

those of us dis **LABELED**

a guide to awareness and understanding

Brought to you by the Human Development Institute at the University of Kentucky,
the Kentucky Office of Vocational Rehabilitation and Kentucky AgrAbility

those of us **disLABELED**

Before you read this booklet, please take a second look at the title. In previous editions, people assumed that it's called *Those of Us Disabled*. But it's not. The last word is actually *DisLabeled*. The people who compiled and updated this information thought that this word might make you think about the label of disability and how that label is used. Sometimes we use labels as a way to help get access to something we need. We have labels on food to tell us all about the food we buy at the grocery store. We have labels on clothing to tell us how to care for a garment. Labels tell us everything we need to know. Right? Not when it comes to disability. Sometimes we only see the label that comes with a disability and we lose the person. We think the label of the disability tells us everything we need to know. But that is not the case.

Each person with a disability is first and foremost a person. Like everyone, a person who happens to have a disability has unique strengths and much to offer. This booklet will provide accurate information on some disabilities. Good information can help take away the mystery that accompanies the unknown. Knowledge leads to easier communication and the development of positive relationships.

There are many types of disabilities. This publication includes only a sample. Some disabilities, such as mild learning disabilities, epilepsy, and slight hearing impairments may be completely unnoticed. Other disabilities, like missing limbs, mobility impairments, and blindness are much more obvious. There are also temporary disabilities, such as broken bones, that go away or heal. Still other disabilities, both physical and mental, don't occur until later in life. Chances are good that you or someone you know has a disability.

How Do I Get From **Here** to **There**?

People with disabilities may require a variety of resources to obtain the services they need. Many people might not be aware of the agencies and organizations around the state available to provide guidance and help. The quest for information can seem long and complicated. The following guide shows some agencies and other sources that may be able to help.

Commission for Children with Special Health Care Needs (CCSHCN) – Provides medical, therapy, and equipment to children in Kentucky with physical disabilities.

Web site: <http://chfs.ky.gov/ccshcn/>

Phone: (800) 232-1160

Cabinet for Health and Family Services (CHFS) – Provides Medicaid benefits to eligible individuals which may be used to purchase durable medical equipment.

Web site: <http://chfs.ky.gov/>

Phone: (800) 372-2973

Department of Veterans Affairs – Provides medical care, disability benefits, vocational rehabilitation, and education and training.

Web site: <http://veterans.ky.gov> or www.va.gov

Phone: (502) 564-9203

Human Development Institute (HDI) – Kentucky's University Center for Excellence. HDI focuses its efforts on improving lifelong opportunities and services for individuals with disabilities, their families and the community. The Institute provides a strong foundation for more than 40 research, training and service projects.

Web site: www.ihdi.uky.edu

Phone: (859) 257-1714

Kentucky Assistive Technology Services (KATS) – The KATS Network Coordinating Center located in the McDowell Center in Louisville, in addition to four regional AT resource centers and two partner satellite centers around Kentucky. The mission of this collaborative system is to make assistive technology (AT) information, devices and services easily obtainable for people of any age and/or disability.

Web site: www.katsnet.org

Phone: 800-327-5287

Kentucky Commission on the Deaf & Hard of Hearing (KCDHH) – KCDHH provides information, referral and advocacy services and an interpreter referral service for state agencies.

Web site: <http://kcdhh.ky.gov>

Phone: (800) 372-2907

Kentucky Council on Developmental Disabilities – Mission to create change through visionary leadership and advocacy so that people have choices and control over their own lives.

Web site: <http://chfs.ky.gov/kcdd>

Phone: (877) 367-5332

Office for the Blind – Assists people with visual impairments and blindness in becoming members of the workforce.

Web site: <http://blind.ky.gov>

Phone: (877) 592-5463

Office of Vocational Rehabilitation – Assists people with physical and mental disabilities in entering the workforce.

Web site: <http://ovr.ky.gov>

Phone: (800) 372-7172

Social Security Administration – Eligible individuals can receive Medicare benefits.

Web site: www.ssa.gov

Phone: (800) 772-1213.



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Chapter One – Definitions

Intellectual Disabilities

Intellectual disabilities are characterized by significant limitations both in intellectual functioning and in adaptive behavior as expressed in conceptual, social, and practical adaptive skills. This disability originates before the age of 18. A complete and accurate understanding of intellectual disability involves realizing that it refers to a particular state of functioning that begins in childhood, has many dimensions, and is affected positively by individualized supports. People with intellectual disabilities may learn differently, and have many individual strengths and abilities. What can be most disabling about having an intellectual disability are low expectations of other people.

Whether you have an intellectual disability or not, it's always a good idea to plan ahead for your future. If you do happen to have an intellectual disability, planning can help make sure supports and services are there when needed. When planning takes place, consider what will be needed in each of the following areas and involve people who can help make it happen!

- independence
- relationships
- work or volunteering
- school
- living situation
- health
- recreation
- choices

For more information on services available in Kentucky for people who happened to have intellectual disabilities, contact the Kentucky Division of Mental Retardation at <http://dmhmrs.chr.state.ky.us>

Myths and Facts About Intellectual Disability

Myth: Intellectual disability is the same as mental illness.

Fact: Mental illness is a disorder in thinking, emotions, or behavior and can develop at any time during a person's life span. A person who has an intellectual disability has a developmental disability.

Myth: People with intellectual disabilities are all alike.

Fact: People with intellectual disabilities are as different from each other as any two other people are.

Myth: Most people with intellectual disabilities live in institutions.

Fact: Nationwide, less than 5 percent of people with intellectual disabilities live in institutions. Most people with intellectual disabilities live in their communities.

