

GENERAL ETIQUETTE

For

Interacting with People with Disabilities

If you are interacting with people with disabilities for the first time: BE YOURSELF !

As in any new situation, everyone will feel more comfortable if you relax.

Tips on Conversation:

1. Talk with the person with a disability, not their spouse, assistant, interpreter, or others nearby. Maintain the eye contact and body language you would normally use during any other conversation.
2. An important thing to remember in any conversation with someone who has a disability is: “assume nothing.” If you have a question about what to do, what language or terminology to use, or what assistance — if any — they might need, the person with the disability should be your first and best resource. Do not be afraid to ask their advice.
3. Be patient — not only with the person with the disability, but with yourself. Frustration may come from both sides of the conversation, and needs to be understood and dealt with by both parties.
4. The most important thing to focus on during a conversation with a person who has a disability is the overall goal. It is simply communication between two individuals. Ultimately, it is what is communicated — not how it is communicated — that will be important.

SPECIFIC DISABILITIES

The following summary of the characteristics of different types of disabilities contains many true statements, but no absolute truths: *Remember that every person with a disability is an individual.*

While this summary is about disabilities, it is important to remember that you are not interacting with disabilities; you are interacting with *individuals* with disabilities. Remember also that they are people first.

It is most important to ask the individual what terminology they prefer, or if they need assistance. With this in mind, the following general guidelines are offered.

BLIND OR VISUALLY IMPAIRED

Things to Know:

1. Most persons who are blind have some sight, rather than no sight at all.
2. Many people who are blind are mobile and independent. Some people who are blind view blindness not as a disability as much as an inconvenience.
3. While many people who are blind can use Braille, the majority of persons who are blind do not.

Things to Do:

1. Introduce yourself. Identify who you are and what your job or role is. Give the person verbal information that is visually obvious to those who can see. If you have met before, remind them of the context; they won't have the visual cues to jog their memory.
2. Be descriptive when giving directions. Saying "over there" has little meaning to someone who cannot see you point. "Four doors after turning right from the elevator" would be much more helpful.
3. Always ask someone if they need your assistance and how you can assist them. Lead someone who is blind only after they have accepted your offer to do so. Allow them to hold your arm, rather than you holding them. It is important to let people with vision impairments control their own movements.
4. Many techniques are used as tools for independence, but individuals with disabilities use only things that work for them. Remember to describe sights or objects from their perspective, not yours. Tell them when you have brought new items into their environment, describing what they are and, most importantly, where you have put them.

Things to Avoid:

1. Do not move items (furniture, personal items) after their position has been learned by the person. This can be frustrating and, in some cases, dangerous for the person with a disability.

2. Do not use references that are visually oriented like, “over there near the green plant.”
3. Do not interact with a service dog while it is working (in harness).

Things to Consider:

1. Persons who are blind have more often been told what to do rather than asked what they would prefer doing. This attitude is not acceptable towards any person.

DEAF AND/OR HEARING IMPAIRED

Things to Know:

1. Most persons who are deaf or hearing impaired have some hearing, rather than no hearing at all.
2. Sign language is not another form of English; it is an official language with its own grammar, contexts and rules. Not all persons who are deaf use sign language.
3. Lip-reading, while helpful without sound clues, is only 30% - 50% effective, and sometimes less. Not all persons who are deaf lip-read.
4. Long conversations with persons who can lip-read can be very fatiguing to the person who has the disability.
5. Not all persons who are deaf write and read.
6. Not all persons who are deaf speak.

Things to Do:

1. Find out how the person communicates best.
2. If the person uses an interpreter, address the person, not the interpreter.
3. If the person reads lips, speak in a normal, not exaggerated, way. Short simple sentences are best.
4. If the person lip-reads, avoid blocking their view of your face. Make sure the lighting is good.
5. Gain the person’s attention before starting a conversation.

6. If there is some doubt in your mind whether you were understood, rephrase your statement and assure that understanding has been reached.
7. Be aware of situations where a person may be waiting for a service (transportation, a table, the start of an activity) where the common way to communicate is an announcement or the calling of the person's name. Advise them when their name is called. Make sure you take notes when someone cannot hear you, and develop an alternative method of notifying them.

Things to Avoid:

1. Do not become impatient or exasperated with the person if it takes longer to communicate.
2. Make sure there are no physical barriers between you and the person you are in conversation with.
3. If the person is using hearing aids, avoid conversations in large, open and noisy surroundings.

Things to Consider:

1. Persons who may deal very well one-on-one in communication may have a hard time with two or more speakers, especially if there are many interruptions and interjections.
2. Showing impatience to someone who is deaf or hearing impaired may cause the less assertive person to back off from telling you of his or her needs.
3. When someone asks, "What did you say?" the answers, "Never mind," "Nothing," or "It's not important," are very common replies. These are insulting and demeaning because they communicate that the person is not worth repeating yourself for.

