

Disability 101 for Researchers: A Closer Look at Communication

Carolyn Phillips and Liz Persaud
Tools for Life, Georgia Institute of Technology

December 3, 2014



Rehabilitation Engineering Research Center on
Technologies to Support Successful Aging with Disability

Our research is funded by the Department of Education (National Institute on
Disability and Rehabilitation Research, H133E130037)



Agenda

- Join us for a unique webinar and discussion focused on people first language and communication for researchers and other professionals working on disability related projects.
- Presenters will share a brief history of disability culture and explain the difference between the "medical model" and "social model".
- Discussion will center on how each of these models can be applied to research and studies for and about people with disabilities as well as when and what language should be used in appropriate settings and environments.
- Presenters will focus on the importance of people first language, disability neutral versus disability negative terminology, and value laden language and how it applies to conducting research.
- This will provide a platform where professionals can learn about and discuss communication focused on people with disabilities and provide helpful tips and strategies while engaging in important conversations.

Webinar Archives



- We are recording this session.
- Archives and handouts can be found at:
<http://www.gatfl.gatech.edu/>



RERC TechSAge Vital Stats

- Funded by: National Institute on Disability and Rehabilitation Research (NIDRR), Dept. of Ed
- Timeline: Oct 1, 2013 – Sept 30, 2018
- Amount: \$4.6 million (\$925k/year) + ~ \$1 million GT cost share
- Interdisciplinary: CoA (ID, GIS, AMAC), CoS (Psych), CoE (BME), CoC (HCI/HCC), IPaT (IMTC, Awarehome), GTRI, Emory Ctr. for Health in Aging, CS/Engineering USC

Mission

- Our mission is to conduct advanced rehabilitation engineering R&D to prevent, minimize or reverse the disabling effects of age-related losses and contextual factors on the independence, health and participation of people who are aging with chronic conditions or long-term impairment.

Core Principles and Strategies

- Universal design as fundamental to all efforts
 - Ensuring that environments, products, services and interfaces work for people of all ages and abilities
- Focus on people with long-term disability who are experiencing age-related limitations
- (Dis)ability exists on a continuum
 - Everyone functions at different levels due to personal and environmental factors

Tools for Life



We're here to help Georgians with disabilities gain access to and acquisition of assistive technology devices and assistive technology services so they can live, learn, work, and play independently in the communities of their choice.

