactory to the employer, the job coach gradually decreases his/her presence. Eventually, only periodic checking of the worker's situation will be necessary. A job coach is frequently called an employment specialist or "trainer". Job coaching is a type of supported employment.)

**LEARNING DISABILITY:** A group of neurological conditions (e.g., dyslexia, dysgraphia, dyscalculia) which affect the person's ability to receive, interpret, and use information. A person with a learning disability may have normal intelligence; however, there is a significant discrepancy in intelligence level and his/her ability to learn and perform certain tasks. Individualized instruction assists the person in improving his/her learning and performance abilities. A learning disability is lifelong.

**LEAST RESTRICTIVE ENVIRONMENT:** A requirement in P.L. 94-142 that, to the maximum extent appropriate, students with disabilities are to be educated with students who do not have disabilities, and that special classes, separate schooling, or other removal of students with disabilities from the regular educational environment should occur only when the severity of the disability is such that education in regular classes with the use of supplementary supports and services cannot be achieved satisfactorily.

**LEGAL BLINDNESS:** Corrected visual acuity of 20/200 or less in the better eye or visual field contraction of 20 degrees or less.

**MAINSTREAMING:** Purposeful, planned efforts to integrate persons with disabilities into the "mainstream" of society. This term is usually used in a school setting to refer to the integration of students with disabilities in classrooms of students who do not have disabilities. (See INCLUSION.)

**MENTAL RETARDATION:** Refers to substantial limitations in present functioning, usually resulting in a developmental disability. It is characterized by significantly subaverage intellectual functioning, existing concurrently with related limitations in two or

more of the following applicable adaptive skill areas: communication, self-care, home living, social skills, community use, self-direction, health and safety, functional academics, leisure, and work. Mental retardation manifests before age 18. (American Association on Mental Retardation, 1992)

**MUSCULAR DYSTROPHY:** A hereditary, progressive degeneration of the muscles with accompanying weakness.

**MULTIPLE SCLEROSIS:** An unpredictable, potentially disabling disease of the central nervous system caused by hardening of patches of the brain and spinal cord. Onset usually occurs from age 20 to 40, resulting in difficulties in walking, talking, sensing, seeing, and grasping.

**NORMALIZATION:** (See definition of SOCIAL ROLE VALORIZATION.) A guiding principal for human services during the 1970's and 1980's espoused in the United States by Wolf Wolfensberger based upon the concept developed by Denmark's N.E. Bank-Mikkelsen and Norway's Bengt Nirje.

**OCCUPATIONAL THERAPY:** Therapeutic use of self-care, work, and recreational activities to increase independence, enhance development, and prevent disability; may include adaptation of tasks or environment to achieve maximum independence and optimum quality of life.

**PERSON-CENTERED:** Approach to planning services and supports for individuals with disabilities which helps individuals discover their choices, make decisions based upon those choices, and then honors those decisions. The process focuses on needs, desires and values of the individual and seeks to address those needs based upon the individual's desires and values.

**PERSONAL ASSISTANCE:** One or more persons assisting another person with tasks which that individual would typically do if he or she did not have a disability. It includes assistance with bathing, dressing, getting in and out of bed or one's wheelchair, toileting, eating, cooking, cleaning house, and on-the-job support. It also includes assistance from another person with

cognitive tasks like handling money and planning one's day or fostering communication access through interpreting and reading services. (National Association of Developmental Disabilities Councils)

**PHYSICAL THERAPY:** Treatment provided by therapists or trained individuals, using biochemical and neurophysiological principles, and devices to assist in relieving pain, restoring maximum body function, and preventing disability. For persons with developmental disabilities, the primary focus is on enhancing body function and prevention of further debilitation.

**PRADER-WILLI SYNDROME:** A condition involving excessive eating with a typical onset in infancy. Mental retardation is often seen in association with this syndrome.

**PRODUCTIVITY:** As defined by federal law, a) engagement in income-producing work by a person with a developmental disability which is measured through improvements in income level, employment status, or job advancement, or b) engagement by a person with a developmental disability in work which contributes to a household or community. (See P.L. 101-496)

**RESPIRE CARE:** Temporary, periodic care of an individual with a disability by a person other than a family member, thus providing family members time away from the continuous care of the individual. Respite care may be center-based in a licensed facility, in the private home of a volunteer or paid caregiver, or in the individual's own home with a temporary caregiver.

**SEIZURE:** An involuntary muscular contraction symptomatic of injury to the brain; a symptom of epilepsy.

**SELF-ADVOCACY:** On an individual level, self-advocacy is speaking and/or acting on one's own behalf through decision-making and exercising one's individual rights as a citizen of a community. When self-advocates work together, self-advocacy becomes an organized movement of persons with disabilities to unify their individual voices for social and political action, to advocate for their rights as citizens of this country, and to work for services and supports which will assist them in reaching their full potential.

**SERVICE COORDINATION:** Assistance provided to persons in gaining access to needed social, medical, vocational, and educational services or supports. Also called "case management."

**SHELTERED WORKSHOP:** A facility that serves persons with disabilities through the use of supervised work and various rehabilitative activities (e.g., vocational evaluation, basic education, personal care training, etc.). The goal of the service is twofold: 1) to assist individuals in becoming employed in regular employment in the community and 2) to employ persons who are viewed as not capable of competitive employment in the near future.