PEOPLE WHO USE WHEELCHAIRS OR OTHER MOBILITY DEVICES

Things to Know:

1. There are many reasons (not just being paralyzed) which might require someone to use a wheelchair. These might include loss of stamina or equilibrium, or a temporary condition like a fracture or recovery from surgery.

2. There are a wide range of physical capabilities among people who use wheelchairs. This means that persons who use them may require different degrees of assistance, or no assistance at all.
3. Some persons do not use wheelchairs exclusively, but may also use canes, leg braces and, in some cases, no assistive devices at all—or only for short periods.
4. All wheelchairs are not the same. Different sizes and shapes meet different needs. Some wheelchairs move manually and others are motorized. Just because one person can access an area in his or her wheelchair does not mean that everyone with a wheelchair may be able to do so.

Things to Do:

1. If you are asked to fold, carry or store a wheelchair, treat it with the same respect that you would if you were holding someone's eyeglasses. They are similar in many ways. Wheelchairs can break, they are difficult to have repaired on short notice and on weekends, and it is extremely disruptive to the user when they are out of commission.
2. When you meet someone seated in a wheelchair, extend your hand to shake if that is what you normally do. A person who cannot shake hands will let you know. They will appreciate being treated in a normal way.
3. When speaking to someone who uses a wheelchair, remember to give the person a comfortable viewing angle of yourself. Having to look straight up is not a comfortable viewing angle.

Things to Avoid:

1. Do not approach someone who is using a wheelchair and start pushing him or her without asking.
2. When communicating, do not stand too close to the person in a wheelchair. Give him or her some space.

Things to Consider:

1. It is a very common experience for persons who use wheelchairs to be told that some place is accessible when it is not. Listen carefully when anyone who uses a wheelchair tells you that some area which you thought was accessible is not.
2. Do not assume that the person using a wheelchair needs assistance. Ask the person if there is anything special you can provide.

CONDITIONS WHICH CAUSE DIFFICULTY WITH SPEECH

Things to Know:

1. There are many reasons for having difficulty with speech. Deafness, cerebral palsy, stroke, head injury, physical malformation of speech mechanisms, and general speech impairment are just a few.
2. It is not unusual in stressful situations for someone's speech to become harder to understand.

Things to Do:

1. If you do not understand what a person is saying, bring it to his or her attention immediately and ask how the two of you may communicate more effectively.
2. If it is a stressful situation, try to stay calm. If you are in a public area with many distractions, consider moving to a quiet or private location.
3. Consider writing as an alternative means of communication.
4. If there is no solution to the communication problem that can be worked out between you and the person, consider asking if there is a person who could translate or interpret what he or she is saying.

Things to Avoid:

1. Do not pretend to understand when you really do not.
2. Do not become exasperated or impatient with the communication process.
3. Do not finish sentences for the person with a disability.

Things to Consider:

1. Many persons with difficulty speaking find themselves in situations where people treat them as if they are drunk, developmentally disabled or mentally ill. They are accustomed to being avoided, ignored, or even hung up on by phone.
2. Accessibility for persons with difficulty in speech lies within your power. Your patience and communication skills are as important to someone with speech that is

difficult to understand as a grab bar or a ramp is to someone who uses a wheelchair.

DEVELOPMENTAL DISABILITIES

Things to Know:

1. Developmental Disability refers to conditions occurring before adulthood which sometimes result in below average intelligence, impaired motor functioning, cerebral palsy, autism or other disabling conditions.
2. A low intelligence test score alone does not necessarily indicate that a person is developmentally disabled.
3. What is seen by most people is behavior reflecting slow, arrested, or incomplete development before a person reaches the age of eighteen.
4. It is important to remember that, even though someone is an adult, there are certain characteristics which are described as childish or childlike, leading to the erroneous conclusion that a person has a "mental age of 4 or 5". A person who is 30 years old with a mental age of five has had 25 more years of life experience upon which to base his or her behavior.
5. Because each person with a developmental disability is an individual, there is no "overall" description one can give to alert that a person is developmentally disabled. Every person with a developmental disability will display characteristics differently, with varying levels of intensity.
6. Not all people with developmental disabilities look disabled, nor will they act in the same way when making contact with people.

Things to Do:

1. A calm, patient attitude on your part will prove to be your most effective tool.
2. Be aware that a "yes" response may be inappropriately given out of fear of disapproval or in an attempt to please.
3. If a person with a developmental disability is lost, be aware that residents of Board and Care homes may have their names printed on their clothes, collar or similar location.

Things to Avoid:

1. People with developmental disabilities may not have any speech, or may have very limited speech. Avoid frightening a person with developmental disabilities, as they may be unable to respond because of fear. They may, however, respond to questions, especially those requiring a “yes” or “no” answer.

