

Why a Guide?

The language we use—and how we use it—makes a difference in the way we describe people with physical or cognitive disabilities and how we relate to them.

It is not a question of political correctness to say that some words, phrases and images are simply inappropriate. Conversely, other words describe people and situations succinctly and accurately.

The guide focuses mainly on language but also on images and certain actions you may take while communicating. You may be a family member or friend, a health care professional, a prospective employer, a front-line retail employee or a journalist. Whatever the situation, this guide looks at specific words and actions, examines perceptions and offers straightforward advice you can use.

In the same way that there is no manual covering every detail and possibility for everyday discourse, this is not a comprehensive guide. The best advice is always to use common sense and patience and to treat everyone as an equal.

What is a disability?

"The adjective is the banana peel of the parts of speech."

Clifton Fadiman

About 3.5 million Canadians have physical disabilities of one type or another. That constitutes about 12 percent of our population – a significant group by any standard.

But what is a disability? There are many definitions, and agreeing on one is almost impossible. One problem is that we tend to confuse disability (which is a condition of the person) with barriers presented by the built environment, availability of services, or societal prejudices.

Defining what disabled means also seems to change as time passes and as society becomes more attuned to people with disabilities and their needs.

A world of abilities and disabilities

We do know this much: Our world of abilities and disabilities includes people from all societies and walks of life, regardless of ethnicity or nationality. People with disabilities are as universal as the ability to show compassion *and* as the tendency towards insensitivity.

A physical disability may result from a spinal cord trauma or another injury and, indeed, issues surrounding mobility and function are most commonly seen as the defining characteristics of a disability. However, many people acquired a physical disability through a disease or a neuro-muscular condition. Other people have communication, visual or hearing disabilities, which do not necessarily fall under the physical disability definition.

Acquired brain injury (ABI) is an area of disability that sometimes involves physical issues but often does not. The area of affected brain function is perhaps the most difficult to define and tends to lead to the most misunderstandings during interaction.

People with physical differences, such as facial disfigurement, are also very common. Again, defining this form of disability can be tricky, but it usually has to do with how one person's physical appearance begins to alter another person's perception of that individual. And, once again, many people with physical differences would not describe themselves as having a disability.

There are many other conditions and situations that would constitute a disability, too many to list here.

What does all this add up to? We know that in many countries – certainly in Canada – tremendous progress has been made in ensuring that people with disabilities have every opportunity to be full and contributing members of society. The success of any and all these efforts comes down to sensitivity: The ability of one group of people to understand the desire of another to lead fulfilling lives. The next step is finding the will and resources to turn those sensitivities into actions.

However, the process is not always a matter of providing bricks and mortar – curb cuts, accessible housing, specialized tools and equipment, or the proper rehabilitation and treatment facilities — it is also a matter of education, awareness, and establishing comfort levels. A practical response to the needs of people with disabilities always follows the realization that their issues need to be addressed as a matter of fairness.

We believe improving the way we interact with and describe people with disabilities is crucial. All it takes is a few adjustments, a little patience, and a modicum of understanding, and anyone can interact comfortably with a person with a disability.

The goal is not bridging the "normal world" and the "disabled world" but creating one world that includes people with disabilities, and those without.

Describing

"Words should be weighed, not counted."

Yiddish Proverb

Often, the words you use to describe people with disabilities may seem innocuous. In fact, these days, there is even a bit of a backlash in regard to words and political correctness: "Why shouldn't I say 'handicapped' for goodness sake? Why is everyone so sensitive?" But, the wrong words can be hurtful, even if they seem innocuous.

The best rule of thumb to keep in mind is "people, not adjectives." Here are some distinctions.

