Partners in Justice

Resource Guide
on
Intellectual (Cognitive) Disabilities for Professionals in the Criminal Justice System

“This project is supported by The Arc of North Carolina and the NC Council on Developmental Disabilities and the funds it receives through P.L.106-402, the Developmental Disabilities Assistance and Bill of Rights Act of 2000.”

Introduction

On a daily basis, our criminal justice system addresses the challenge of balancing individual rights and public safety. Faced with making difficult decisions on short notice, law enforcement personnel rely on tried and tested protocols as well as their own common sense and a system of beliefs about human behavior.

When people with intellectual impairments such as mental retardation or autism interact with the criminal justice system, elements of their disabilities brush against these protocols and beliefs, resulting in serious misunderstanding and sometimes tragedy. The goals of public safety and fairness can both be compromised.

The North Carolina Council on Developmental Disabilities and The Arc of North Carolina recognized a need for sharing information between the criminal justice and human services systems, and, therefore, funded the Partners in Justice Project.

** On July 25, 2003, President Bush renamed the President's Committee on Mental Retardation the President's Committee for People with Intellectual Disabilities. In keeping with this decision, this document includes the term "intellectual disabilities" in the Title and Glossary.*

About The Partners in Justice Project

A Project of The Arc of North Carolina

In recent years, the number of people with mental retardation and other intellectual disabilities who live in their communities has increased dramatically, and the philosophy is that the preferred living environment is almost exclusively in their own homes or with their own families. Although most people with intellectual disabilities are productive, law abiding citizens, some may become involved with the criminal justice system as offenders. Also, an alarming number of people with intellectual disabilities are victims of crime or witnesses to crimes against others.

The Partners in Justice project provides information and training to:

- Justice system professionals including judges, attorneys, magistrates and law enforcement officers on how to recognize when an individual has an intellectual disability and where to go for assistance;

- Individuals with intellectual disabilities and their families on how to avoid contact with the justice system, and what to do if they do become involved with the system as a witness, a victim, or an offender; and

- Human service workers, teachers and others on the judicial process allowing them to help people with intellectual disabilities and assure the justice system accommodates the disabilities.

Partners in Justice is developing a network of trainers across the state who can provide information and technical assistance to law enforcement agencies, attorneys, consumers and their families, and human service workers. Project staff are available free of charge to provide training in local communities and to provide instruction and training materials to individuals who wish to become trainers.

For more information, contact:
Marian Hartman - MarianHartman@nc.rr.com; or
Ann Elmore - Ann-Elmore@nc.rr.com; or visit The Arc of North Carolina web site at **www.arcnc.org**.

Traits Often Seen in People with Intellectual Disabilities

May not communicate at age level:

- Limited vocabulary;
- Difficulty understanding/answering questions;
- Mimics answers/responses;
- Unable to communicate events clearly in his/her own words; and/or
- Unable to understand complicated instructions or abstract concepts.

May not understand consequences of situations:

- Unaware of seriousness of situations;
- Easily led or persuaded by others; and/or
- Naïve eagerness to confess or please authority figures.

May not behave appropriately:

- Unaware of social norms and appropriate social behavior;
- Acts younger than actual age, may display childlike behavior;
- Displays low frustration tolerance and/or poor impulse control; and/or
- May “act out”, become emotional, or try to leave if under pressure.

May have difficulty performing tasks:

- Inability to read or write;
- Inability to tell time;
- Difficulty staying focused and easily distracted; and/or
- Awkward/poor motor coordination.

Traits Often Seen in People with Autism Spectrum Disorder

People with Autism Spectrum Disorders may:

Not make eye contact:

- Don't misinterpret limited eye contact as deceit.

Have difficulty with communication:

- May not talk (nonverbal);
- May communicate with sign language, picture cards or gestures;
- May have trouble understanding what YOU say;
- May need direct, short instructions such as "Stand up now";
- May have a delayed response to questions; and/or
- May not read facial expressions or body language.

Invade another's personal space unknowingly;

Over-react to being touched;

Have seizures; and/or

Show odd behaviors such as flapping hands or pacing.

Traits Often Seen in People with Brain Injury

People who have experienced a Brain Injury may:

- Have trouble processing or remembering information;
- Not follow instructions;
- Be perceived as belligerent or unmotivated;
- Experience headaches and fatigue;
- Become easily frustrated;
- Not perceive how behaviors affect others; relationships can become strained;
- Lose impulse control; may do or say things that are not socially appropriate (e.g. sexual acting out); and/or
- Become emotionally volatile, may have outbursts of anger, aggression, or crying.