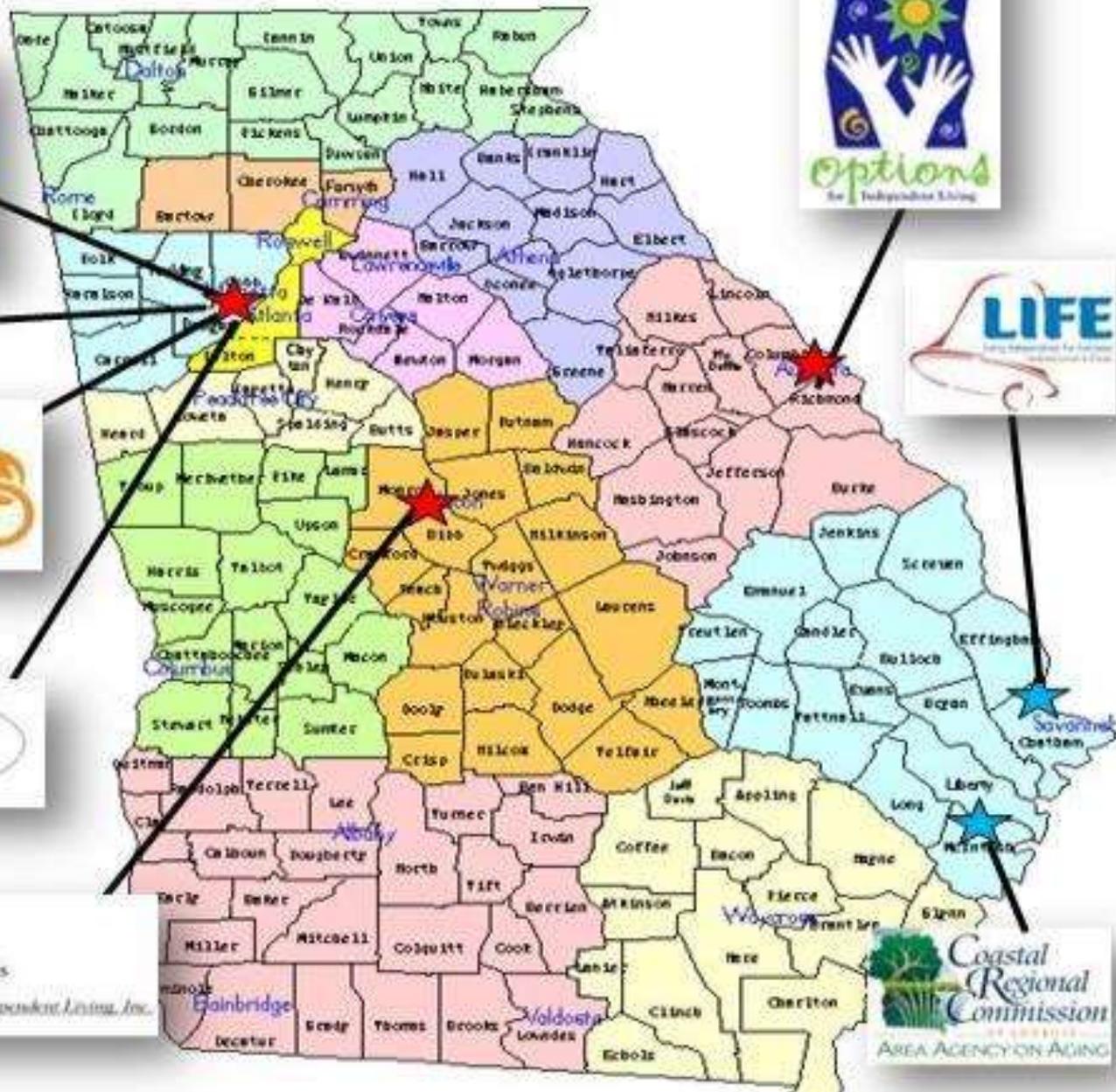


Tools for Life, Georgia's Federal AT Act Program

- **TFL developed Georgia's Plan for AT**
 - We serve individuals of all ages & all disabilities in Georgia
 - Over 50,000+ thru various activities throughout the year
- **TFL Network**
 - Assistive Technology Resource & Outreach Centers
 - AT Lending Libraries
 - Training and Demonstrations
 - AT Reuse
 - AT Funding Education/Assistance and Resources
- **Online Resources**
 - www.gatfl.gatech.edu - 5,000 unique visitors a month



Georgia's Assistive Technology Act Program



- TRAINING
- FUNDING
- PUBLICATIONS
- TFL WIKI
- MEET THE TFL TEAM
- MEET THE ADVISORY COUNCIL
- DIRECTIONS/MAP
- JOIN OUR MAILING LIST
- SCHEDULE A TOUR

Welcome AT Services Try AT Get AT AT Guides Research



CUSTOMIZED AT TRAINING
for Individuals or Groups



Welcome to Tools for Life

Tools for Life, Georgia's Assistive Technology Act Program, is dedicated to increasing access to and acquisition of assistive technology (AT) devices and services for Georgians of all ages and disabilities so they can live, learn, work and play independently and with greater freedom in communities of their choice.

Tools for Life and the TFL Network work collaboratively together to accomplish our mission through:

2014 GATE SEMINAR

DEC 5 Georgia Tech Student Center

WEBINARS

OCT 29 [Lighting the Path: A Guided Discussion on AT for Dementia](#)

NOV 6 [Unlocking Communication in the Severely Impaired Child](#)

- ◊ [Current Webinar Schedule](#)
- ◊ [Webinar Archives](#)

TOOLS FOR LIFE APPFINDER



...for Living, Learning, Working, and Playing.

AT ONLINE EXCHANGE



AT FUNDING GUIDE
DOLLARS & SENSE
NAVIGATING THE AT FUNDING STREAM

Defining Assistive Technology



Assistive technology – “Any item, piece of equipment, product system, whether acquired commercially, modified, or customized, that is used to increase, maintain, or improve functional capabilities of individuals with disabilities.”

Assistive technology service – “Any service that directly assists an individual with a disability in the selection, acquisition, or use of an assistive technology device.”



Public Law 108-364



Why Assistive Technology?