**SOCIAL ROLE VALORIZATION:** The creation, support, and defense of valued social roles for people who are socially devalued or are at-risk of social devaluation. For persons with disabilities, this involves focusing on the abilities of individuals, not the disabilities, thus enabling society to place value on their contributions rather than seeing them as unimportant, or causing harm, to society.

**SPEECH IMPAIRMENT:** The inability or limited ability to communicate effectively through verbal and/or language skills.

**SPINA BIFIDA:** A condition occurring during fetal development, characterized by incomplete enclosure of the spinal cord by the backbone, which often limits motor activity to varying degrees.

**SUPPLEMENTAL SECURITY INCOME:** Direct monthly cash payments to provide minimum income for individuals who meet a financial needs test and who are elderly, blind, or have a disability.

**SUPPORTED EMPLOYMENT:** Employment of a person with a disability in the competitive labor market, with support provided to assist the worker in sustaining and continuing in employment. Wages may range from slightly below the statutory minimum to above the minimum wage. Supported employment includes job coaching, mobile work crew, industrial enclave and entrepreneurial models.



**TELECOMMUNICATION DEVICE FOR PERSONS WHO ARE DEAF OR HARD OF HEARING (TDD):** A device similar to a computer keyboard, either with a cradle on which to rest a telephone handset or connected directly to the telephone, which allows the user to communicate by typing messages on the keyboard and receiving messages on the screen above the keyboard.

**TOURETTE'S SYNDROME:** A condition characterized by involuntary, multiple motor movements and/or one or more vocalizations, usually referred to as tics. Motor tics usually involve the head, but may affect other parts of the body. Vocal tics often include the uttering of obscenities.

**TRANSITION:** The process of moving from one "set" of services to another "set" of services. For a student nearing completion of school, this term describes a planned, multi-agency process for the movement of an individual from a school program to adult life in the community. The process involves parents and students, special education teachers, ancillary services personnel (physical therapists, speech and language clinicians, etc.), and adult service system representatives, and focuses on the student's individual vocational, residential, social, and continuing educational needs. For a young child, the term describes a planned, multi-agency process for the movement of the child from an early intervention program to a preschool program or from a preschool program to a school setting. The process involves parents and students, early intervention and/or preschool staff, and school staff (including special education teachers, physical therapists, speech and language therapists, etc.), and focuses on the individual's vocational, residential, social, and continuing educational needs.

**TUBEROUS SCLEROSIS:** A condition involving lesions of the skin and brain. Its three main features are lesions of the skin (e.g., butterfly-like rash on the face), seizures that begin in infancy, and mental retardation.

**UNIVERSAL DESIGN:** An approach to accessibility that concentrates on making *all* aspects of an environment



accessible to *all* people, regardless of their level of ability. Examples of universal design include lever handles rather than round door knobs for doors; lower light switches; water controls located towards the outside of the tub; adjustable closet rods and shelves; dual height water fountains; playground equipment accessible to all children, including those who use wheelchairs; and consumer items (e.g., microwave ovens, televisions, radios) with touch-sensitive controls.

# ACRONYMS

## Terminology

<b>ABE</b>	Adult Basic Education
<b>ADA</b>	Americans with Disabilities Act
<b>ADAP</b>	Adult Developmental Activity Program
<b>ADC</b>	Adult Day Care
<b>ADHD</b>	Attention Deficit Hyperactivity Disorder
<b>AT</b>	Assistive Technology
<b>CAP-MR/DD</b>	Community Alternatives Program for Persons with Mental Retardation and Other Developmental Disabilities
<b>CC</b>	Closed Captioned
<b>CDC</b>	Child Development Center
<b>CP</b>	Cerebral Palsy
<b>CSLA</b>	Community Supported Living Arrangements
<b>DD</b>	Developmental Disabilities
<b>ECI</b>	Early Childhood Intervention
<b>FAS</b>	Fetal Alcohol Syndrome
<b>G.S.</b>	General Statute (North Carolina Law)
<b>ICF-MR/DD</b>	Intermediate Care Facility for Persons with Mental Retardation and Other Develop- mental Disabilities
<b>IEP</b>	Individualized Education Program
<b>IFSP</b>	Individualized Family Services Plan
<b>IHP</b>	Individualized Habilitation Plan
<b>IWRP</b>	Individualized Written Rehabilitation Program
<b>MD</b>	Muscular Dystrophy
<b>MR</b>	Mental Retardation
<b>MS</b>	Multiple Sclerosis
<b>OT</b>	Occupational Therapy
<b>P.L.</b>	Public Law (Federal Law)
<b>PT</b>	Physical Therapy
<b>SSI</b>	Supplemental Security Income
<b>TDD</b>	Telecommunication Device for Persons Who are Deaf or Hard of Hearing
<b>TS</b>	Tourette's Syndrome or Tuberos Sclerosis
<b>VR</b>	Vocational Rehabilitation