- **The disabled • people with disabilities.** There is no such group as "the disabled," only people with disabilities. To use the word "disabled" is a label and a stereotype because a person's disability may affect only one aspect of his or her life. Try telling a wheelchair basketball player that she is disabled. A person may feel extremely able, just unable to walk.
- **Handicap • disability.** A disability is a personal functional limitation. A handicap is an environmental or attitudinal barrier. For example, a wheelchair user is handicapped by stairs but if an elevator or a ramp is available, there is no handicap. The word handicap refers back to the days when people with disabilities were forced to beg – cap in hand – to survive.
- **Disease, illness • disability.** Not everyone who has a disability is ill or has a disease. For example, a person with cerebral palsy does not have a disease. Rather, he or she has a condition. On the other

hand, a person with ALS does have a degenerative disease. A quadriplegic individual is not ill...unless he happens to have the flu!

- **Blind • visually impaired.** A person who has no sight whatsoever is, technically, blind and the term is acceptable. However, many people who have some sight are "legally blind" and are best described as "visually-impaired," "vision-impaired" or having a "vision or visual disability." These terms are general enough to cover all degrees of visual impairment.
- **Deaf, hard-of-hearing, hearing-impaired.** Any of these words and terms is acceptable. Like people who are visually impaired, there are many degrees of hearing impairment and you should be precise in your description. Deaf usually implies a total loss of hearing.
- **Old words and new words.** Some words used to be acceptable but are inappropriate these days. Words such as "crippled," "victim," "invalid," and "afflicted" are value judgments. They are also labels. You may see a person with a disability as a victim, but he or she may not feel that way. A person with ALS should not be described as being "afflicted" but simply as having ALS. (How that person feels about it is another matter.) No one is ever "confined" to a wheelchair. Wheelchair or scooter users get in and out of their chairs to sleep, swim, drive, make love, or do many other activities.

Words, Fairness and the Media

"A word is half his that speaks and half his that hears it."

Michel Eyquem Montaigne

Journalists and writers who are describing people with disabilities for print or other media should take into account all of the suggestions in this booklet. If your focus is on an individual, their disability, or how they adjust to it, fine. But there are other aspects to the lives of people with disabilities that you may not be aware of. Keep in mind that people with disabilities are members of society who contribute according to their abilities. Here are some word distinctions and suggestions.

- **Sympathy • empathy.** You may be tempted to use "sympathy" to describe *your* feelings about a person with a disability. If you feel sorry for that person, so be it. But you likely mean "empathy"— that you understand their disability and situation in life.

- **Client, consumer, resident • patient.** A person being treated in a hospital is a patient. A person receiving rehabilitation services is more accurately described as a client or consumer. A person who lives at a long-term care facility is a resident. Most facilities have a preferred term; try to be consistent in your article or broadcast.
- **Noble, courageous, inspiring • adjusting.** You may be amazed at how people with disabilities have adjusted and think them noble, courageous, and inspiring. Be careful with these words. Most people with disabilities reject these adjectives and will tell you they have simply adjusted to the barriers that life has thrown in their way as best they can. No courage required.
- **Portray a whole person.** People with disabilities have emotions, experience pain and pleasure, and have opinions. They are straight and gay, single and married, conservatives and liberals — you get the point. A profile of a person with a disability may only spend a little time on that disability. In fact, it may be the least interesting part of the story.
- **Mundane is still mundane.** Don't take this portrayal of a whole person to ridiculous lengths. People with disabilities do pay bills, drive cars, eat meals, etc. By all means, mention these kinds of things but it isn't necessary to marvel at them.
- **Abilities as well as disabilities.** All of us adapt to our lives in many subtle and not-so subtle ways. What we *can do* usually overshadows what we can't. So too, people with physical disabilities. It is more relevant and fair to focus on what a person with a disability can do than it is to focus on what they can't do.

Carrying on a Conversation

"To do all the talking and not be willing to listen is a form of greed."