Cerebral Palsy

Cerebral palsy is a group of chronic conditions affecting body movement and muscle coordination. It is not progressive (does not get worse), though secondary conditions can co-exist and change through time. Though cerebral palsy cannot be “cured”, therapy and training can help a person improve his or her ability to function.

There are three general forms of cerebral palsy:

1. **Spastic:** includes stiff and jerky motions; this is the most common form of cerebral palsy. For example, a person may walk in a “scissored” fashion, which means that the person walks with one leg crossing ahead and then the other.
2. **Athetoid:** entails constant movements of the arms, legs, face and tongue that are random, involuntary, and uncontrolled. People with this type of cerebral palsy find it difficult to maintain purposeful motions.
3. **Ataxic:** is characterized by the inability to maintain normal balance. Problems with depth perception and speech are also associated with this form of cerebral palsy.

Less common forms of cerebral palsy are the following:

1. **Tremor:** is characterized by rhythmic shaking movements in one part of the body.
2. **Rigid:** is evidenced by extreme spasticity as muscles contract slowly and stiffly.

For more information on cerebral palsy, visit the United Cerebral Palsy Foundation at <http://www.ucp.org/> or call (800) 872-5827 TTY: (202) 776-0406.

Myths and Facts About Cerebral Palsy

Myth: All people with cerebral palsy have mental retardation

Fact: Only about half (50%) of those with cerebral palsy will also have mental retardation. Additionally, some individuals with CP have gifted levels of intelligence. Inaccurate diagnoses are sometimes made due to problems with communication.

Myth: People with cerebral palsy cannot understand what people say and cannot follow directions.

Fact: Even though people with cerebral palsy sometimes do not speak clearly, this does not mean that they cannot understand what is being said or intellectually follow directions. Many people with cerebral palsy are very intelligent.

Myth: A person can catch cerebral palsy.

Fact: Cerebral palsy is not contagious.

Epilepsy

Epilepsy, or seizure disorder, refers to a group of disorders of the central nervous system that cause recurring seizures. Epilepsy may develop from a wide variety of causes and a known cause is identified in only about one third of all newly diagnosed patients. Seizures result from an excessive electrical discharge in the brain. This discharge may be confined to one area of the brain (partial seizure) or may occur throughout the whole brain (generalized seizure). There are many different types of seizures and people may experience just one type or more than one. Experts divide seizures into generalized seizures and partial seizures.

1. **Generalized tonic clonic seizures:** (formerly grand mal seizures) are the most common and best known type of generalized seizure. These seizures begin with stiffening of the limbs (the tonic phase), followed by jerking of the limbs and face (clonic phase). During the tonic phase, breathing may decrease or cease altogether, producing cyanosis (blueing) of the lips, nail beds, and face. Breathing typically returns during the clonic (jerking) phase, but it may be irregular. Incontinence may occur as a result of the seizure. Contrary to popular belief, nothing should be placed in the mouth during the seizure; turning the patient on one side will help prevent choking and keep the airway clear. It usually lasts one to three minutes.
2. **Absence:** originally called petit mal, absence seizures are momentary losses of consciousness. The person may stop what he or she is doing, stare into space, drop something, or blink their eyes rapidly. These seizures last five to thirty seconds and may take place many times a day. Absence seizures are commonly associated with children between four and 14 years of age.
3. **Simple Partial:** People who have simple partial seizures do not lose consciousness during the seizure. Simple partial seizures are characterized by involuntary movements of one limb or sensory disturbances of one part of the body. Sometimes the person can talk normally to other people during the seizure, however, some people, although fully aware of what's going on, find they can't speak or move until the seizure is over.
4. **Complex Partial:** Complex partial seizures affect a larger area of the brain than simple partial seizures and they affect consciousness. The person might have tantrums, repetitive movements like lips smacking, picking at clothes, or rubbing hands or legs. These seizures can last a few minutes or several hours. During a complex partial seizure, a person cannot interact normally with other people, is not in control of his or her movements, speech or actions; doesn't know what he or she is doing; and cannot remember afterwards what happened during the seizure. *Note: Simple partial seizures may evolve into complex partial seizures; and a partial seizure may progress to a generalized seizure.
5. **Status Epilepticus:** these continue for long time without the person regaining consciousness and can be life-threatening.

For more information on epilepsy, visit the Epilepsy Foundation at <http://www.epilepsyfoundation.org/>

Myths and Facts about epilepsy/ seizure disorders

Myth: People with epilepsy cannot work.

Fact: Seizures can be controlled with medication in the majority of cases. People with epilepsy can be and usually are successfully employed.

Myth: You should put a hard object in the person's mouth during a seizure to keep the person from swallowing their tongue.

Fact: A person will not swallow the tongue. Do not put anything in their mouth!

Visual Impairments

There are more than 47,000 Kentuckians with visual impairments that affect their lives at work, at home, and in their communities. They include people your age, from your part of the state, with similar needs and questions. Visual disabilities range from partial to total loss of sight. A person is legally blind if he or she sees with the better eye at 20 feet or less what a person with “normal” vision sees at 200 feet (20/200 vision). A person who is legally blind may have some vision, or may have no vision at all. A person who is visually impaired has eyesight between 20/70 and 20/200. The assistance that a person with a visual impairment requires depends on the degree of sight loss and when the loss occurred.

A person who is visually impaired may use magnifying glasses, enlarged print, and other strategies. A person who is legally blind relies more on the other senses to perceive the world, but still can be completely independent. This person may use a cane or a service dog, also called a guide dog. It’s important to remember that guide dogs aren’t pets, but working animals that enable a person who is blind to get to work, go shopping, or go anywhere else that person chooses to go.