## **Government Agencies**

<b>ADD</b>	U.S. Administration on Developmental Disabilities
<b>CEC</b>	Council for Exceptional Children
<b>DEC</b>	Developmental Evaluation Clinic or Division of Exceptional Children
<b>DEHNR</b>	Department of Environment, Health and Natural Resources
<b>DFS</b>	Division of Facility Services
<b>DHR</b>	Department of Human Resources
<b>DMA</b>	Division of Medical Assistance
<b>DOA</b>	Division of Aging
<b>DOC</b>	Department of Correction
<b>DPI</b>	Department of Public Instruction
<b>DSB</b>	Division of Services for the Blind
<b>DSDHH</b>	Division of Services for the Deaf and the Hard of Hearing
<b>DSS</b>	Division of Social Services (state agency) Department of Social Services (county agency)
<b>DVRS</b>	Division of Vocational Rehabilitation Services
<b>DYS</b>	Division of Youth Services
<b>ERADC</b>	Eastern Region Assistive Device Clinic
<b>GACCY</b>	Governor's Advocacy Council on Children and Youth
<b>GACPD</b>	Governor's Advocacy Council for Persons with Disabilities
<b>HHS</b>	U.S. Department of Health and Human Services
<b>ICC</b>	Interagency Coordinating Council for P.L. 99-457
<b>MCH</b>	Division of Maternal and Child Health
<b>MH/DD/SAS</b>	Division of Mental Health, Developmental Disabilities and Substance Abuse Services
<b>NCATP</b>	North Carolina Assistive Technology Project
<b>NCCDD</b>	North Carolina Council on Developmental Disabilities
<b>NCCHI</b>	North Carolina Council for the Hearing Impaired

## **Consumer and Professional Organizations**

<b>AAMR</b>	American Association on Mental Retardation
<b>AAUAP</b>	American Association of University Affiliated Programs
<b>ACCEPT</b>	Advocacy Center for Children's Education and Parent Training
<b>ADD</b>	Association of Directors of Developmental Day Centers
<b>AMI</b>	Alliance for the Mentally Ill
<b>Arc, THE</b>	Formerly ARC or Association for Retarded Citizens
<b>ASNC</b>	Autism Society of North Carolina
<b>CLA</b>	Community Living Association
<b>EANC</b>	Epilepsy Association of North Carolina
<b>ECAC</b>	Exceptional Children's Assistance Center
<b>LDA</b>	Learning Disabilities Association of North Carolina
<b>MDA</b>	Muscular Dystrophy Association
<b>NADDC</b>	National Association of Developmental Disabilities Councils
<b>NAPAS</b>	National Association of Protection and Advocacy Services
<b>NASMRPD</b>	National Association of State Mental Retardation Program Directors
<b>NCAD</b>	North Carolina Association of the Deaf
<b>NCADCC</b>	North Carolina Alliance of Disabled and Concerned Citizens
<b>NCAET</b>	North Carolina Association for the Emotionally Troubled
<b>NCARF</b>	North Carolina Association of Rehabilitation Facilities
<b>NCDBA</b>	North Carolina Deaf-Blind Associates
<b>NCHIF</b>	North Carolina Head Injury Foundation
<b>NORCARR</b>	North Carolina Association of Residential Resources
<b>SBA</b>	Spina Bifida Association
<b>SPEAK</b>	Statewide Parent Education and Advocacy for Kids
<b>TASH</b>	The Association for Persons with Severe Handicaps
<b>UCP</b>	United Cerebral Palsy

## **University Related Programs**

<b>AHEC</b>	Area Health Education Center
<b>CDL</b>	Clinical Center for the Study of Development and Learning (UNC-CH)
<b>DDIRP</b>	Developmental Disabilities Intervention and Research Program (ECU)
<b>DDTI</b>	Developmental Disabilities Training Institute (UNC-CH)
<b>FPGCDC</b>	Frank Porter Graham Child Development Center (UNC-CH)
<b>FSN</b>	Family Support Network (UNC-CH)
<b>HDRTI</b>	Human Development Research and Training Institute (Western Carolina Center)
<b>TEACCH</b>	Treatment and Education of Autistic and Related Communication Handicapped Children (Division TEACCH of UNC-CH)

# RELEVANT FEDERAL STATUTES

## **Public Law 102-569: The Rehabilitation Act Amendments of 1992**

Substantially changes the Rehabilitation Act of 1973 and its subsequent amendments to build on the foundation of the Americans with Disabilities Act; states that the purposes of the act are "to empower individuals with disabilities to maximize employment, economic self-sufficiency, independence, and inclusion and integration into society" and "to ensure that the Federal government plays a leadership role ... by assisting states and providers of services in fulfilling the aspirations of individuals with disabilities for meaningful and gainful employment and independent living."

**Title I - State Grants:** Provides grants "to assist states in operating a comprehensive, coordinated, effective, efficient and accountable program of vocational rehabilitation ... so that individuals with disabilities may prepare for and engage in gainful employment"; shifts focus of eligibility from the individual proving that he/she can work to the agency proving that he/she cannot work; requires states to develop a state plan which addresses the following new areas: 1) transition from school, 2) rehabilitation technology, 3) personal assistance services, 4) increased choice and control for individuals with disabilities in determining their vocational goals and objectives, 5) the establishment of a State Rehabilitation Advisory Council and its responsibilities, 6) outreach to unserved or underserved populations, and 7) the development of a strategic plan for expanding and improving rehabilitation services.

**Title II - Research:** Authorizes the National Institute on Disability and Rehabilitation Research (NIDRR) and establishes a Rehabilitation Research Advisory Council.

**Title III - Training and Demonstration Projects:** Authorizes NIDRR to continue supported employment demonstration projects.

**Title IV - National Council on Disability:** Requires the President to solicit recommendations for appointments from a broad range of organizations representing individuals with disabilities; requires that a majority of the membership must be individuals with disabilities or their family members.

**Title V - Rights and Advocacy:** Revises Section 504, the

anti-discrimination clause, to utilize standards of employment discrimination as stated in Titles I and V of the Americans with Disabilities Act.