Tips for Communicating with a Person with an Intellectual Disability

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People with intellectual disabilities may need assistance to ensure that their rights are protected. These tips may be helpful:

- Speak directly to the person. Make eye contact before you speak and say her/his name often. Note: People with Autism Spectrum Disorder may find it difficult to make or maintain eye contact. This should not be interpreted as a sign of guilt.
- Keep sentences short.
- Use simple language. Speak slowly and clearly.
- Clearly identify yourself, explain why you are there.
- Ask for concrete descriptions (colors, clothing, etc.).
- Break complicated instructions or information into smaller parts.
- Use pictures or symbols of actions, if needed, to help convey meaning.
- Be patient and take time giving or asking for information.
- Ask "who," "what," or "where" questions. "When" or "how" questions may be more difficult to answer. Avoid confusing questions about time, sequences, or reasons for behavior.
- Repeat questions more than once if necessary. If the person does not seem to understand, ask it in a different way.
- Do not ask leading questions or questions phrased in a way to solicit a certain answer.
- Phrase questions open-ended when possible (e.g. "Tell me what happened.")
- Treat adults as adults, regardless of their disabilities.
- If you are unsure if the person really understands what you are saying, ask the person to repeat it in his/her own words.
- Be sensitive to self-blame and fear.
- Pay attention to non-verbal cues, over compliance, resistance and body language.

Myths about Mental Retardation

Myth 1: Mental retardation is the same as mental "illness."

The fact is: Mental retardation is a developmental disability characterized by below average intellectual functioning. With the appropriate intervention and education, a person with mental retardation can lead a satisfying and productive life in the community.

Myth 2: Mental retardation is a contagious disease.

The fact is: Mental retardation is not a disease and it is certainly not contagious. It is a condition that affects an individual because of some change or damage with the developing brain and neurological system. Mental retardation is a lifelong condition. There is no "cure".

Myth 3: People with severe and profound mental retardation should be locked away in institutions for their own and society's safety.

The fact is: Research shows that most people with severe and profound mental retardation can learn to at least care for their basic needs. Many can perform useful work with support and can otherwise adapt to normal patterns of life. It has been proven that the most effective environment for everyone to learn and develop is in the community and offers a family-like atmosphere of care and nurturing.

Myth 4: Educational and vocational training will not help people with mental retardation.

The fact is: Most persons with mental retardation can learn, although at a slower rate, and are capable of living in the community with little or no support services.

Early intervention is critical since it is proven that the earlier the disability is identified and services are provided, the greater the probability the individual will enjoy a productive and meaningful life in the community. Vocational programs help prepare individuals for work. Supported employment helps people find jobs in the competitive work environment.

Myth 5: We do not know what causes mental retardation and it cannot be prevented.

The fact is: Mental retardation can be caused by any condition which impairs development of the brain before or during birth or in early childhood. More than 250 causes have been discovered, but they account for only about one-fourth of the causes of mental retardation. The most well-known are: Rubella or German measles in the pregnant female, meningitis, toxoplasmosis, Rh factor, and chromosomal abnormalities such as Down Syndrome. Mental retardation can be prevented in some cases. Some prevention strategies include:

- Access to good prenatal and postnatal care for mother and child.
- Improved nutrition in pregnant women and infants.
- Avoiding the use of drugs and alcohol during pregnancy.
- Newborn screening to detect disorders such as hypothyroidism and PKU.
- Routine screening and immunizations of mothers to prevent Rh blood factor.
- Use of child seats and seat belts to prevent head injuries.
- Screening for lead poisoning for all children under the age of 5.

Dual Diagnosis or Co-Occurring Disorders

When an Intellectual Disability is Complicated by Mental Illness

Good mental health is an essential ingredient in quality of life and is a goal for all people, including those with intellectual disabilities.

Mental illness is a disease resulting in severe disturbances of behavior, mood, thought processes, cognition, and/or social and interpersonal relationships. Mental illness may occur at any time of life, may be temporary or episodic, and may respond to treatment.

The presence of mental illness in individuals with normal intellectual abilities is difficult at best. In individuals with intellectual disabilities, it is devastating without appropriate interventions.

An intellectual disability caused by mental retardation results in abnormal thought *processes* – not abnormal thoughts – and is a permanent condition. A person with an intellectual disability caused by mental retardation will have below average intellectual functioning, slow thought processes, and difficulty learning.

Dual diagnosis is the term applied when an individual experiences more than one disorder. Most commonly, dual diagnoses are described by mental health professionals as mental illness with a co-occurring substance abuse issue. The impact of an intellectual disability co-occurring with mental illness is described below.

Individuals who are diagnosed with an intellectual disability *and* mental illness have more difficulty adjusting to life in the community. In this time when emphasis is on community living and providing services in the least restrictive environment, experts predict that even this most difficult group can be assisted by positive behavior support directed by mental health professionals and medication treatment programs prescribed by a physician. Individuals with both intellectual disabilities and mental illness are best served by providers specially trained to work with these individuals.

People with dual diagnoses are limited not only by intellectual ability but by the behavior generated by the mental illness. The presence of mental illness often disrupts habilitation efforts. When mental illness occurs in a person with an intellectual disability, behavior management alone will not be as effective as combining treatment for both disabilities.

How many people with intellectual disabilities are mentally ill?