Things to Consider:

1. Medication may slow their speech or reactions, or cause them to walk in a manner which arouses suspicion.

CEREBRAL PALSY

Things to Know:

1. Cerebral palsy is a condition that results from damage to the central nervous system before birth, or early in life.
2. “Cerebral” refers to the brain and “Palsy” to a disorder of movement or posture.
3. It is neither progressive nor communicable, and has little or no relation to intelligence.
4. Cerebral Palsy is characterized by an inability to fully control motor functions. A person with Cerebral Palsy may have spasms; involuntary movement; disturbance of gait or mobility; seizures; abnormal sensation and perception; impairment of sight, hearing, or speech; and mental retardation.

Things to Do:

1. To the uneducated observer, a person with Cerebral Palsy may be thought to be ill or drugged. Your experience with others who are under the influence of a variety of drugs could help you to determine the difference.

Things to Avoid:

1. Do not make assumptions about the intelligence of persons with Cerebral Palsy.

Things to Consider:

1. Over a half million people in the United States have Cerebral Palsy. Many are wheelchair users and you may refer to the previous section concerning wheelchairs for additional information.

EPILEPSY

Things to Know:

1. Epilepsy is a symptom of a disorder of the central nervous system occurring either as a result of head trauma or as a condition present from birth, which may result in seizures.
2. Epilepsy is not a disease, nor is it progressive, related to intelligence, or necessarily related to another disability.
3. One person in a hundred has epilepsy; however, 80% of those diagnosed will have good control of seizures through medication.
4. There are three seizure patterns:
 - The Grand Mal convulsion consists of a loss of consciousness, stiffening, muscle rigidity and spasms.
 - The Petit Mal seizure may not be readily recognized, as it usually consists of a lapse of from 5 - 25 seconds and gives the appearance of daydreaming or staring.
 - The Psychomotor seizure may be seen only as staring or confusion, dizziness or fear, or other behavior such as lip smacking or erratic arm movements.

Things to Do:

1. At the scene of a seizure, your best action would be to keep the person from getting injured by removing objects from the area which might cause injury (chairs, tables, etc.).
2. If the person is still unconscious after a seizure, turn him or her on their side, with the face downward.

Things to Avoid:

1. Do not restrain the movements of a person having a seizure.
2. Do not put anything between the teeth.

3. Do not give the person anything to drink.

Things to Consider:

1. Medical aid for epilepsy is usually not necessary unless a seizure lasts longer than 15 minutes.
2. The person may not remember what has happened, and may require your assistance for a short period of time while getting reoriented.
3. Seizures usually draw a crowd of onlookers. This is an excellent opportunity to set an example for others by your conduct, and educate the uninformed as to successful intervention techniques.

AUTISM

Things to Know:

1. Autism is a severely incapacitating lifelong developmental disability that appears during the first three years of life.
2. In it's broad definition, autism or autistic-like symptoms occur in about five out of every thousand children.
3. Autism is four times more common in males than in females, and is found throughout the world in families of all racial, ethnic and social backgrounds.
4. Symptoms of autism include:
 - Slow development, or lack of physical, social and learning skills.
 - Immature rhythm of speech and limited understanding or use of words.
 - Abnormal responses to sensations: sight, hearing, touch, pain, balance, smell, taste, etc.
 - Abnormal ways of relating to people, objects and events.

Things to Do:

1. Quite often, when you come into contact with people with autism, they will be in their neighborhood or where family or friends are near.

2. There are no hard and fast rules for dealing with people who have autism.
3. Be aware of the symptoms of autism.
4. A calm, persistent approach should work best.

Things to Avoid:

1. Resist the natural tendency to counter aggression or non-compliance with physical control, since merely touching someone with autism might cause them to flee.
2. Attempting to confine a person who is autistic might cause great fear and resistance.

Things to Consider:

1. Autism is perhaps the most challenging disability with which to cope.
2. At first glance, the actions of persons with autism may seem to be hostile, antagonistic, bizarre or drug-induced.
3. People with autism sometimes feel pain when others would not, and at other times feel no pain.
4. Your attention may be drawn to people who are autistic by their “odd” behavior.
5. People with autism may show a fascination with something inanimate (especially wheels or circular objects), walk into traffic without looking, or be engaged in other aggressive or self-injurious behavior.

PSYCHIATRIC DISABILITIES AND NEUROLOGICAL DISORDERS (ALZHEIMER’S DISEASE, MENTAL ILLNESS, TRAUMATIC BRAIN INJURIES)

Disabilities which do not manifest themselves with physical symptoms can present unexpected complications when interacting with anyone you do not know. What might be considered a “normal” conversation could change without warning or apparent cause.