*Title VI - Employment Opportunities for Individuals with Disabilities:* Renews emphasis on supported employment for individuals with severe disabilities; revises the definition of supported employment and provides for three related services: supported employment services, ongoing support services, and extended services.

*Title VII - Independent Living Services and Centers for Independent Living:* Maintains these two services; establishes Independent Living Services for Older Individuals Who Are Blind.

*Title VIII - Special Research, Training and Demonstration Projects:* Gives specific attention to transportation in rural areas and ways to increase choice of individuals with disabilities.

#### **Public Law 102-119: Individuals with Disabilities Education Act Amendments of 1991 (IDEA)**

Amends P.L. 101-476 (Individuals with Disabilities Education Act) by: 1) extending coverage of the act to schools for Native Americans operated by the Bureau of Indian Affairs in the U.S. Department of the Interior; 2) including children who are at risk of having substantial developmental delays without early intervention services, as covered under the act; 3) providing for a specific focus on underserved populations, such as low-income, minority, inner-city and rural; 4) adding new services which may be covered by the act, such as assistive technology devices; 5) emphasizing greater parental involvement in the development and implementation of the Individualized Family Service Plan; and 6) revising the membership of the Interagency Coordinating Council.

#### **Public Law 101-336: Americans with Disabilities Act of 1990**

A civil rights act for persons with disabilities; prohibits discrimination on the basis of disability according to five titles:

*Title I - Employment:* Prohibits discrimination in hiring, training, promotion, retention, compensation or benefits of any qualified individual because he or she has a disability or associates with someone with a disability (e.g., spouse, child, parent) by any employer with twenty-five (25) or more employees; requires reasonable

accommodation in the work setting by the employer. Beginning on July 26, 1994, this title will apply to any employer with fifteen (15) or more employees.

*Title II - Public Service:* Guarantees full access to local and state government services including, but not limited to, public recreation programs, public buildings, public broadcasting, and public documents; specifically focuses on publicly and privately owned transportation, requiring: 1) that all new vehicles purchased or leased must be accessible to persons with physical disabilities, 2) that paratransit services must be accessible to, and usable by, persons with disabilities, and 3) that new or remodeled bus and rail terminals must be accessible.

*Title III - Public Accommodations:* Requires privately operated businesses utilized by the public to make realistic plans to accommodate the needs of customers with disabilities. This section covers such businesses as banks, hotels, restaurants, stores, medical offices, day care centers, private schools and colleges, amusement parks, barber shops, and theaters.

*Title IV - Telecommunications:* Requires telephone companies to provide TDD relay services to persons with hearing disabilities on a 24-hour basis at no additional charge; also requires all television public service announcements produced with any federal funding to be closed captioned.

*Title V - Implementation:* Prohibits states from claiming immunity for their actions; prohibits retaliation and coercion against anyone who seeks to enforce someone's rights under this law; clarifies the definition of "persons with a disability" by listing exclusions; amends the Rehabilitation Act of 1973 to comply with the provisions of this act.

### **Public Law 101-392: Carl D. Perkins Vocational and Applied Technology Education Act of 1990**

Provides grants to states for vocational education programs, requiring that students with special needs must be provided with equal access to recruitment, enrollment, and placement activities, as well as equal access to the full range of vocational education programs available to other students; also requires that vocational education be provided in the least restrictive environment and, where appropriate, be included as part of the Individualized Education Program.



**Public Law 101-431: Television Decoder Circuitry Act**

Requires televisions with screens of 13 inches and larger to have built-in decoder circuitry for the display of closed captioned television transmission by July 1993.

**Public Law 101-476: Individuals with Disabilities Education Act (Amended P.L. 94-142)**

Retains the same provisions of P.L. 94-142 and 99-457 with the following changes: (1) Changes the phrase "handicapped children" to "children with disabilities" throughout the law; (2) Mandates that transition services be provided as a part of the Individualized Education Program (IEP) beginning no later than age 16; (3) Defines assistive technology services and includes them in the support services that are to be provided if identified in the IEP; and (4) Places greater emphasis on meeting the needs of children with disabilities of ethnic and cultural diversity.

**Public Law 101-496: Developmental Disabilities Assistance and Bill of Rights Act of 1990**

Provides federal funding to states and territories for planning, systems change, public education, protection and advocacy services, interdisciplinary training, and technical assistance in order to meet the needs of persons with developmental disabilities; promotes independence, productivity, integration, inclusion and interdependence of persons with developmental disabilities in all aspects of community life; funding goes to three entities in each state and territory: State Planning Councils, State Protection and Advocacy Systems, and University Affiliated Programs; In North Carolina, these three agencies are, respectively, the North Carolina Council on Developmental Disabilities, the North Carolina Governor's Advocacy Council for Persons with Disabilities, and the Clinical Center for the Study of Development and Learning at the University of North Carolina at Chapel Hill.

**Public Law 101-508: Community Supported Living Arrangements Services Amendments**

Establishes a new, limited option under the Medicaid program to permit from two to eight states to provide community supported living arrangement services for persons with developmental disabilities without regard to whether such individuals are at risk for institutionalization (as required for ICF-MR/DD and the

Medicaid Home and Community Based Waiver). This represents a major Medicaid policy change in that it does not link the receipt of Medicaid funds for community living to institutional admission criteria and standards. Community supported living arrangements are defined as services designed to assist an individual in activities of daily living necessary to permit such individual to live in the individual's own home, family home, or rental unit.