For more information about services available in Kentucky, you can contact the Kentucky Office for the Blind
Phone (Toll Free): (800) 321-6668 or (877) 592-5463
Phone: (502) 564-4754
TDD: (502) 564-2929
<http://blind.ky.gov/>

For more information on visual impairments, visit the American Foundation for the Blind: <http://www.afb.org/>

Myths and Facts About Visual Impairments

Myth: It is okay to pat a guide dog.

Fact: Guide dogs are working animals. Always ask first, and don’t be offended if the owner prefers you not to pat the guide dog. Patting a guide dog may distract the dog from work.

Myth: You shouldn’t say things like “see you later” to a person who is blind.

Fact: People who have visual impairments use these phrases as naturally as you do.

Myth: You should talk louder to people who are blind because they can’t see you.

Fact: The inability to see has nothing to do with hearing. Speak in a normal tone.

Myth: People who are blind develop a “sixth sense”.

Fact: Although most people who are blind develop their remaining senses more fully, they do not have a sixth sense.

Mobility Impairments

There are around 8 million Americans who have some kind of mobility impairment. This may mean the person uses adaptive equipment like a cane, crutches, walker, wheelchair or scooter. A person with a mobility impairment simply uses different ways to get around. Often times, assistive devices help him or her to overcome mobility obstacles. Mobility impairments may result from a number of different medical conditions, such as multiple sclerosis, cerebral palsy, spina bifida, diabetes, muscular dystrophy, or spinal cord injury. Temporary impairments, like broken legs, can also result in mobility impairments.

A spinal cord injury (SCI) usually results from an acute traumatic event to the spinal column and can result in a mobility impairment. Each year, 12,000 to 15,000 people sustain spinal cord injuries. Motor vehicle accidents account for nearly half of spinal cord injuries, followed by falls and violent injuries. Other causes of SCI are infection, multiple sclerosis, or tumors. Because different parts of the spinal cord are responsible for different body functions, the degree of loss of function depends on the level at which the injury occurs. Typically, as the point of injury to the spinal cord moves upward, the extent of body function loss increases. Spinal cord injuries can be classified as:

Paraplegia – affects two limbs

Tetraplegia – affects four limbs

A spinal cord injury can also be described as complete or incomplete.

Incomplete – some function remains below the level of injury

Complete – no function remains below the level of injury

Sometimes the spinal cord is only bruised or swollen after the initial injury. As the swelling goes down, the nerves may begin to work again. The longer there is no improvement, the less likely it is that there will be any improvement. Conversely, if an individual shows some sign of recovery, the likelihood of improvement increases, but there are no guarantees that more function will return. Some individuals have involuntary movements, such as twitching or shaking. These movements are called spasms. Spasms are not a sign of recovery. A spasm occurs when a wrong message from the nerve causes the muscle to move. The person often cannot control this movement. In addition to movement and feeling, a spinal cord injury affects other body functions. The lungs, bowel, and bladder may not work the same as before the injury. There may also be changes in sexual function. During rehabilitation, the rehabilitation team will help the person adjust and adapt to a new lifestyle. Goals of rehabilitation are to help the person become independent and prevent secondary conditions, like pressure ulcers, which may lead to significant medical issues.

For more information on spinal cord injury, contact The National Spinal Cord Injury Association at www.spinalcord.org or (310) 588-6959.

Here are some suggestions to remember when you meet someone who uses a wheelchair for the first time.

- Always ask the person if he or she would like assistance before your help. Your help may not be needed or wanted.
- Don't hang or lean on a person's wheelchair, which the person often considers part of their personal space. You probably would not lean on a person's shoulder, so do not lean on someone's wheelchair.
- Speak directly to the person in the wheelchair, not to someone nearby as though the person did not exist.
- Don't demean or patronize the person by patting him or her on the head.
- Don't discourage children from asking questions about the wheelchair. Open communication helps to overcome fearful and misleading attitudes.
- When a person using a wheelchair transfers out of the wheelchair to a chair, car, or bed, don't move the wheelchair out of reach, unless asked by the user of the wheelchair.
- It is acceptable to use expressions like "See you later. I've got to run." when speaking to a person who uses a wheelchair. These types of expressions are used figuratively as frequently as they are used literally.
- Be aware of the person's physical capabilities. Some people use wheelchairs to conserve energy and are able to walk.
- Don't classify someone who uses a wheelchair as sick. Wheelchairs are used for a variety of reasons by people who are considered quite healthy.
- Don't assume that using a wheelchair is a tragedy. A wheelchair provides freedom and independence to the person using it.
- Don't say a person is "confined" to a wheelchair or "wheelchair-bound" - the person's life may not be anymore "confined" than yours!

A good information source to learn more about mobility impairments is New Mobility magazine. You can visit the Web site at www.newmobility.com or call (888) 850-0344

Myths and Facts About Spinal Cord Injury

Myth: Women who have a spinal cord injury can never have children.

Fact: Wrong! A woman with an SCI still has the ability to become pregnant, sustain the pregnancy, and give birth.

Myth: There are as many women as men who sustain spinal cord injuries.

Fact: Nearly 80 percent of SCI occur among men.

Learning Disabilities

A learning disability is a very general term that describes specific learning problems. A learning disability can affect the way a person is able to understand or use certain skills. Learning disabilities can affect a person's skills in listening, speaking, reading, writing, reasoning, or doing math. People with learning disabilities aren't dumb. In fact, they typically have average or above average intelligence. It's just a matter of a person's brain processing information in a different way.