For a person without a disability, technology makes things easier.

For a person with a disability, technology makes things possible.



Who are We Serving

- Over 54,000,000 individuals in the United States have disabilities that affect their ability to:
 - see
 - hear
 - communicate
 - reason
 - walk
 - perform other basic life functions

Guiding Principles



- We, collectively, are brilliant and can find innovative paths and create brighter futures.
- We must think, live, and act from a place of abundance. We do have enough time, money and resources.
- We must focus on abilities.
- You have the power to make the difference.

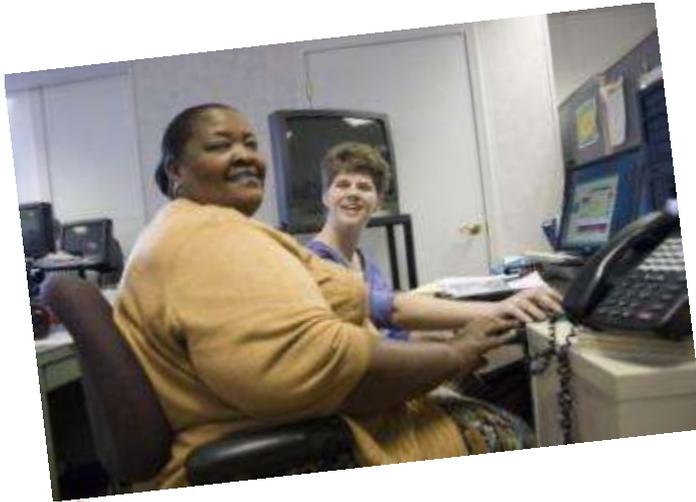


Guiding Principle and Public Law

- Disability is a natural part of the human experience and in no way diminishes the right of individuals to:
 - (A) live independently;
 - (B) enjoy self-determination and make choices;
 - (C) benefit from an education;
 - (D) pursue meaningful careers; and
 - (E) enjoy full inclusion and integration in the economic, political, social, cultural, and educational mainstream of society in the United States.

Public Law 108-364

More Facts to Think About



- People with disabilities are the largest minority group in America.
- This group cuts across racial, ethnic, religious, gender and age boundaries.
- Anyone can become a member of this minority group at any time.

What is Disability Culture?

- Disability culture embodies a broad definition.
- The words, "disability," and "culture" are each value-laden, and have different connotations.
- We all identify with more than one culture.

One Definition

What is Disability Culture?

- **“People with disabilities have forged a group identity. We share a common history of oppression and a common bond of resilience.** We generate art, music, literature, and other expressions of our lives and our culture, infused from our experience of disability. Most importantly, we are proud of ourselves as people with disabilities. We claim our disabilities with pride as part of our identity. We are who we are: we are people with disabilities.”

Steven E. Brown, Ph.D.

Co-Founder, Institute on Disability Culture

Published in a 1996 issue of MAINSTREAM Magazine

Defining Medical Model

- Under the medical model, impairments or differences should be 'fixed' or changed by medical and other treatments, even when the impairment or difference does not cause pain or illness.
- People with disabilities are to be adapted to fit into the world as it is.

Medical Model of Disability

- The emphasis is on dependence.
- Focus is on the impairment, rather than the needs of the person.
- Often, institution is the norm where basic needs can be met.

Medical Model: Barriers

- Environmental and design barriers make it difficult to have a successful future whether it is in work, school, leisure and entertainment facilities, transport, training, higher education, housing or in personal, family and social life.
- Practices and attitudes are seen as "disabling".

Defining Social Model

- Disability is caused by the way society is organized, rather than by a person's impairment or difference.
- Views that the position of disabled people and the discrimination against us are socially created and has little to do with our impairments.
- Restructuring society

Social Model of Disability

- Explores ways of removing barriers that restrict life choices for disabled people.
- When barriers are removed, disabled people can be independent and equal in society, with choice and control over their own lives.

Social Model: Solutions

- Traditional medical model did not explain their personal experience of disability or help to develop more inclusive ways of living.
- Encourages people with disabilities to redefine what "disability" means to them.
- Perpetuates confidence and self-esteem.