**Public Law 100-407: Technology-Related Assistance for Individuals with Disabilities Act of 1988**

Assists states in developing comprehensive, consumer-responsive programs in technology-related assistance for individuals with disabilities of all ages. This program enables states to: 1) increase the awareness of the needs of individuals with disabilities for technology and support services; 2) increase the awareness of policies, practices, and procedures that facilitate or impede the availability of such technology or services; 3) increase the availability of and funding for technology and support services; 4) increase the awareness and knowledge of the efficacy of technology and support services among individuals with disabilities, and those involved with them, including insurers and employers; 5) increase the capacity of public and private agencies and other groups to provide technology and support services to those with disabilities; 6) increase coordination among such agencies and groups; and 7) increase the probability, during times of transition, that an individual will, to the extent appropriate, be able to keep technology and access needed support services; supports the provision of technical assistance, information, training, and public awareness programs, as well as model demonstration and innovative projects in technology and support services for individuals with disabilities.

**Public Law 99-457: Education of the Handicapped Act Amendments of 1986**

Amended P.L. 94-142 to include children with disabilities, aged three and four, in the entitlement of a free and appropriate public education in accordance with all provisions in P.L. 94-142 (Part B); also implemented a new program to provide financial assistance to states for the establishment of a statewide system of comprehensive, coordinated, multi-

disciplinary, and inter-agency early intervention services for infants and toddlers (birth to age two) with or at risk for disabilities and for their families (Part H).

**Public Law 94-142: Education for All Handicapped Children Act of 1975 (see also Public Law 101-476 and 102-119)**

Landmark legislation guaranteeing free and appropriate public education for all children from the ages of five through twenty-one, regardless of the disability presented by the child. This law was designed to remove restrictions that had denied children with disabilities equal access to educational opportunities. It contains six principles that provide a foundation for special education: 1) Zero reject--no child regardless of the severity of handicap may be rejected by a public school system; 2) nondiscriminatory evaluation; 3) individualized education programs; 4) educational placement in the least restrictive environment; 5) due process; and 6) parent participation.

**Public Law 93-112: The Rehabilitation Act of 1973 (as amended) (see also Public Law 102-569)**

Provides grants to states to: 1) conduct a comprehensive program of rehabilitation services, including diagnosis, evaluation, therapy, medical treatment, and training necessary for job placement of persons who have mental or physical disabilities that prevent them from working; 2) establish a Client Assistance Program for the protection of persons in accessing rehabilitation services; 3) assist in the development of collaborative, interagency supported employment; and 4) provide independent living services for persons with severe disabilities.

*Section 504* of this act prohibits discrimination against persons with disabilities in programs receiving federal assistance, including education, employment and access to public services.

**U.S. Social Security Act of 1935 (as amended)**

*Title II - Social Security Assistance:* Direct monthly cash payments to surviving children of workers who are retired, deceased, or disabled who were eligible to receive Social Security benefits. Children with disabilities may continue to receive payments after their eighteenth birthday if the disability occurred prior to age twenty-two.

*Title V - Maternal and Child Health Services Block Grant:* Assistance to states to assure that mothers and

children, particularly those with low income or with limited access to health services, have access to quality maternal and child health services. These services are aimed at: 1) reducing maternal and infant mortality; 2) reducing the incidence of preventable diseases and disabling conditions among children; 3) promoting the health of mothers and children; and 4) maximizing the health status of children with disabilities.

*Title XVI - Supplemental Security Income:* Direct monthly cash payments to provide minimum income for individuals who meet the financial needs test and who are elderly, blind, or have a disability.

*Title XIX - Medicaid:* Federal funding to match state funds for the provision of medical care for individuals meeting a financial needs test, which includes many persons with disabilities.

*Title XIX - ICF-MR/DD:* Funds long-term care in a residential setting for individuals with mental retardation and related conditions who need active treatment; may also fund a Home and Community-Based Waiver which provides services for individuals with mental retardation and related conditions who do not live in a Medicaid certified residential setting.

*Title XX - Social Services Block Grant:* Federal funding to states for services directed at the goals of: 1) achieving or maintaining economic self-support to prevent, reduce, or eliminate dependency; 2) achieving or maintaining self-sufficiency, including reduction of dependency; 3) preventing or remedying neglect, abuse, or exploitation of children and adults unable to protect their own interests, or preserving, rehabilitating or reuniting families; 4) preventing or reducing inappropriate institutional care by providing for community-based care, homebased care, or other forms of less intensive care; and 5) securing referral or admission for institutional care when other forms of care are not appropriate, or providing services to individuals in institutions.

#### **U.S. Housing Act of 1937, 1949 and 1959 (as amended)**

*Section 7:* Funds contracts with local authorities to provide social services to "frail elderly and handicapped individuals," minimally providing two meals a day.

*Section 8:* Provides direct payment and vouchers to fund rental subsidies for housing costs of eligible persons

(based upon income), which may include persons with disabilities.

**Section 202:** Long-term direct federal loans to private nonprofit corporations and consumer cooperatives to provide housing for persons who are elderly or have disabilities.