The rate of mental illness among individuals with intellectual disabilities varies considerably depending on age, type of mental illness and statistical analysis. Rates of 10 to 40 percent have been reported for individuals served by community agencies. Some researchers report that the rate of psychiatric disability in people with *mental retardation* may be four to five times greater than in the general population. Statistics for people with all intellectual disabilities are not available. Conduct and behavioral problems occur for about one in five people with intellectual disabilities living in the community.

Why do people with mental retardation develop mental illnesses and behavior problems?

Scientists still do not know for certain what causes mental illness. Most researchers believe that both biological and psychological risk factors are involved to varying degrees depending on the specific disorder. Some disorders may be wholly or largely caused by biochemical and structural abnormalities in the brain and some people may possibly have a genetic predisposition. Biochemical and structural abnormalities seem to be especially important in the occurrence of psychosis and explosive behavior. Life history, environment and individual stressors also may contribute to the severity of psychosis and may precipitate increases in symptoms and behaviors in susceptible individuals.

People with dual diagnoses are not successfully treated in psychiatric facilities because of their intellectual disabilities; nor are they successful in a facility designed to habilitate people with intellectual disabilities because of the mental illness and need for psychotropic medications. Programs designed for people with intellectual disabilities typically do not have appropriate staff to address the needs of people with mental illness. There is a great risk to other program participants if a person with mental illness is included in a program where the staff are not trained to treat a person with mental illness.

Many cases of abnormal behavior are caused by the intellectual disability itself as the individual lacks the ability to keep behaviors within a socially acceptable norm. Those without that mental ability to control behavior need positive behavior support. When mental illness is acerbated by a neurochemical imbalance, psychotropic medication may be helpful.

What types of treatment *are* available?

Extraordinary progress has been made in the last 20 years with regard to outcomes and treatment of mental illnesses in the general population. However, these advances are difficult to adapt for use with people with intellectual disabilities. Families continue to have great difficulty locating appropriate services.

> **Psychopharmacology.** Many disorders can be controlled or alleviated with psychotropic medication; however, there has been a tendency to over-medicate people with intellectual disabilities. Careful monitoring of the side effects of medications is critical and often environmental adaptations can effectively mitigate behaviors. Even when used appropriately, medications are only part of an array of treatments that may promote wellness.

Counseling/Psychotherapy. People with mild intellectual disabilities may benefit from counseling. Many individuals cope better when another person listens to their problems and provides social support and understanding. However, mental health professionals with experience counseling people with intellectual disabilities are few, and the process is long and repetitive.

Intellectual Behavior Therapy. This treatment teaches people with mild intellectual disabilities to recognize situations that get them into trouble and to develop alternative behaviors and solutions to their problems. Although widely used with the general population, intellectual behavior therapy has been adapted only recently for use with people with intellectual disabilities.

Positive Behavior Support. This approach is widely used with people with mental retardation. In positive behavior support, the focus is on relationship and instruction rather than consequence and punishment. The approach often leads to significant behavioral improvements, at least during the time the treatment is in effect.

Social Skills Training. Individuals are gradually taught effective social interactions and appropriate social behavior. This should be part of a daily living process rather than a discrete process.

What types of services are available for the individual who has both intellectual disabilities and mental illness?

Historically, people with dual diagnoses were shuttled between service systems and, in the process, underserved. Today, the needs of individuals with dual diagnoses are still overshadowed by the primary diagnosis of an intellectual disability.

Without agencies identified to deal specifically with this population, persons with dual diagnoses are often passed from agency to agency, from institution to institution, from group home to group home, as different therapies and treatments are tried. The resulting frustration only leads to a deepening of the problem.

The national trend toward deinstitutionalization from both psychiatric hospitals and mental retardation centers has significantly complicated the issue, as there are few service providers qualified to address both the intellectual disability and the mental illness. Availability of qualified providers is further hindered by legal considerations such as licensing and liability. Thus, many individuals with dual diagnoses end up in the legal system as their behaviors deteriorate, and social stigma influences the way in which they are viewed by society.

Ideally, an individual with dual diagnoses will find a provider who employs a team approach and has staff who are cross-trained in both disabilities to provide treatment, supports and services. An interdisciplinary team may consist of program specialists, clinical social workers, nurses and medical doctors, dietitians, paraprofessionals, and residential care staff. Participating in the life of the community with skill building activities like work, leisure activities, developing a network of friends and families for support, and adjunctive therapies are components that enhance community inclusion, reduce stigma and promote well-being and optimum health.

Since individuals with dual diagnoses are intimately involved with their caregivers, the caregivers can provide valuable information regarding changes in the individuals’ functioning. Because behavior is a form of communication, even individuals who are nonverbal may express themselves in ways that assist in achieving personal outcomes.

Presently, treatment sites and community-based programs exist in some places, but are not universally available throughout the United States. Finding appropriate services may require persistence. For information on dual diagnosis services, contact the local chapter of The Arc; a nearby University Affiliated Program in Mental Retardation and Developmental Disabilities; or the NC Division of Mental Health, Developmental Disabilities and Substance Abuse Services. The National Association for People with a Dual Diagnosis (800-331-5362) may be able to recommend a local psychiatrist or psychologist.