The term learning disability is used to cover a broad range of situations . Because there are so many ways that a learning disability can impact someone, it is vital to develop strategies to maximize successes that individuals with learning disabilities achieve. There is a great deal of overlapping between areas of learning. Therefore children with learning disabilities may show a combination of characteristics. Up to 20% of Americans have some kind of learning disability.

Learning disabilities are characterized by a significant difference in a person's achievement in some areas when compared to his or her overall intelligence. A student with a learning disability may show one or more of the following characteristics:

1. Difficulty in an academic area (reading, writing, written expression, spelling, math calculations, or math reasoning)
2. Memory or perception problems
3. Speech and language disorders

For more information, visit the National Dissemination Center for Children with Disabilities at <http://nichcy.org/resources/LD1.asp>

Myths and Facts About Learning Disabilities

Myth: Kids grow out of learning disabilities.

Fact: A learning disability can't be "cured". The key is finding strategies to enhance the person's learning style.

Myth: People with learning disabilities aren't as smart as other people.

Fact: People with learning disabilities have the same capability of intelligence as a person without a learning disability.

Myth: There is nothing you can do to make learning easier if you have a learning disability.

Fact: There are many strategies to enhance learning, depending upon the type of difficulties that are encountered. Examples include calculators, e-textbooks, extended time for testing, spell checkers, and structured environments. Above all, be flexible and creative to find solutions.

Autism

Autism is a disorder of the central nervous system, but the specific mechanism that causes autism is unknown. Someone who has autism can have difficulty identifying and expressing feelings, difficulty communicating and using language, and difficulty in establishing social relationships. Autism also is characterized by some form of repetitive and restricted stereotyped interest, ritual or other behavior. Autism is a behaviorally defined neurodevelopmental disorder that begins in early childhood. The primary way of determining if someone has autism is through observation of behavior.

Autism lasts throughout a person's lifetime, but for many children, symptoms of autism lessen with treatment and with age. There is no cure for autism, but early interventions can lead to good outcomes. Autism is considered a spectrum disorder because different children are affected to different degrees. Other disabilities on the spectrum include Autistic Disorder, Pervasive Developmental Disorder-Not otherwise specified, Asperger Syndrome, and Rett's Syndrome.

About 1 in every 1000 people in the United States has autism, and the number of children diagnosed with autism spectrum disorders appears to be increasing. Although there is a concern that the actual number of children with autism spectrum disorders is increasing, several factors, such as improvements in diagnostic methods and the view of autism spectrum disorders as being on a continuum, can account for the increase. As many as 1.5 million people in this country may have some form of autism. Autism affects all races, ethnic groups, and socioeconomic levels.

For more information, visit the National Dissemination Center for Children with Disabilities at <http://nichcy.org/resources/autism.asp>

Myths and Facts about Autism

Myth: Only boys have autism.

Fact: Autism is not limited to boys, but boys are 3-4 times more likely than girls to have autism.

Myth: There is nothing that can be done if you have autism.

Fact: There are a variety of therapies and behavioral interventions that have led to positive results for people with autism, including educational/behavioral interventions and appropriate medications.

Mental Illness

Mental illnesses may disrupt a person's thinking, feeling, mood, and ability to relate to others. A mental illness can make daily life difficult. Mental illnesses may affect one in four Americans in a given year. There are numerous types of mental illnesses. They range in severity from mild to disabling. Some examples are:

1. **Psychotic Disorders:** A group of diseases characterized by disturbance or bizarre thinking and behavior, extreme withdrawal, and hallucinations. Schizophrenia is a psychotic disorder.
2. **Mood and Anxiety Disorders:** This group of impairments can range from intermittently debilitating to severely handicapping. The major disorders include bipolar affective (manic-depressive), depression, obsessive-compulsive disorder, panic disorder, phobias, and post-traumatic stress disorder (PTSD).
3. **Organic Brain Disorders:** Illnesses such as brain tumors, hardening of the arteries, and injuries can cause mental illness. Types of organic mental disorders include delirium and intoxication syndromes.
4. **Personality Disorders:** These disorders are defined by long-term patterns of behavior and coping difficulties. There are 10 personality disorders which include paranoia, borderline, obsessive-compulsive, dependent, and antisocial.

Mental illnesses can be treated in a variety of ways. These can include counseling and medication to reduce symptoms. For more information on mental health issues, contact the Comprehensive Care Center in your area or the Kentucky Department for Mental Health and Mental Retardation.

For more information, visit the National Alliance on Mental Illness at <http://www.nami.org/>

Myths and Facts About Mental Illness

Myth: A person who has been mentally ill can never be normal.

Fact: Mental illness can be temporary. A previously well adjusted person may have an episode of illness lasting for weeks or months, and then may go for years-even a lifetime-without further difficulty. About 6 percent of people in the US live with a serious mental illness, but treatment options and supports can help the person to have a life of quality.

Myth: A person with mental illness can only work at low level jobs, if at all.

Fact: People who recover from a mental illness and return or enter the workforce, have career potentials that depend on their particular talents, abilities, and motivation, as well as their current state of physical and mental health – just like individuals without a history of mental illness.

Myth: No one I know has a mental illness.

Fact: Mental illness touches many lives. Since nearly 20 percent of the population has some form of mental illness at one point in their lives, you or a loved one will probably experience dealing with these issues.

Alzheimer's Disease

Alzheimer's Disease is a progressive disease of the brain that is characterized by a loss of mental abilities. It is estimated that now more than 5 million Americans have Alzheimer's. The majority of people who develop the disease do so after age 60, though a small proportion show signs in their 50's. Though there is no cure for Alzheimer's, there are treatments for the symptoms.