Common Ways People with Disabilities are viewed and treated:

- Unfortunately, and inaccurately, people with disabilities are often viewed as:
 - victims, or objects of pity
 - horrible or grotesque
 - burdens, either on society or on their families and carers
 - evil, or some threat to the comfort and safety of others
 - unable, or assumed to be unable, to do things
 - having multiple disabilities (such as assuming that a person who uses a wheelchair also has an intellectual disability)
 - childlike
 - "special"
- Such misconceptions are based on insufficient or inaccurate information about people with disabilities and can perpetuate inappropriate interactions.

Understanding Attitudinal Barriers

- People with disabilities face many barriers every day—from physical obstacles in buildings to systemic barriers in employment and civic programs.
- Often, the most difficult barriers to overcome are attitudes other people carry regarding people with disabilities.
- Whether born from ignorance, fear, misunderstanding or hate, these attitudes keep people from appreciating—and experiencing—the full potential a person with a disability can achieve.

Types of Attitudinal Barriers

- **Inferiority** - Because a person may be impaired in one of life's major functions, some people believe that individual is a "second-class citizen." However, most people with disabilities have skills that make the impairment moot in the workplace.
- **Pity** - People feel sorry for the person with a disability, which tends to lead to patronizing attitudes. People with disabilities generally don't want pity and charity, just equal opportunity to earn their own way and live independently.
- **Hero worship** - People consider someone with a disability who lives independently or pursues a profession to be brave or "special" for overcoming a disability. But most people with disabilities do not want accolades for performing day-to-day tasks. The disability is there; the individual has simply learned to adapt by using his or her skills and knowledge, just as everybody adapts to being tall, short, strong, fast, easy-going, bald, blonde, etc.

Types of Attitudinal Barriers (cont'd)

- **Ignorance** - People with disabilities are often dismissed as incapable of accomplishing a task without the opportunity to display their skills. In fact, people with quadriplegia can drive cars and have children. People who are blind can tell time on a watch and visit museums. People who are deaf can play baseball and enjoy music. People with developmental disabilities can be creative and maintain strong work ethics.
- **The Spread Effect** - People assume that an individual's disability negatively affects other senses, abilities or personality traits, or that the total person is impaired. For example, many people shout at people who are blind or don't expect people using wheelchairs to have the intelligence to speak for themselves. Focusing on the person's abilities rather than his or her disability counters this type of prejudice.

Types of Attitudinal Barriers (more)

- **Stereotypes** - The other side of the spread effect is the positive and negative generalizations people form about disabilities. For example, many believe that all people who are blind are great musicians or have a keener sense of smell and hearing, that all people who use wheelchairs are docile or compete in paralympics, that all people with developmental disabilities are innocent and sweet-natured, that all people with disabilities are sad and bitter. Aside from diminishing the individual and his or her abilities, such prejudice can set too high or too low a standard for individuals who are merely human.
- **Backlash** - Many people believe individuals with disabilities are given unfair advantages, such as easier work requirements. Employers need to hold people with disabilities to the same job standards as co-workers, though the means of accomplishing the tasks may differ from person to person. The Americans with Disabilities Act (ADA) does not require special privileges for people with disabilities, just equal opportunities.

Types of Attitudinal Barriers (even more)

- **Denial** - Many disabilities are "hidden," such as learning disabilities, psychiatric disabilities, epilepsy, cancer, arthritis and heart conditions. People tend to believe these are not bona fide disabilities needing accommodation. The ADA defines "disability" as an impairment that "substantially limits one or more of the major life activities." Accommodating "hidden" disabilities which meet the above definition can keep valued employees on the job and open doors for new employees.
- **Fear** - Many people are afraid that they will "do or say the wrong thing" around someone with a disability. They therefore avert their own discomfort by avoiding the individual with a disability. As with meeting a person from a different culture, frequent encounters can raise the comfort level.

Tips for Breaking Down Barriers



- ✓ Power of Language
- ✓ Value Laden Language
- ✓ disAbility negative vs disAbility neutral Language
- ✓ Tips for Interacting with People with disAbilities
- ✓ Understanding and Using Assistive Technology



The Power of Language



- **Language is continually evolving**, and that includes language related to people with disabilities.
- Staying current is important, not to show that you are "politically correct" but to communicate effectively and with respect.



Putting It into Perspective



“The difference between the right word and the almost right word is the difference between lightning and the lightning bug.”