Guardianship

Full guardianship is a severe limitation of a person's civil rights and can be a significant barrier to the ideal of self-determination for people with disabilities. North Carolina law and practices are geared to a routine and automatic finding that a person is incompetent and needs a full guardian. There is little consideration of less restrictive alternatives and no requirement that the actual functioning capacity of the person for whom guardianship is sought be evaluated before full guardianship is ordered. Families and service providers are often unaware of any alternatives.

Within existing North Carolina law however, there are options that can be used to make guardianship procedures more sensitive to individual diversity and choice and create limited guardianships that are more tailored to the strengths and needs of the person for whom guardianship is sought. Limited guardianship is the tool to make this happen, but within our court system, it has not been a user-friendly option.

With a grant from the North Carolina Council on Developmental Disabilities, Carolina Legal Assistance has established five pilot sites where the Clerk of Superior Court is working with lawyers, human service agencies and advocates to test new forms that make limited guardianship a practical reality for people with disabilities. The forms include a Guardianship Capacity Questionnaire to help families, court officials and agencies determine if a person needs a guardian at all, and if so, how a limited guardianship order can be drafted to address the life domains where the person needs help without infringing on those life domains where they can remain independent.

Benefits - Just the Basics

Citizens of North Carolina have a number of financial assistance programs available to them if they are disabled or poor. Many people with intellectual disabilities will qualify for benefit programs. Each program has its own set of eligibility requirements. This is an overview of benefits programs available to help people with disabilities afford medical treatment and some of the costs of daily living in the community. Federal programs include:

Social Security Disability Insurance (SSDI) provides benefits to individuals who are disabled or blind and who are insured by workers' contributions to the Social Security trust fund. These contributions are the Federal Insurance Contributions Act (FICA) social security tax paid on their earnings or those of their spouses or parents. Social Security Disability Insurance pays benefits to people who cannot work because they have a medical condition that is expected to last at least one year or result in death. Federal law requires this very strict definition of disability. While some programs give money to people with partial disability or short-term disability, Social Security does not. Certain family members of workers with disabilities also can receive money from Social Security.

Supplemental Security Income (SSI) is administered by the Social Security Administration for people who are aged, blind or disabled, including children under age 18 who have limited income or resources to guarantee a certain level of income. SSI recipients have contributed nothing or not enough to the Social Security System to be eligible for benefits on their own earnings record.

An application for SSI is also an application for Medicaid. Individuals who are eligible for SSI automatically qualify for Medicaid. Eligibility for Medicaid begins with the first day of the month in which eligibility for SSI begins and continues as long as the individual remains eligible for SSI.

To be eligible for disability, an individual must meet the federal definition of disability. For purposes of Medicaid and SSI, that definition is "a physical or mental impairment which prevents an individual from engaging in any substantial gainful activity (or for a child under 18, an impairment of comparable severity) and which has lasted or is expected to last for at least 12 months or is expected to result in death."

Medicaid is health insurance that helps many people who can not afford medical care to pay for some or all of their medical bills. Medicaid is available only to certain low-income individuals and families who fit into an eligibility group that is recognized by federal and state law. Medicaid sends payments directly to the health care providers. Some co-pay may be required.

Through the NC Department of Health and Human Services, eligible individuals may receive funding through the following sources:

The Community Alternatives Program for Persons with Mental Retardation/Developmental Disabilities (CAP-MR/DD) is a special Medicaid program serving individuals who would otherwise require care in an intermediate care facility for people with the mental retardation/developmental disabilities (ICF/MR). It allows these individuals the opportunity to receive services in the community instead of residing in an institutional or group home setting.

The Community Alternatives Program for Disabled Adults (CAP-DA) provides a package of services to allow adults (age 18 and older) who qualify for nursing facility care to remain in their private residences. The program is available in all North Carolina counties.

Intermediate Care Facility/Mental Retardation (ICF/MR) provides funding for people with mental retardation who live in congregate settings such as the state-operated mental retardation centers and large private residential facilities for people with mental retardation.

Skilled Nursing Facility (SNF) is a long-term care facility which provides twenty-four hour skilled nursing care with a RN or LPN on duty at all times. Funding to support placement in a SNF may come from private or public (Medicaid) sources.

Special Assistance (SA) is an additional funding source for individuals who are disabled. It augments state and federal support and pays cash benefits to eligible recipients who reside in licensed facilities authorized to receive SA payments. To be eligible for SA, an individual must be eligible for SSI, or ineligible for SSI solely due to income. It is 50% State and 50% county funded and is paid in the following categories:

a. Adult Care Home—Cash payments and medical assistance for eligible individuals who are aged, disabled or blind residing in a licensed adult care home facility.

b. Certain Disabled—Cash payment only for individuals in a private living arrangement who meet the state's definition of disability. (This program is not available in all counties.)

c. In-home—Cash payments and medical assistance for eligible individuals who are aged, disabled or blind residing in a private living arrangement, and who are at risk of placement in an adult care home.