There are several different signs of early Alzheimer's disease. It's important to remember that most people experience forgetfulness or become disoriented; however, a person with Alzheimer's experiences forgetfulness and disorientation much more frequently and to a higher degree. Typically, others notice gradual changes in the individual with Alzheimer's. It usually takes some time to realize that something serious might be wrong.

Signs of Alzheimer's include:

- Difficulty performing familiar tasks, such as buttoning a shirt.
- Time and place disorientation, for example, feeling lost when standing across the street from home.
- Loss of judgment, for example, dressing inappropriately by wearing several shirts, or only one sock.
- Problems with abstract thinking, like forgetting what numbers are and how to use them.
- Misplacing things, for instance, putting a wallet in the refrigerator or laundry in the oven.
- Changes in mood, such as rapid mood changes, from calm to tears to rage, for no apparent reason.

For more information, visit the Alzheimer's Association at <http://www.alz.org/>

Myths and Facts About Alzheimer's Disease

Myth: People with Alzheimer's disease are always in nursing homes.

Fact: More than 70 percent of the people with Alzheimer's disease live at home.

Myth: If you forget people's names from time to time, you probably have Alzheimer's.

Fact: Everyone forgets now and then. You should only become concerned when memory loss is frequent and begins to affect tasks in your daily life.

Myth: Only very old people get Alzheimer's disease.

Fact: It's true that nearly half of the people 85 and older have Alzheimer's, but it can develop as early as the late 40's.

Hearing Impairments

There are over 21 million Americans with some degree of hearing impairment. A hearing impairment is a hearing loss that prevents a person from totally receiving sounds through the ear. If the loss is mild, the person has difficulty hearing faint or distant speech. A person with a hearing impairment may use a hearing aid to amplify sounds. If the hearing loss is severe, the person may not be able to distinguish any sounds. Types of hearing loss include:

1. **Conductive:** caused by diseases or obstructions in the outer or middle ear that usually affects all frequencies of hearing. Conductive losses are typically correctable with the help of a hearing aid.
2. **Sensorineural:** results from damage to the inner ear. This loss can range from mild to profound and often affects certain frequencies more than others. Sounds are often distorted, even with a hearing aid.
3. **Mixed:** combination of conductive and sensorineural hearing loss.

People with hearing impairment can communicate using numerous methods of communication such as American Sign Language (ASL), finger spelling, lip reading, written communication, and oral communication.

Do you know about Kentucky's Relay Service? Using this free service allows you to call anyone with a Telecommunication Device for the Deaf (TDD). Simply call (800) 800-6057 with any phone and give the operator the phone number of the person with the TDD you wish to contact. There are also web-captioning telephone services available.

To learn more about this and other resources, visit the Kentucky Commission on the Deaf and Hard of Hearing at <http://kcdhh.ky.gov/>

Myths and Facts About Hearing Impairments

Myth: All people who are deaf can read lips.

Fact: Some people who are deaf are very skilled lip readers, but many are not. Only about 30 percent of speech is visible on the lips because many speech sounds have identical mouth movements (example-p and b look exactly alike on the lips).

Myth: All people who are deaf are mute.

Fact: Some people who are deaf speak very clearly. Others choose not to speak using their mouth. Deafness usually has little effect on the vocal chords, and very few people who are deaf are mute. In fact, that word is not a very good one. Let's use ...very few people who are deaf cannot vocalize.

Myth: People who are deaf can't use the phone.

Fact: People who are deaf use telecommunication aids such as TDDs to use the phone. Consider cell phones too. Text messaging can be a very good way to communicate!

Chapter Two – Profiles

Tim Farmer

Tim Farmer is a life-long Kentuckian, and has been an outdoor lover since childhood. In 1984, a motorcycle accident left the Carter County outdoorsman without the use of his right arm. Thanks to a strong will and adaptability, Tim regained the capacity to continue doing the many things he loved. He learned to shoot a rifle cross-shouldered, tie fishing line with his mouth, and shoot a bow and arrow with his teeth (with bull's-eye accuracy).

In 1995, this resiliency led him to Kentucky Afield, a popular weekly outdoor sporting series on Kentucky Educational Television (KET). Farmer is host and executive producer of the series. Each week, he finds himself in the woods and on the water from Pikeville to Paducah.

Tim's disability, however, is hardly noticeable on screen. "It's not really a distraction at all," Farmer says. "It's simply how I and many Kentuckians must live our life, I'm just lucky to be in a position to share the joys of the outdoors with viewers around the state at the same time. Many have called me to ask how they can overcome physical barriers themselves to get back to enjoying the outdoors. For most, it wasn't as difficult as they thought. I felt like I'd made a real impact. It's hard to describe. Just in showing people that they still can do what they want to do."

Most viewers are familiar with the fact that Farmer participates in hunting and fishing activities one-handed. Though his show does not focus on Farmer's disability, viewers with various disabilities repeatedly call in to get information and advice on adaptive equipment. As is true for most everyone, fancy adaptations aren't needed to meet Farmer's needs.

For fishing pole modifications, he uses a fighting belt with attached PVC pipe in which the pole sits. A strap from the pipe around his neck adds stability for those hard fighting fish. Another working device Farmer uses is a bow that he pulls back with his teeth. How well can something like this really work? Well enough to rank Farmer 23rd in the world against non-disabled archers.

Farmer's attitude toward work and play closely mirrors his philosophy on life. "After the accident, I knew it was going to change my life forever. But I also knew that I would adapt and go on and that it would be okay. What are the other choices?"



Chastity Ross

Chastity Ross is was born in Richmond, Kentucky 30 years ago. Chastity was born with severe scoliosis. She was missing one arm and with one leg much shorter than the other. Chastity's significant physical limitations caused much concern regarding her attending public school. She was walking by school-age, but not very steadily. She was a very small person, so the concern was being run over by the other students, falling down steps, and all other potential for serious injury.