# RELEVANT STATE STATUTES

## **G.S. 35A: Incompetency and Guardianship**

G.S. 35A, Article 5: Appointment of Guardian for Incompetent Person

## **G.S. 108A: Social Services**

G.S. 108A-40 through 47: State-County Special Assistance for Adults

G.S. 108A-50: State Benefits for Certain Adoptive Children

G.S. 108A, Article 6: Protection of the Abused, Neglected or Exploited Disabled Adult Act

## **G.S. 115C-106, Article 9 (Sections 106-146.4): Special Education**

G.S. 115C-111: Free Appropriate Education for All Children with Special Needs

G.S. 115C-146.1 through 146.4: Handicapped Children, Ages Three to Five

## **G.S. 122C: Mental Health, Developmental Disabilities and Substance Abuse Act of 1985**

G.S. 122C-63: Assurance for Continuity of Care for Individuals with Mental Retardation

G.S. 122C, Article 3: Clients' Rights

G.S. 122C, Article 4: Organization and System for Delivery of Mental Health, Developmental Disabilities and Substance Abuse Services

## **G.S. 130A: Public Health**

G.S. 130A, Article 5: Maternal and Child Health

## **G.S. 131D: Inspection and Licensing of Facilities**

G.S. 131D-2: Licensing of Domiciliary Homes for the Aged and Disabled (includes Group Homes for Adults with Developmental Disabilities)

G.S. 131D-19 through 34: Domiciliary Home Residents' Bill of Rights

## **G.S. 143B-177 through 179: Council on Developmental Disabilities**

**G.S. 143B-179.5: Interagency Coordinating Council for Handicapped Children from Birth to Five Years of Age**

**G.S. 143B-216.31: Council for the Deaf and Hard of Hearing**

**G.S. 143B-403.1 through 403.2: Governor's Advocacy Council for Persons with Disabilities**

**G.S. 168: Handicapped Persons**

G.S. 168-2: Right of Access to and Use of Public Places

G.S. 168-3: Right to Use of Public Conveyances, Accommodations, etc.

G.S. 168-8: Right to Habilitation and Rehabilitation Services

G.S. 168-9: Right to Housing

G.S. 168-20 through 23: Family Care Homes (Group Home Zoning Law)

**G.S. 168A: Handicapped Persons Protection Act**

# NORTH CAROLINA DEPARTMENTS AND AGENCIES

NORTH CAROLINA DEPARTMENT OF ADMINISTRATION,  
Administration Building, 116 W. Jones Street, Raleigh,  
NC 27603-8003

- **Governor's Advocacy Council for Persons with Disabilities**, 1318 Dale Street, Suite 100, Raleigh, NC 27605-1275, (919) 733-9250, 1-800-821-6922 (Voice/TDD)

NORTH CAROLINA DEPARTMENT OF ENVIRONMENT,  
HEALTH AND NATURAL RESOURCES, Archdale  
Building, 512 N. Salisbury Street, P.O. Box 27687,  
Raleigh, NC 27611-7687, (919) 733-4984

- **Division of Maternal and Child Health**, 1330 St. Mary's Street, P.O. Box 27687, Raleigh, NC 27611-7687, (919) 733-3816
  - Children and Youth Section, (919) 733-7437
  - Prevention Services, (919) 733-0385

NORTH CAROLINA DEPARTMENT OF HUMAN  
RESOURCES, Adams Building, 101 Blair Drive, Dorothea  
Dix Campus, Raleigh, NC 27603-2041, (919) 733-4534

- **CareLine**: 1-800-662-7030 (Voice/TDD). Dial toll free from anywhere in North Carolina and an Information and Referral Counselor of the NC Department of Human Resources will answer you questions or connect you with the responsible agency. CARE-LINE seeks to link those in need to existing resources.
- **Council on Developmental Disabilities**, 1508 Western Boulevard, Raleigh, NC 27606, (919) 733-6566 (Voice/TDD)
- **Interagency Coordinating Council**, Adams Building, 101 Blair Drive, Dorothea Dix Campus, Raleigh, NC 27603, (919) 733-5995
- **Division of Aging**, CB 29531, 693 Palmer Drive, Raleigh, NC 27626, (919) 733-3983
- **Division of Facility Services**, Council Building, 701 Barbour Drive, Raleigh, NC 27603-2008, (919) 733-2342 (Director's Office)
  - Day Care Section, (919) 733-4801
  - Licensure Section, (919) 733-2786
  - Certificate of Need Section, (919) 733-6360
- **Division of Medical Assistance**, P.O. Box 29529, Kirby



Building, 1985 Umstead Drive, Raleigh, NC 27626-0529,  
(919) 733-2060

- **Division of Mental Health, Developmental Disabilities, and Substance Abuse Services**, Albemarle Building, 325 N. Salisbury Street, Raleigh, NC 27603, (919) 733-7011
  - Developmental Disabilities Services, (919) 733-3654
  - Mental Health Services, (919) 733-4660
  - Alcohol and Drug Services, (919) 733-4670
  - "Thomas S." Services, (919) 733-1763
  - "Willie M." Services, (919) 733-0696
  - Area Program Support, (919) 733-0596
- **Division of Services for the Blind**, Fisher Building, 309 Ashe Avenue, Raleigh, NC 27606, (919) 733-9822
- **Division of Services for the Deaf and the Hard of Hearing**, Anderson Building, 695-A Palmer Drive, Raleigh, NC 27626, (919) 733-5199 (Voice), (919) 733-5930 (TDD)
- **Division of Social Services**, Albemarle Building, 325 N. Salisbury Street, Raleigh, NC 27603, (919) 733-3055
  - Family Services Section, (919) 733-7145
  - Children's Services Branch, (919) 733-9467
  - Adult and Family Services Branch, (919) 733-3818
- **Division of Vocational Rehabilitation Services**, 805 Ruggles Drive, P.O. Box 26053, Raleigh, NC 27611, (919) 733-3364 (Voice/TDD)
  - Access, NC, (919) 733-3364
  - Client Assistance Program, (919) 733-3364
  - Independent Living Program, (919) 733-3364
  - Supported Employment Program, (919) 733-3364
  - North Carolina Assistive Technology Project, 1110 Navaho Drive, Suite 101, Raleigh, NC 27609, (919) 850-2787, 1-800-852-0042 (Voice/TDD)
- **Division of Youth Services**, Dobbins Building, 705 Palmer Drive, Raleigh, NC 27626, (919) 733-3011
- **Mental Health Study Commission**, Albemarle Building, 325 N. Salisbury Street, Raleigh, NC 27603, (919) 733-6077