To learn more about benefits, contact the county Department of Social Services.

Choosing Words the “People-first” Way

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 preferable to say “people with disabilities.” Putting the word “people” first places emphasis on the person instead of the disability. The disability is no longer the primary, defining characteristic of an individual but merely one aspect of the whole person.

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

Here are some suggestions on how to incorporate people-first language into your written and verbal communications.

AVOID: “afflicted with” a particular condition, such as polio or multiple sclerosis
USE: “someone who had polio” or “person with multiple sclerosis”

AVOID: crippled, confined to a wheelchair, wheelchair bound, wheelchair user
USE: person with a physical disability, person who uses a wheelchair

AVOID: deaf and dumb, deaf mute
USE: person who does not hear or hear well, person who does not speak, person who uses an alternative communication device. Note: Many people who are deaf, advocate for the term "deaf person" to symbolize the pride they feel as part of the deaf community.

AVOID: epileptic
USE: person with epilepsy, person with a seizure disorder

AVOID: cerebral palsied, spastic
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, the handicapped, handicapped
USE: person with a disability, people with disabilities

AVOID: physically challenged, intellectually challenged, retarded
USE: person with a disability, people with intellectual disabilities

AVOID: brain injured person, brain dead, "not right", "off a little", "not cooking on all burners"
USE: survivor of a brain injury, person with a brain injury, person who has sustained a brain injury

Glossary

Accessible: Buildings, structures, programs, transportation services, public services, etc. that are designed or modified to enable people with disabilities to use them without undue difficulty and that conform to Americans with Disabilities Act (ADA) requirements. Examples include ramps for entering and exiting buildings, TTY relay services for telephone use, lifts on public transportation, and documents in Braille, large print, CD, etc.

Accommodation: The removal of barriers or making special arrangements that allow full participation of persons with disabilities in all activities in keeping with the provisions of Section 504 of the Rehabilitation Act and the Americans with Disabilities Act.

Americans with Disabilities Act of 1990 (P.L. 101-336): Guarantees equal opportunity for individuals with disabilities in employment, public accommodation, transportation, state and local government services and telecommunications.

Attention Deficit Disorder (ADD): A diagnosis with symptoms that may include difficulty paying attention, being easily distracted and the inability to focus more than a few moments on mental tasks. (See attention deficit hyperactivity disorder.) Most people with ADD alone are not eligible for developmental disabilities services.

Attention Deficit Hyperactivity Disorder (ADHD): A diagnosis with symptoms that may include difficulty focusing attention and effort to tasks, difficulty in impulse control or delay of gratification and increased activity unrelated to the current task or situation.

Autism Spectrum Disorder (ASD): Disorders of communication and behavior. ASDs are brain dysfunctions that affect a person's ability to understand what he/she sees, hears, and otherwise senses.

Benefits (Financial): Any of a number of financial public assistance programs from federal, state or local sources that may be available to provide funding for eligible applicants who have intellectual disabilities. Some types of benefits are Supplemental Security Income, Social Security Disability Insurance, Medicaid, Community Alternatives Programs/ Mental Retardation, Community Alternatives Program/Disabled Adult, Specialized Nursing Facility, Intermediate Care Facility/ Mental Retardation, Special Assistance. See Benefits Section, page 17.

Brain Injury: Any level of injury to the brain often caused by an impact with the skull.

> **Acquired Brain Injury (ABI):** A brain injury that occurs after birth. It can be a result of an internal injury (e.g., tumor, stroke, aneurysm), an external injury (e.g., motor vehicle accident, fall, sports injury) or ingestion of a toxic substance. Traumatic Brain Injury (TBI) is a form of ABI.
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> **Congenital Brain Injury (CBI):** A brain injury that is present at birth and may be due to genetic or environmental occurrences.
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> **Traumatic Brain Injury (TBI):** A brain injury from externally inflicted trauma such as incidents involving motor vehicles, falls, acts of violence and sports injuries. TBI can range from mild (concussions) to severe, with outcomes ranging from a few symptoms to lifelong impairment.

Cognitive Disability: See Intellectual Disability.

Consumers: People with disabilities or parents/guardians of people with disabilities who may use or need services or supports. Other commonly used terms are “participants” and “clients.”
See Self-Advocates.

Developmental Disability (DD): North Carolina General Statute 122C-3(12a) defines a developmental disability as a severe, chronic disability of a person which is attributable to mental or physical impairment or combination of mental and physical impairments; is manifested before the person attains age 22, unless the disability is caused by traumatic head injury and is manifested after age 22; is likely to continue indefinitely; results in substantial functional limitations in three or more of the following areas of major life activity: (a) self-care, (b) reception (understanding) and expressive language, (c) learning, (d) mobility (ability to move), (e) self-direction (motivation), (f) the capacity for independent living, (g) economic self-sufficiency; reflects the person's need for a combination or sequence of special interdisciplinary services which are of a lifelong or extended duration and are individually planned and coordinated; or when applied to children from birth through four years of age, may be evidenced as developmental delay.