Chastity attended Model Laboratory School which is on the campus of Eastern Kentucky University from kindergarten to 12th grade. Then after graduation went to Eastern Kentucky University where she earned a Bachelor's Degree in special education and a non teaching minor in sign language.



Chastity still lives in Richmond, only now with her husband, newborn baby, and two foster children. She is a full time case manager for an agency that serves people with developmental disabilities.

What stands out in Chastity's mind as the starting point for her success is the people surrounding her during the time throughout her childhood spent in Shriners's Hospitals.

Chastity said, "Because people expected such great things of me that is what I thought I was supposed to do. I'm supposed to go to college, that's what people do. I believed from early on that I was supposed to get a degree and get a job because, because that was the language around me, and that's very important."

Chastity also stressed the importance of self-advocacy, and the difference it has made in her life. "I think sometimes people confuse advocacy with complaining or standing up and throwing a fit, and that's not what it is.

Being able to advocate for yourself can simply just be asking questions, such as what do I want and how can I get there? Then having the people around you to help you get there. It isn't always about picket signs and marching.

Advocating is about you standing up and saying hey this is what I need, and standing up doesn't mean you're yelling. Advocating for yourself is just saying hey, this is what I can do, where can I go, where I can use what I have, and use what I can do to better my life as an adult."

Shannon and Paula Caldwell

Shannon Caldwell and Paula Hester met in the fourth grade. They were both attending the Kentucky School for the Blind. Their friendship continued throughout their high school years, and in 1999 Paula and Shannon were married. Shannon was born blind and in the third grade discovered he had severe hearing loss in both ears. He grew up on a family farm in rural eastern Kentucky. Shannon says his mom instilled a work ethic in him and always expected him to complete his share of farm chores. “As I grew up I learned that it is respectable to be blind. There is no reason to be ashamed of who I am. Blindness is just a trait of me like my hair color. I learned things on that farm that no one can teach in a classroom. I know life is meant to be experienced.”

Shannon chose to pursue education in his life experience. “I graduated from the Kentucky School for the Blind in Louisville where I got a high school diploma, then went to Kentucky Community and Technical College System and graduated with highest honors with an Associate of Arts degree. From there I transferred to the University of Kentucky where I again graduated with highest honors with a Bachelor’s Degree in Social Work and a Minor in Sociology. Since then I have worked under contract in various roles with the Human Development Institute and have served on several boards and councils offering my advice as a person who is blind and hard of hearing to help improve quality of life for individuals who have disabilities. I also volunteer by giving motivational speaking engagements to educate the public about changing what it means to be blind.”



Paula grew up in Owensboro, Kentucky. She was born premature, and as a result of prolonged time in an incubator, Paula has never seen colors or objects. Paula also graduated with a Bachelor’s Degree in Social Work from the University of Kentucky. Paula found public school and college to be a instigator of independence in her life.

“There was not anyway to get around it. I was on my own. I had no other choice but to rely on my community resources and learn to use my assertive skills to advocate for help getting materials, transportation, and other daily needs.” Paula talks about her relationship with Shannon as a team effort. “We know what each other looks like, and we connected by our personality and common interests. We learn that together. We get lost and figure out what we did wrong. Just like when a sighted person gets lost driving. We are a couple working together who like to advocate people first.” Paula wants others to hear her message, “Blindness is nothing to be ashamed of. I like to let my community know I am a person who just happens to be blind. No blind person is the same, just as no person with any disability is the same. We are people first.”

Megan McCormick

Megan is the youngest of six children. Megan is currently enrolled in college classes, just as each of her brothers and sisters did before her. The only notable difference is that Megan has Down syndrome, a type of intellectual disability.



Megan and her family have been committed to her education from the beginning. She began in kindergarten in a regular curriculum, with additional private tutoring from Montessori teachers.

She also had occupational therapy, physical therapy, and speech therapy beginning at this early age. Megan's middle and high school years included two hours of daily private tutoring.

Accommodations such as notes from teachers, large font texts, and extra time to complete tests were provided, but Megan completed high school on time with the additional honor of having been a Governors Scholar all four years.

Megan's vocational goal is to be an occupational therapy assistant.

Since high school she has pursued experience in this field through her job with a local occupational therapy practice.

In addition to her job and academic pursuits, Megan has been very active in extra-curricular activities. These have included ballet, jazz, gymnastics, cheerleading, swimming and piano.

Megan says, "I hope I can show that with the necessary support services, people with cognitive disabilities can continue higher education. I know that I have a long way to go to make my dream come true, but I hope that someday I will be employed full time as a certified occupational therapy assistant."

Chapter Three – Etiquette

Etiquette for Appropriate Language Usage

Get into the habit of using “person first language.” Everyone has traits that they don’t think define them as a person. For instance, would you want to go through life as “Bad Hair Stephanie”, or “Gap-Tooth Jeff”? Similarly, referring to someone as “the disabled woman” or “the wheelchair-bound child” emphasizes the disability more than the person, and is very de-humanizing. This suggests to a person with a disability that you only see a disability and not a person. A person with a disability is not a victim, and should not be thought of as someone’s patient. Everyone experiences obstacles, regardless of whether or not they have a disability. It is the manner that a person chooses to live that tells what kind of person he or she is. Look beyond a person’s disability. Recognize that a disability is not a person’s whole identity, but only a part of the individual. A person with an impairment may not even consider it to be a disability. Don’t worry about using politically correct catch phrases to define disability, just concentrate on the person.