NORTH CAROLINA DEPARTMENT OF PUBLIC  
INSTRUCTION, 301 N. Wilmington Street, Raleigh, NC  
27601-2825, (919) 715-7100

- **Division for Exceptional Children**, 301 N. Wilmington Street, Raleigh, NC 27601-2825, (919) 715-1563
- **Council on Exceptional Children**, 301 N. Wilmington Street, Raleigh, NC 27601-2825, (919) 715-1563

# UNIVERSITY RELATED PROGRAMS

**Carolina Literacy Center**, CB 8135, UNC-CH, Chapel Hill, NC 27599-8135, (919) 966-7486.

**Center for Accessible Housing**, NCSU, P.O. Box 8613, Raleigh, NC 27695-8613, (919) 515-3082

**Clinical Center for the Study of Development and Learning**, CB 7255, UNC-CH, Chapel Hill, NC 27599-7255, (919) 966-5171

**Developmental Disabilities Intervention and Research Program**, 324 Erwin Building, East Carolina University, Greenville, NC 27858, (919) 757-6164

**Developmental Disabilities Training Institute**, CB 3370, UNC-CH, Chapel Hill, NC 27599-3370, (919) 966-5463

**Division TEACCH**, CB 7180, UNC-CH, Chapel Hill, NC 27599-7180, (919) 966-2173

**Family Support Network**, CB 7340, UNC-CH, Chapel Hill, NC 27599-7340, (919) 966-2841, 1-800-TLC-0042

**Frank Porter Graham Child Development Center**, CB 8180, UNC-CH, Chapel Hill, NC 27599-8180, (919) 962-4250

**North Carolina Area Health Education Center Program**, CB 7165, UNC-CH, Chapel Hill, NC 27599-7165, (919) 966-2461

**The Human Development and Training Institute**, Western Carolina Center, 300 Enola Road, Morganton, NC 28655, (704) 433-2896

# **NORTH CAROLINA ORGANIZATIONS: CONSUMER, ADVOCACY AND PROFESSIONAL**

**Advocacy Center for Children's Education and Parent Training (ACCEPT)**, 1320 Glenwood Avenue, Greensboro, NC 27403, (919) 272-6373

**Association for Retarded Citizens/North Carolina, Inc.** (See The Arc of North Carolina, Inc.)

**Association of Self-Advocates of North Carolina, c/o The Arc of North Carolina**, P.O. Box 20545, 16 Rowan Street, Suite 204, Raleigh, NC 27619, (919) 782-4632, 1-800-662-8706

**Autism Society of North Carolina, Inc.** 3300 Woman's Club Drive, Raleigh, NC 27612, 1-800-442-2762

**Beginnings for Parents of Hearing Impaired Children**, 1504 Western Blvd., Raleigh, NC 27606, (919) 834-9100 (Voice/TDD). Parents may call 1-800-541-HEAR.