Democritus of Abdera

If you are meeting someone who has a disability for the first time, it may be difficult to figure out where to look, what to say, or even where to stand. Relax. The person with the disability is probably used to this. Here are a few suggestions for interacting with people who have disabilities:

- **Introductions...as per usual.** Most things you normally do or say when you meet someone holds true for people with disabilities. "Hi, how are you?" "Good to meet you." "How's it going?" Any of these

standard greetings will be just fine when you meet a person with a disability. Offer a handshake. (It would be a good idea to place your other hand slightly below as a support.) Those with limited manual dexterity will sometimes shake your hand in their own fashion. Normally, even a person with no use of his arms, hands, or digits will appreciate the contact. Do be aware that some people may find a firm handshake painful. Take it easy.

- **Talk to who you are talking to.** Often, people with communication disabilities will be accompanied by an aid, a friend, or a interpreter. While not ignoring this third party, remember who you are speaking to. If your business is with the person with the disability, let the third person act as an almost invisible interpreter.
- **Making contact.** Many people find the issue of touching a person with a disability perplexing – but it should be no more so than for anyone else. Most people feel comfortable with a certain amount of physical contact during conversation; some people feel more comfortable giving it. A hand on a shoulder, a hand, or a knee may be quite appropriate. You will just have to get comfortable with the person and the situation. Keep in mind that a person with arthritis or similar condition may be in some pain.
- **Everyday language.** We all use phrases and sentences that, upon reflection, may seem inappropriate when talking with a person who has a disability. Don't censor yourself into virtual silence. It is fine to say to a person who uses a wheelchair, "Shall we go for a walk?" or to a person with a communication disability, "It's been nice talking with you." People who are visually impaired often say "See you later."
- **Acquired brain injury (ABI).** A person who has a physical disability may also have ABI. You may or may not know this. Or a person may have no physical disability but still have an acquired brain injury (ABI). Acquired brain injury can be mild (with very subtle symptoms) or severe (with major symptoms.) Virtually all the advice offered in this booklet will apply to a person with ABI and physical disabilities. In particular, you should be aware of possible behavioral symptoms which may include: verbal outbursts, impulsivity, irritability and anger, immaturity, or even paranoia. Patience is the best policy. Later you may inquire if the person you were talking to has ABI.
- **That's rather personal.** A professional caregiver may require certain information of a personal nature from a person with a disability. Otherwise, if you are tempted to ask a personal question

of a person with a disability ask yourself first, "Would I ask this of anyone else?" If the answer is yes, then proceed.

People with Communication Disabilities

"Language is the Rubicon that divides man from beast."

Max Müller

People with communication disabilities may use a variety of tools and techniques to communicate. These include laboured speech, grunts, simple hand signals, letter and picture boards, and computers with paper, screen, and voice output. Here are a few useful pointers for talking with someone who has a communication disability:

- **Take the time to make a conversation work.** It will take longer to speak with a person who has a communication disorder. When you are planning a conversation, meeting, or interview, budget extra time.
- **Find a private or quiet place to talk.** You will need to focus quite intently on your conversation so the fewer distractions, the better.
- **Look or wait for instructions.** Often, a person with a communication disability will let you know how they communicate, how their machine works, or if there are some basic ground rules. If they don't tell you, then ask. Picture or letter boards are standard issue for people with communication disabilities. Even electronic-voice computer users will have one as a back-up. There will be instructions on the board — and then just follow along.
- **Speak on the same intellectual level.** A person with a communication disability (or a cognitive disability) does not necessarily lack of intelligence. As is always the case, intelligence depends entirely on the individual. Don't talk down to your speaking partner; assume you are being understood unless it is obvious you are not.
- **If you don't understand what is being said, say so.** Perhaps you need to rephrase your question. If in doubt, confirm responses with your speaking partner.
- **Yes/No questions.** Sometimes these kinds of questions are appropriate, especially in a professional setting where basic information is required. However, few people enjoy talking this way. Give your speaking partner a chance to speak.

People who use Wheelchairs or Scooters

"Before using a fine word, make a place for it."