People with disabilities are contributing and productive members of the community and can be very healthy and physically fit. When you think about disabilities, remember disabilities and people are all different, only a few of which have been covered in this publication. You can’t always tell if a person has a disability, but by showing everyone the same kind of respect, you won’t run the risk of mistakenly assuming that some people are less able than others. Focus on abilities instead of limitations. Some simple things to remember when writing or talking about disability issues are listed below.

Good Phrases	Bad Phrases
SAY Person with a disability	NOT Disabled person
SAY People who are blind/visually impaired	NOT The Blind
SAY Person who has polio	NOT Victim of polio
SAY Person who has experienced. . .	NOT Crippled, invalid, pitiful, handicap
SAY Words that accurately describe the individual	NOT Judgmental stereotypes such as Courageous, brave, inspirational, heroic language-“superhuman”
SAY Person who uses a wheelchair	NOT Confined to; Wheelchair-bound
SAY Person who has seizures	NOT Has fits
SAY Words of acceptance and respect	NOT Words of sympathy or pity

People AREN'T Conditions. Is anyone really normal??

The 10 Commandments of Etiquette for Communication with People with Disabilities

1. Speak directly to the person with a disability, not through a companion or sign language interpreter who may be present.
2. Offer to shake hands when introduced. People with limited hand use or an artificial limb can usually shake hands and offering the left hand is an acceptable greeting. If they can't, they will let you know.
3. Always identify yourself and others who may be with you when meeting someone with a visual disability. When conversing in a group, remember to identify the person to whom you are speaking. When dining with a friend who has a visual disability, ask if you can describe what is on his or her plate.
4. If you offer assistance, wait until the offer is accepted. Then listen or ask for instructions.
5. Treat adults as adults. Address people with disabilities by their first names only when extending that same familiarity to all others. Never patronize people using wheelchairs by patting them on the head or shoulder.
6. Do not lean against or hang on someone's wheelchair. Bear in mind that people with disabilities treat their chairs as extensions of their bodies. And so do people with guide dogs and help dogs. Never distract a work animal from their job without the owner's permission.
7. Listen attentively when talking with people who have difficulty speaking and wait for them to finish. If necessary, ask short questions that require short answers, or a nod of the head. Never pretend to understand; instead repeat what you have understood and allow the person to respond.
8. Recognize that all people learn and understand in different ways. If someone is having difficulty understanding you, make your point in a different way. You might: rephrase, use examples, write it down, make abstract ideas more concrete, or break down an idea into smaller parts.
9. Tap a person who has a hearing disability on the shoulder or wave your hand to get his or her attention. Look directly at the person and speak clearly, slowly, and expressively to establish if the person can read your lips. If so, try to face the light source and keep hands, cigarettes and food away from your mouth when speaking. If a person is wearing a hearing aid, don't assume that they have the ability to discriminate your speaking voice. Never shout to a person. Just speak in a normal tone of voice.
10. Relax. Don't be embarrassed if you happen to use common expressions such as "See you later" or "Did you hear about this?" that seems to relate to a person's disability.



Disability Myths and Facts Sheet

Myth: People with disabilities lead totally different lives than people without disabilities.

Fact: More than 54 million people in the U.S. have physical or mental disabilities. They are just like everyone else: they work, they play, and they have families. When you meet a person with a disability, you may find you share similar interests.

Myth: People who don't have disabilities are insensitive about disabilities and the lives of people with disabilities.

Fact: Everyone will have some kind of disability some time in their lives. It is wrong to assume that all people without disabilities are insensitive about disability issues.

Myth: People with disabilities are happier with "their own kind".

Fact: Some people do believe this. For years, people with disabilities were seen together because they attended separate schools, and lived in separate homes outside of their community. But today, people with disabilities are no longer segregated by schools and communities.

Myth: People with disabilities have different goals from people without disabilities.

Fact: This is absolutely wrong! Disability permeates all segments of society. People with disabilities are all different, with different backgrounds. Everyone has different goals, regardless of who they are, with or without a disability.

Myth: All people with disabilities are handicapped and/or crippled.

Fact: The terms "disabled", "handicapped", and "crippled" are sometimes used interchangeably. In fact, the last two terms carry negative connotations, suggesting a person with a disability isn't a complete person. A disability does not always equate to handicap. It often means that a person with a disability may do the exact same things as someone else, just a little bit differently.

Myth: When all architectural barriers are removed, people with disabilities will be completely equal members of society.

Fact: The most important barriers to be erased are attitudinal. Putting in ramps and audible cross walks is easy compared to changing someone who believes a lot of the myths in this booklet. Until everyone realizes we are all equal, important, and worthy, people with disabilities will not be able to fully enjoy the same opportunities. Change begins with you.

Farming with a Disability

Kentucky AgrAbility has been serving rural Kentuckians with disabilities since 1993. The University of Kentucky Cooperative Extension Service has provided education and technical assistance to agriculture operators and farm families who face the challenges of a disability. Farm families may feel that an injury or disability may make it too difficult to continue farming activities. But with our help, they can. Kentucky AgrAbility provides expertise in developing new strategies or using new technologies to keep agricultural producers on the job and in the fields.



AgrAbility services include:

- Provide direct on-farm technical assistance, such as modifying tools, equipment, and machinery.
- Facilitate networking among farmers with disabilities to share ideas, experiences, and support.
- Help find financial support for assistive technology and farm equipment modifications.
- Network with national organizations that provide assistive technology for farmers with disabilities.
- Access and make recommendations to make homes and farm buildings more accessible.
- Refer individuals to appropriate agencies and organizations that best meets their needs.
- Train rural healthcare professionals and providers on Rehabilitation Technology in Agriculture.
- Participate in rural safety, injury prevention, and disability awareness and education programs.