The onset of the broad group of disabilities which affect the brain can be from a variety of causes: injury, illness, age, drug abuse, trauma or for no apparent reason. In some cases, the person with a disability may exhibit no symptoms most of the time; even

medical professionals can have difficulty identifying the full extent of the mental disability, or its causes.

Things to Know:

1. Alzheimer's Disease normally affects people who are older. Childlike characteristics or symptoms may suddenly appear, and memory loss is the most common sign that Alzheimer's Disease is present. People who have Alzheimer's Disease often wander away from their residences, and may have very plausible explanations of where they think they are going.
2. Mental Illness covers a broad range of psychiatric disabilities: schizophrenia, manic depression, severe depression, and most anxiety disorders. Some of these mental illnesses can be treated with medicine but, because they do not recognize that they are ill, people who have mental illness frequently stop taking their medication.
3. Traumatic Brain Injury (TBI), or head injuries, can occur in accidents which sometimes appear minor. A person with a TBI may not recognize that their characteristics or actions change when the injury's symptoms are manifested. Even if there are normally no signs of a TBI present, a sudden change in speech pattern or volume, a burst of anger, or an indecipherable sentence could be an indication that a head injury has occurred.

Things to Do:

1. Mental disabilities can be so varied that there are no easy rules for dealing with the symptoms they cause.
2. Be alert for unusual characteristics, actions or phrases; if they present, assume that there may be some type of disability present.
3. A calm, friendly approach works best while interacting with anyone.

Things to Avoid:

1. Resist the natural tendency to counter aggression or non-compliance with physical control, since merely touching someone with a mental disability might cause them to flee or react violently.
2. Tones of voice, actions, or appearance which are threatening to a person with a mental disability could trigger an unexpected or unwanted reaction.

Things to Consider:

Neurological disorders and the broad range of mental illnesses present challenges for medical professionals, family members, friends, and the people affected by the disabilities. Your interactions and conversations with people who have such disabilities may be frustrating or unnerving at times. By remaining calm, friendly and helpful you should be able to attain your objective despite the complications which are involved.

HIDDEN DISABILITIES

Not all disabilities are apparent. A person may have trouble following a conversation, may not respond when you call or wave to them, may make a request that seems strange to you, or may say or do something that seems inappropriate. The person may have a hidden disability, such as low vision, a hearing impairment, a learning disability, traumatic brain injury, mental retardation, or mental illness.

Don't make assumptions about the person or their disability. Be open-minded.

LEARNING MORE

Lack of knowledge or misinformation may lead you to shy away from interacting with persons with certain disabilities. Preconceptions about mental illness, AIDS, cerebral palsy, Tourette Syndrome, Alzheimer's Disease and other disabilities often lead to a lack of acceptance by those around the person.

Remember that we are all complex human beings; a disability is just one aspect of a person. Learning more about the disability may alleviate your fears, and can pave the way for you to see the person for who they really are. Keep practicing, and enjoy the experience.

LANGUAGE TIPS

There are some general hints which can help make your communication and interactions with people with all types of disabilities more successful:

1. The preferred terminology is "*disability*" or *disabled*, not "*handicap*" or "*handicapped*." Never use terms such as "*retarded, dumb, psycho, moron*" or "*crippled*"; they are very demeaning and disrespectful to people with disabilities.
2. Remember to put *people first*. It is proper to say "*person with a disability*", rather than "*disabled person*."

3. If you are unfamiliar with someone, or their disability, it is better to wait until they describe their situation to you than to make your own assumptions about them. Many types of disabilities have similar characteristics, and your assumptions may be wrong.

Repeated Reminders — Tips on Conversation:

1. Talk with the person with a disability, not their spouse, assistant, interpreter, or others nearby. Maintain the same eye contact, tone of voice and body language you would normally use during any other conversation.
2. An important thing to remember in any conversation with someone who has a disability is: “assume nothing.” If you have a question about what to do, what language or terminology to use, or what assistance — if any — they might need, the person with the disability should be your first and best resource. Do not be afraid to ask their advice.
3. Unless you know that you are speaking with someone who has a cognitive or hearing disability, use your normal speaking speed. It is always a good idea to speak clearly, without mumbling or slurring words.
4. Don’t be overly friendly, paternalistic, or condescending when speaking to a person with a disability. Most people, even if they are unable to speak to you in a “normal” manner, have normal or above-average intelligence. Your use of abnormal speech or simplistic language will lessen the chances of having a successful conversation.
5. Be patient — not only with the person with the disability, but with yourself. Frustration may come from both sides of the conversation, and needs to be understood and dealt with by both parties.

Once again, the most important thing to focus on during a conversation with a person who has a disability is the overall goal. ***It is simply communication between two individuals.*** Since about 20% of people in our society have some type of disability, you never really know when that will be a factor in one of your conversations.