Joubert

Interacting with people who use wheelchairs or the increasingly common scooters is usually a matter of applying common sense.

- **Allow for personal space.** People who use wheelchairs or scooters have personal space that will vary from individual to individual but always includes the wheelchair or scooter itself. Whether you touch the person or his or her wheelchair is a matter of personal preference. But remember that the wheelchair is part of a person's body.
- **Keep access in mind.** If a person with a disability is visiting you, keep access in mind. If no ramp, lift, or elevator is available, reschedule the meeting for a better location or arrange to have someone available to help with lifting. Make sure accessible parking is available.
- **Eye to eye and get comfortable.** Try to speak with the person at their physical level so that they will not have to strain by looking up constantly. Ideally, sit or kneel opposite the person. Otherwise sit as close as is comfortable. If you need to help the person move, ask how best to get the job done. You may be asked to adjust wheelchair position or some other small item. The wheelchair user knows the routine.
- **A wheelchair is a tool.** Resist the urge to rest a hand, foot, or otherwise lean on a wheelchair or scooter unless you have established that level of comfort with the person. Electric devices have very sensitive controls. Don't place items on a wheelchair table or scooter basket unless that space is offered.

Interacting in the Workplace

"Language is more to the mind than light is to the eye."

William Gibson

The workplace can present special challenges for people with disabilities and those who interact with them. You may be a front-line service provider or you may work with or for a person with a disability. Here are a few examples of how to interact in the workplace and make it a more friendly environment for people with disabilities. (Guides detailing how to adapt a workplace for people with disabilities are also available.)

- **Know the environment.** Your workplace may or may not be directly accessible for people with certain disabilities. Learn its deficiencies and attributes.
- **External accessibility.** Wheelchair or scooter users may need a ramp, elevator, or lift. If these are not available, find out if there is an alternative entrance such as a loading dock that may be more accessible. If you know a person who uses a wheelchair or scooter is coming, you may arrange to have some help lifting him or her over barriers. If not, arrange another place to meet.
- **Internal accessibility.** If your workplace does not have a wheelchair or scooter-accessible counter, find another place on the premises to talk business. Be prepared to move furniture and provide a quiet place to talk.
- **Patience required.** Show patience when interacting with people who have a communication disability or ABI. Yes, your time is limited – and so is the other person's. But the job or interaction still needs to be done successfully and hurrying things won't help. Also keep in mind that the person with a disability who is visiting your workplace is likely on new and unfamiliar ground and may feel uncomfortable – which may show itself in different ways.
- **Assume the best.** If a person with a disability is in your workplace, they want to be there and expect to be treated like anyone else. Even if a person is very difficult to understand or perhaps has extreme involuntary movements, don't assume they are in the wrong place.
- **Be willing to read out loud.** For vision impaired or other people with disabilities, it may be necessary to read out loud from certain documents. Do so in a clear and normal speaking voice.

People with Hearing and Vision Disabilities

There are a variety of rules for talking with people who have hearing or vision disabilities. A great deal of literature is available from your local agency for the hearing and vision impaired. Here are a few basic suggestions:

Deafness or hearing loss

- **Getting attention.** Make sure the person has your attention by waving, nodding, or gently tapping his or her shoulder.
- **Be clear.** Look directly at the person. This is particularly important for lip readers. Be somewhat more demonstrative with facial expressions and body movements, although try not to overdo it.
- **Don't shout.** People with a hearing loss have already compensated in one way or another for their disability. There is no need for you to do so as well.

Blindness or vision impairment

- **Identify yourself.** Clearly identify yourself and anyone else who is accompanying you. The person should know how many people and who is in the room and where.
- **Shaking hands.** Usually, the person who has the vision disability will offer to shake hands. If he or she doesn't, don't worry. Verbal introductions will suffice.
- **Giving directions.** The correct way to offer guidance towards a chair or couch is to place the person's hand on the back or arm of a chair or couch. He or she will give you instructions or find the way.