**Carolina Legal Assistance**, P.O. Box 2446, Raleigh, NC 27602, (919) 856-2121

**Coalition 2001**, P.O. Box 20545, Raleigh, NC 27619, (919) 782-4632

**Community Living Association**, P.O. Box 25746, Raleigh, NC 27611-5746, (919) 782-5485

**Cystic Fibrosis Foundation**, P.O. Box 639, Wilson, NC 27894, (919) 291-7190, 1-800-682-6858

**Deaf-Blind, Multihandicapped Association of North Carolina, inc.**, 2316 Carey Road, Kinston, NC 28501, (919) 522-5140

**Easter Seal Society of North Carolina**, 2315 Myron Drive, Raleigh, NC 27607, (919) 783-8898, 1-800-662-7119

**Epilepsy Association of North Carolina, Inc.**, 721 Tucker Street, Raleigh, NC 27603, (919) 834-2876, 1-800-451-0694

**Epilepsy Information Service**, 1-800-642-0500. In Winston-Salem, NC, call (919) 748-2319.

**Exceptional Children's Assistance Center (ECAC)**, P.O. Box 16, Davidson, NC 28036, 1-800-962-6817

**Family Support Network of North Carolina**, Campus Box 7340, UNC-CH, Chapel Hill, NC 27599-7340, 1-800-TLC-0042

- Fragile X Southeast Network**, P.O. Box 3364, Duke University Medical Center, Durham, NC 27710, (919) 684-5513
- Learning Disability Association of North Carolina**, P.O. Box 3542, Chapel Hill, NC 27515, (919) 967-9537
- March of Dimes Birth Defects Foundation**, 4112 Pleasant Valley Rd., Suite 208, Raleigh, NC 27612, (919) 787-6511, 1-800-849-2663
- Mental Health Association of North Carolina**, 115½ West Morgan Street, Raleigh, NC 27601, (919) 828-8145
- Muscular Dystrophy Association**, 3203 Woman's Club Drive, Suite 207, Raleigh, NC 27612, (919) 783-0222
- National Federation of the Blind of North Carolina**, 601 Dixie Trail, Raleigh, NC 27607, (919) 828-6328
- National Multiple Sclerosis Society, Greater Carolina Chapter**, 1515 Mockingbird Lane, Suite 1000, Charlotte, NC 28209, (704) 525-2955, 1-800-477-2955
- North Carolina Adult Day Care Association**, 206 Mt. Sinai Church Road, Shelby, NC 28150, (704) 484-0405
- North Carolina Alliance for Parents of the Visually Impaired, Inc.**, 5512 Old South Road, Raleigh, NC 27606, (919) 828-6483
- North Carolina Alliance for the Mentally Ill**, 3716 National Drive, Suite 213, Raleigh, NC 27612, (919) 783-1807
- North Carolina Alliance of Disabled and Concerned Citizens**, 47 Jeffress Avenue, Asheville, NC 28803, (704) 274-5032
- North Carolina Association for the Emotionally Troubled**, c/o Caramore Community, P.O. Box 2576, Chapel Hill, NC 27515, (919) 967-3402
- North Carolina Association of Directors of Developmental Day Centers (ADD)**, Frankie Lemmon School, 1800 Glenwood Avenue, Raleigh, NC 27608, (919) 821-7436
- North Carolina Association of Rehabilitation Facilities**, P.O. Box 51254, 4905 Pine Cone Drive, Suite 5, Durham, NC 27717, (919) 493-7655
- North Carolina Association of Residential Resources**, c/o Howell's Center, 101 Howell Drive, La Grange, NC 28551, (919) 566-9011
- North Carolina Association of the Deaf, Inc.**, P.O. Box 477, 7801 Corder Drive, Charlotte, NC 28212, (704) 563-9400

- North Carolina Center for Public Policy Research**, P.O. Box 430, Raleigh, NC 27602, (919) 832-2839
- North Carolina Chapter of the American Association on Mental Retardation**, c/o Developmental Disabilities Section, Division of Mental Health, Developmental Disabilities, and Substance Abuse Services, 325 N. Salisbury Street, Raleigh, NC 27603, (919) 733-3654
- North Carolina Chapter of the National Tuberous Sclerosis Association**, 1005 Indianhead Circle, Snow Hill, NC 28580, (919) 747-8592, 1-800-NCC-NTSA
- North Carolina Child Advocacy Institute**, 1318 Dale Street, Suite 110, Raleigh, NC 27605, (919) 834-6623
- North Carolina Council for the Blind**, 1909 Southgate Drive, Raleigh, NC 27610, (919) 733-5048
- North Carolina Council of Community Mental Health, Developmental Disabilities and Substance Abuse Programs**, P.O. Box 26206, 215 N. Dawson Street, Suite 123, Raleigh, NC 27611, (919) 755-0680
- North Carolina Deaf-Blind Associates, Inc.**, 1401 Ridgeway Avenue, Durham, NC 27701, (919) 596-7184 (Voice), (919) 833-1062 (TDD)
- North Carolina Developmental Disabilities Consortium**, 1515 Mockingbird Lane, Suite 901, Charlotte, NC 28209-3240, 1-800-626-1627
- North Carolina Federation of the Council for Exceptional Children**, 1604 Phillips Drive, Sanford, NC 27330, (919) 776-9281
- North Carolina Head Injury Foundation**, 301 S. Tryon Street, Suite 1710, Charlotte, NC 28282, (704) 332-9834
- North Carolina Registry of Interpreters for the Deaf**, 500 W. Trade Street, Suite 356, Charlotte, NC 28202, (704) 342-5482
- Parents and Professionals for Children with Special Needs**, 6847 Greystone Drive, Raleigh, NC 27615, (919) 876-6364
- Parents Association for Hearing Impaired Children**, 9105 Ransdell Road, Raleigh, NC 27603, (919) 779-1061
- Prader-Willi Syndrome Association of North Carolina**, 2401 Tanglewood Drive, Albemarle, NC 28001, (704) 982-7905
- Special Olympics of North Carolina**, P.O. Box 98209, Raleigh, NC 27624, (919) 878-7978, 1-800-843-6276

**Spina Bifida Association of North Carolina, Inc.**, 207 West Main Street, Mayodan, NC 27027, (919) 548-4888

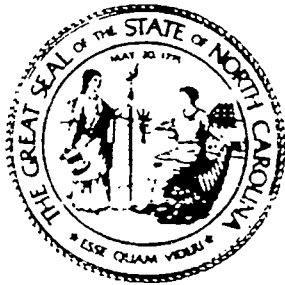
**Statewide Parent Education and Advocacy for Kids (SPEAK)**, 1011 Anderson Street, Wilson, NC 27893, (919) 237-4838

**The Arc of North Carolina, Inc.** (formerly the Association for Retarded Citizens, North Carolina, Inc.), P.O. Box 20545, 16 Rowan Street, Suite 204, Raleigh, NC 27619, (919) 782-4632, 1-800-662-8706

**Tourette Syndrome Association, North Carolina Chapter**, 1507 Fox Hollow Road, Greensboro, NC 27410, (919) 852-1218

**United Cerebral Palsy of North Carolina**, 327 W. Morgan Street, P.O. Box 12728, Raleigh, NC 27605, (919) 832-3787, 1-800-868-3787

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## **NORTH CAROLINA DEPARTMENT OF HUMAN RESOURCES**

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