Down Syndrome: A genetic condition caused by a chromosomal abnormality resulting in some degree of intellectual disability and other developmental delays. Common physical features of Down syndrome include small stature, decreased muscle tone, flattened bridge of the nose and upward slant to the eyes.

Epilepsy: A physical condition that occurs when there is a sudden, abnormal electrical activity in the brain causing a person's consciousness, movement or actions to be altered for a short time. Epilepsy is also called a seizure disorder.

Group Home: A home that is licensed to provide 24-hour residential supports for people who have disabilities in exchange for compensation from state or private funds. Group homes differ in the numbers of people served and in the level of support provided to the persons receiving services. State law dictates how services will be provided and methods of accountability for service provision.

Guardian: A person or organization appointed by the court for the purpose of performing duties related to the care, custody, or control of an individual and which may include, but is not limited to, consenting for medical/surgical or treatment procedures and handling of business and legal affairs. In the case of a minor, it is a parent or someone standing in "loco parentis." See Guardianship Section, page 16.

Handicap: An outdated term referring to physical and social barriers that put people with disabilities at a disadvantage and hinder their ability to fully participate in the community. A person with a disability is not "handicapped" but may be limited by attitudinal, physical and other barriers that society fails to remove.

Independent Living: Independent living refers to achieving the ability to live in the home of one's choice in the community with some level of support that may or may not be reduced over time. It refers to learning skills that enable one to participate in activities of choice in one's community, to manage one's affairs, to have relationships and may include maintaining employment. It also refers to a program operated by Vocational Rehabilitation Services that provides funds to enable people with disabilities to live in their communities.

Independent Living Program: Assists individuals with significant disabilities in achieving independence by providing services that enable them to live and function in the homes and communities of their choice. Vocational Rehabilitation Counselors and program participants jointly develop a plan to provide a viable, cost-effective alternative to institutional living; may help maintain or improve employment opportunities; and may include independent living skills training, home and vehicle modification, peer counseling and advocacy, adaptive aids, prosthetics, consumer-managed personal assistance services, and recreational therapy.

Intellectual Disability: The presence of a sub-average general intellectual functioning associated with or resulting in impairments in adaptive behavior, including mental retardation, acquired brain injuries (stroke), traumatic brain injuries, Autism, and Alzheimers Disease. Intellectual disabilities are chemical or physical alterations within the brain that result in different thought processes.

Learning Disability (LD): A lifelong disorder that affects a person's ability to either interpret what he/she sees and hears or to link information from different parts of the brain. These limitations can appear in many ways—as specific difficulties with spoken and written language, coordination, self-control or attention. A person with a learning disability may have normal intelligence; however, there is a significant discrepancy in intelligence level and ability to learn and perform certain tasks.

Mental Retardation: Mental retardation is characterized by significant limitations in both intellectual functioning and social and practical adaptive skills. This disability originates before age 22.

Personal Assistant: A Personal Assistant is someone who assists a person with a disability in activities of daily living such as: bathing, dressing, mobility, transferring in and out of bed or wheelchair, toileting, eating, cooking, cleaning house, on-the-job personal support, handling money and planning daily activities.

Seizure: Sudden, uncontrollable spasm of muscles caused by excessive electrical activity in the brain. See Epilepsy.

Self-Advocate: An individual who speaks or acts for him/herself. This includes making choices and decisions about one's life. See Consumer.

Self-Determination: The right of people with disabilities to make choices about their own lives, to have the same rights and responsibilities as everyone else, and to speak and advocate for themselves.

Speech Impairment: Any of several speech problems that include articulation impairment (omissions, substitutions or distortions of sound), voice impairment (inappropriate pitch, loudness or voice quality) and fluency impairment (abnormal rate of speaking, speech interruptions and repetition of sounds, words, phrases or sentences) which interfere with effective communication.

Tourette Syndrome: An inherited neurological disorder characterized by sudden, involuntary, repetitive muscle movements and uncontrollable vocal sounds called tics which can include inappropriate words and phrases. A person with TS may touch other people excessively or repeat actions obsessively and unnecessarily.

Vocational Rehabilitation: An agency that provides counseling, training, education, medical, transportation, and other support services to persons with physical or mental disabilities in order to help them become independent or job-ready.

North Carolina Organizations: Grassroots, Advocacy, and Professional Organizations

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Alzheimer's Association– *is a nationwide network of chapters that offer frontline support to individuals affected by Alzheimer's with services that include 24/7 information and referral, safety services, and education and support groups. The Association has a 24-hour toll-free helpline- 800-888-6671 and website: www.Alz-NC.org*

Western Carolina Chapter
3800 Shamrock Drive
Charlotte, NC 28215-3220
704-532-7392 (phone)
704-532-5421 (fax)

Mountain Region Office
31 College Place, Suite D320
Asheville, NC 28801-2644
828-254-7363 (phone)
828-255-0948 (fax)

Triad Area Office
1315 Ashleybrook Lane
Winston-Salem, NC 27103
336-725-3085 (phone)
336-725-3081 (fax)