For more information, visit the Web site at <http://ces.ca.uky.edu/agrability/>

You also can contact:

John Hancock, Project Director
Kentucky AgrAbility Project
University of Kentucky
N106F Ag Science North
Lexington KY 40546-2814
Phone: (800) 333-2814 or (859)257-1845
E-mail: jhancock@uky.edu

The Americans with Disabilities Act

The Americans with Disabilities Act (ADA) was signed into law in 1990. The ADA prohibits discrimination on the basis of disability in employment, programs and services provided by state and local governments, goods and services provided by private companies, and in commercial facilities. Giving people the rights they deserve, the ADA is a civil rights law for people with disabilities.

The ADA defines “disability” as follows:

1. A physical or mental impairment that substantially limits one or more of the major life activities of that person;
2. a record of such a physical or mental impairment; or
3. being regarded as having an impairment.

For more information, visit the following Web sites:

Kentucky ADA Coordinator – <http://ada.ky.gov/>

ADA Home Page – <http://www.ada.gov>

Job Accommodation Network – <http://www.jan.wvu.edu/>

Myths and Facts About The Americans With Disabilities Act

Myth: The ADA is rigid and requires businesses to spend lots of money to make their existing facilities accessible.

Fact: The ADA is based on common sense. It recognizes that altering existing structures is more costly than making new construction accessible. The law only requires that public accommodations (e.g. stores, banks, hotels and restaurants) remove architectural barriers in existing facilities when it is “readily achievable”. Inexpensive, easy steps to take include ramping one step; installing a bathroom grab bar; or painting new lines to create an accessible parking space.

Myth: Restaurants must provide menus in Braille.

Fact: Not true. Waiters can read the menu to a customer who is blind.

Myth: The ADA forces business and government to hire unqualified people because that person has a disability.

Fact: No unqualified job applicant or employee with a disability can claim employment discrimination under the ADA. Employees must meet all requirements of the job and be able to perform the essential job functions with or without reasonable accommodation.

Myth: Accommodating workers with disabilities is expensive.

Fact: Reasonable accommodation is usually far less expensive than many people think. In most cases, an appropriate reasonable accommodation can be made one time only and at little or no cost.



Universal Design - Accessibility for All Ages

The concept of universal design is to simplify life for everyone by making the environment usable by people of all ages, sizes, and abilities. This is particularly important as our population is changing. Many people are surviving permanently disabling injuries and illnesses, and even more are living longer. Universal design promotes creating living spaces that everyone can use. But it doesn't need to be expensive or complicated.

Universal design is a part of everyday living and is all around us. The "undo" command in most software products is a good example. Color-contrast dishes with steep sides that assist those with visual problems as well as those with dexterity problems are another. Additional examples include cabinets with pull-out shelves, kitchen counters at several heights to accommodate different tasks and postures and low-floor buses that kneel and are equipped with ramps rather than lifts. Can you think of others?

Here are some more examples we thought of:

- Smooth ground surfaces of entranceways, without stairs
- Wide interior doors and hallways
- Lever handles for opening doors rather than twisting knobs
- Light switches with large flat panels rather than small toggle switches
- Buttons on control panels that can be distinguished by touch
- Bright and appropriate lighting, particularly task lighting
- Auditory output redundant with information on visual displays
- Closed captioning on television networks

The Principles of Universal Design

1. Equitable use
2. Flexibility in use
3. Simple and intuitive
4. Perceptible information
5. Tolerance for error
6. Low physical effort
7. Size and space for approach and use

For more information, visit the Center for Universal Design at <http://www.design.ncsu.edu/cud/>

Protection and Advocacy

Protection and Advocacy (P&A) is an independent state agency that was designated by the Governor as the protection and advocacy agency for Kentucky. P&A's staff includes professional advocates and attorneys. We are advocates working together with people who have disabilities to promote and protect their legal rights.

Through our information and referral services, we try to answer questions about your rights under disability laws. People with disabilities have the right to family, social, and intimate relationships. They are financially secure, can make life choices, and have opportunities for satisfying work, recreation, spiritual lives, and community service.

If you or someone you know need assistance with pursuing these rights, contact P&A:

100 Fair Oaks Lane, Third Floor
Frankfort, KY 40601
Message line & TTY – (800) 372-2988 or (502) 564-2967
<http://www.kypa.net>

Office of Vocational Rehabilitation

The Office of Vocational Rehabilitation (OVR) is a state/federally funded program whose mission is to assist Kentuckians with disabilities to achieve suitable employment and independence. OVR assists eligible individuals with disabilities achieve their employment goals.

The office is represented across all 120 counties of Kentucky. The agencies philosophy is the recognition and respect of the contributions of all individuals as a necessary and vital part of a productive society.

For more information, contact:

Office of Vocational Rehabilitation
209 St. Clair
Frankfort, KY 40601
Phone: (502) 564-4440 or (800) 372-7172
TTY: 888-420-9874
www.ovr.ky.gov

You CAN Make a Difference



So what can you do to help eliminate barriers that people with disabilities experience? Maybe more than you think!

1. Encourage the participation of people with disabilities in community activities by making sure that meeting and event sites are accessible.
2. Understand children's curiosity about disabilities and people who have them.
3. Speak up when negative words or phrases are used in connection with disability. Refer to etiquette for appropriate language starting on page 17.
4. Accept people with disabilities as individuals with the same needs and feelings you have. Your mother was right when she told you to treat people the way you want to be treated.
5. Understand the reason for accessible parking and leave it for those who need it.
6. Hire qualified people with disabilities.



UNIVERSITY OF KENTUCKY

Human Development Institute

University Center for Excellence in Developmental Disabilities