Foothills Area Office
260 First Avenue, NW Suite 218
Hickory, NC 28601-6161
828-267-7100 (phone)
828-267-0088 (fax)

Eastern North Carolina Chapter
400 Oberlin Road, Suite 220
Raleigh, NC 27605-1351
919-832-3732 (phone)
919-832-7989 (fax)

Wilmington Regional Office
714 Champ Davis Road
Wilmington, NC 28411
910-686-1944 (phone)
910-686-1945 (fax)

The Arc of North Carolina, Inc.– *is a statewide advocacy organization committed to securing for all people with mental retardation and other developmental disabilities the opportunity to choose and realize their goals of where and how they learn, live, work, and play. Local chapters exist in some communities. Call The Arc for further information.*

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919-782-4634 (fax)
www.arcnc.org

Association of Self-Advocates of North Carolina– *is a statewide advocacy organization made up of self-advocates and professionals interested in supporting self-advocacy for people with developmental disabilities.*

P.O. Box 17271
Raleigh, NC 27609
3801 Lake Boone Trail, Suite 260
Raleigh, NC 27607
919-420-7995 (phone)
919-420-7917 (fax)

Attention Deficit Disorder Association– *is a national organization that provides information, resources and networking to adults with AD/HD and to the professionals working with them.*

To identify an ADD group in your area, contact:
Attention Deficit Disorder Association (ADDA)
P.O. Box 543
Pottstown, PA 19464
484-945-2101 (phone)
www.add.org

Autism Society of North Carolina, Inc.– *is an organization committed to providing support and promoting opportunities which enhance the lives of individuals within the autism spectrum and their families.*

505 Oberlin Road, Suite 230
Raleigh, NC 27605-1345
919-743-0204 (phone)
800-442-2762 (toll-free, in NC)
919-743-0208 (fax)
www.autismsociety-nc.org

Brain Injury Association of NC, Inc.– *is an affiliate of the Brain Injury Association of America. The Association has Family and Community Support Centers in Raleigh, Greenville, and Charlotte and 29 local chapters and support groups across the state.*

Triangle Center
P.O. Box 748
Raleigh, NC 27601
919-833-9634 (phone)
800-377-1464 (toll-free helpline)
www.bianc.net

Central Piedmont Center at the Charlotte Institute of Rehabilitation
1100 Blythe Boulevard
Charlotte, NC 28203
704-355-1502 (phone)

Eastern Family and Community Support Center
202 East Arlington Boulevard, Suite T
Greenville, NC 27858
252-439-1900 (phone)

Carolina Legal Assistance– *is a private, non-profit corporation that offers legal representation to children and adults with mental illness and developmental disabilities.*

P.O. Box 2446
Raleigh, NC 27602-2466
919-856-2195 (phone)
919-856-2244 (fax)
www.cladisabilitylaw.org

Coalition for Persons Disabled by Mental Illness (CPDMI)– *is composed of state-wide, non-profit advocacy, consumer, family and provider organizations who advocate for adequate, quality public services for citizens of North Carolina with mental illness.*

1004 Dresser Court, Suite 106
Raleigh, NC 27609
919-872-1005 (phone)
www.cpdmi.org

Epilepsy Information Service– *responds to requests for information about epilepsy, the latest treatment options, and local support groups.*

Medical Center Blvd.
Winston-Salem, NC 27157-1078
336-716-2319 (phone)
800-642-0500 (toll-free)
www.bgsm.edu/neuro/epilepsy/information.htm

The Exceptional Children's Assistance Center– *is a Parent Training & Information Center committed to improving the lives of all children through a special emphasis on children with disabilities. Services are provided at no charge to parents and families.*

907 Barra Row, Suites 102/103
Davidson, NC 28036
704-892-1321 (phone/voice/TTD)
704-892-5028 (fax)
800-962-6817 (Parent Information Line)
www.ecac-parentcenter.org

Governor's Institute on Alcohol & Substance Abuse, Inc.– *is a private nonprofit organization that assists health professionals in addressing the health problems of substance use, misuse, abuse, and dependency in North Carolinians. Its mission is to promote the health and well-being of all North Carolina citizens by fostering improved education, research, and communication among health care professionals regarding the impact of, response to, and prevention of alcohol and other drug use.*

Governor's Institute on Alcohol & Substance Abuse, Inc.
Park Offices 200 - Suite 200
P.O. Box 13374
Research Triangle Park, NC 27709-3374
919-990-9559 (phone)
919-990-9518 (fax)
http://www.governorsinstitute.org

Mental Health Association in NC, Inc.– *is the state's largest private, non-profit mental health organization addressing advocacy, education and service. It promotes mental health and works to eliminate discrimination against people with mental disorders.*

3820 Bland Road
Raleigh, NC 27609
919-981-0740 (phone)
888-881-0740 (toll-free)
919-954-7238 (fax)
www.mha-nc.org

NAMI North Carolina– *seeks to improve the quality of life for individuals and their families living with the debilitating effects of severe and persistent mental illness, and to protect the dignity of people living with brain disorders through advocacy, education, and support. NAMI focuses specifically upon those mental illnesses that are brain disorders. These are serious illnesses that can affect a person's ability to think, feel and relate to other people and the environment.*

NAMI North Carolina
309 Millbrook Road, Ste 121
Raleigh, NC 27609
919-788-0801 (phone)
919-788-0906 (fax)
http://www.naminc

North Carolina Guardianship Association– *was founded in 1997 to train and support individuals who are court-appointed guardians for persons who lack the capacity to make sound personal and business decisions and who have no family members or friends to serve in that capacity.*

NCGA
PO Box 17673
Raleigh, NC 27619
919-266-9204 (phone)
919-266-9207 (fax)
http://www.nc-guardian.org

North Carolina Stroke Association– *is a chapter of the National Stroke Association. It offers regional resource connections and health care professional volunteer hospital visitation programs.*

407 South Hawthorne Road
P.O. Box 571002
Winston-Salem, NC 27157-1002
336-713-5052 (phone-main)
336-713-5053 (phone- Stroke Support & Education)
336-713-5051 (fax)
www.ncstroke.org

NC Mental Health Consumers Organization– *is not affiliated with NAMI NC. It has provided advocacy and support to adults with mental illness since 1989.*

PO Box 27042
Raleigh, NC 27611
919-832-2285 (phone)
919-828-6999 (fax)
800-326-3842 (toll-free)

North Carolina Departments and Agencies

Department of Juvenile Justice & Delinquency Prevention– *is the home of North Carolina's comprehensive juvenile justice system.*

410 South Salisbury Street
Raleigh, NC 27601
1801 Mail Service Center
Raleigh, NC 27699-1801
919-733-3388 (phone)
www.juvjus.state.nc.us

Governor's Advocacy Council for Persons with Disabilities– *is part of a nationwide system of protection and advocacy agencies committed to protecting civil rights and serving citizens with disabilities in North Carolina.*

2113 Cameron Street, Suite 218
1314 Mail Service Center
Raleigh, NC 27699-1344
919-733-9250 (phone)
800-821-6922 (voice)
888-268-5535 (TDD)
919-733-9173 (fax)
www.gacpd.com

NC Council on Developmental Disabilities– *part of a national network of organizations that assist people with developmental disabilities and their families; working to promote the "independence, productivity, integration and inclusion into the community."*

3801 Lake Boone Trail, Suite 250
Raleigh, NC 27607
919-420-7901 (phone)
800-357-6916 (voice, TDD)
919-420-7917 (fax)
www.nc-ddc.org

North Carolina Department of Health and Human Services

Division of Aging and Adult Services– *promotes independence and enhances the dignity of older and disabled persons and their families through a community-based system of opportunities, services, benefits, and protections; readies younger generations to enjoy their later years; and helps society and government plan and prepare for the changing demographics. Working with Area Agencies on Aging and more than 450 public and private local organizations, the Division of Aging supports a wide range of home and community-based services and works to ensure the rights and protections of older people for their social, health, and economic well-being.*

Division of Aging and Adult Services
2101 Mail Service Center
Raleigh, NC 27699-2101
919-733-3983 (phone)
919-733-0443 (fax)
www.dhhs.state.nc.us/aging

CareLine– *guides citizens through the human service system by providing information and referral and assists with problem resolution for concerns or complaints.*

2012 Mail Service Center
Raleigh, NC 27699-2012
919-733-4261 (phone)
800-662-7030 (Voice/Spanish)
877-452-2514 (toll-free)
919-733-4851 (TTY dedicated)
919-715-8174 (fax)
www.dhhs.state.nc.us/ocs

Division of Mental Health, Developmental Disabilities, and Substance Abuse Services (DMH/DD/SAS)– *provides people with or at risk for mental illness, developmental disabilities and substance abuse problems and their families the necessary prevention, intervention, treatment, services and supports they need to live successfully in communities of their choice.*

MH/DD/SAS
325 N. Salisbury Street
3001 Mail Service Center
Raleigh, NC 27699-3001
919-733-7011 (phone)
www.dhhs.state.nc.us/mhddsas

Division of Social Services– *assists and provides opportunities for individuals and families in need of basic economic support and services to become self-supporting and self-reliant.*

DSS
325 N. Salisbury Street
2401 Mail Service Center
Raleigh, NC 27699-2401
www.dhhs.state.nc.us/dss

Division of Vocational Rehabilitation Services– *provides counseling, training, education, medical, transportation, and other support services to persons with physical or mental disabilities in order to help them become independent or job-ready. Vocational rehabilitation counselors work with business and community agencies to help them prepare their worksites to accommodate employees who have physical or mental disabilities.*

Vocational Rehabilitation Services
2801 Mail Service Center
Raleigh, NC 27699-2801
919-855-3500 (phone)
919-733-7968 (fax)
www.dvr.dhhs.state.nc.us

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Partners in Justice 1-800-662-8706