Mark Twain



Value Laden Language



- Says more about our values
- All staff members should be sensitive to the language they use in referring to customers.
- When we refer to the condition instead of the person, we devalue the person.
- People first language is about referring to the person first and the disability (injury, illness or procedures) second.



More to Think About



- It may not be visible.
- It may be temporary.
- Some may have more than one disability.

- It may be the staff member who has the disability.

- Either way, the person is not his or her disability.



What is Value-Laden Language?



- What you say and write may enhance the dignity of people with disabilities or inadvertently reflect stereotypes and negative attitudes.
- Some words and phrases don't recognize the broad range of capabilities of people with disabilities.
- People with disabilities don't need or want to be pitied, nor should they be deemed "courageous" or "special" as they accomplish daily activities or work.



People First Language



- Avoids generic labels
- Emphasizes abilities, not limitations
- Avoids euphemisms (that are condescending and avoid real issues)
- Avoids implying illness or suffering (e.g., afflicted, suffers from, victim of)



Value-Laden Language



Promotes

- Distance
- Stereotypes
- Pigeon-holes

Reduces sense of:

- Self-worth
- Power
- Self-direction



Value-Laden Language: Creates Categories

- We vs. They
- Good vs. Bad
- Strong vs. Weak
- High vs. Low (expectation)
- Sick vs. Well
- Superior vs. Inferior

Emphasize Abilities, Not Limitations

- When talking or writing about people with disabilities, show them as active participants in society.
- Of those people with disabilities between the ages of 21 and 64 in 2005, 49% were actively employed.

Value-Laden Language: Promotes Distance



- Abnormal
- Afflicted
- Burdened
- Defect
- Deformity
- Maimed
- Palsied
- Spastic
- Stricken with
- Sufferer
- Victim
- Invalid



Myth



What does the word "handicapped" mean?



Fact

- "Handicapped" is an archaic term (it's no longer used in any federal legislation) that evokes negative images of pity, fear, and more.
- A legendary origin of the "H-word" refers to a person with a disability begging with his "cap in his hand."

Value-Laden Language: Example #1



- **disAbility-Negative**

- the disabled, the blind, the deaf
- crippled, suffers from, afflicted with, stricken with, victim of, invalid
- impaired, impairment
- normal person, healthy, whole, wheelchair bound

- **disAbility-Neutral**

- people with disabilities, the disability community ("disabled" is an adjective, so must be accompanied by a noun.), the blind community, the Deaf community
- has a disability, is a person with a disability, physically disabled, walks with a cane, uses leg braces
- has a disability
- non-disabled, person without disabilities, uses a wheelchair



Value-Laden Language : Example #2

- **disAbility-Negative**

- The disabled
- The handicapped

- Disabled parking
- Handicapped entrance

- Confined to a wheelchair
- Wheelchair bound

- **disAbility-Neutral**

- People with disAbilities

- Accessible parking
- Accessible entrance

- Person who uses a wheelchair
- Wheelchair user

Value-Laden Language : Example #3

- **disAbility-Negative**

- hearing impaired, hearing impairment
- visually impaired, visual impairment
- dumb, mute
- stutterer, tongue-tied
- CP victim, spastic
- epileptic
- fit, attack

- **disAbility-Neutral**

- deaf, hard of hearing, deaf-blind
- low vision, blind
- person who has a speech or communication disability
- person with cerebral palsy
- person with epilepsy, person with seizure disorder
- seizure, epileptic episode

Value-Laden Language : Example #4

- **disAbility-Neutral**

- people with mental health issues, mental illness, mental disability, psychiatric disability
- developmentally disabled, developmentally delayed, person with mental retardation, person with Down syndrome
- has a learning disability, person with specific learning disability
- person of small stature, short stature; little person

- **disAbility-Negative**

- crazy, lunatic, insane, nuts, deranged, psycho
- retard, mentally defective, moron, idiot, imbecile, Down's person, mongoloid
- slow learner, retarded
- dwarf, midget

Value-Laden Language : Example #5

- **disAbility-Negative**

- paraplegic, quadriplegic
- birth defect
- post-polio, suffered from polio
- homebound

- **disAbility-Neutral**

- man with paraplegia, woman who is paralyzed, person with spinal cord injury
- congenital disability, person with a disability from birth
- person who had polio
- stay-at-home, hard for the person to get out

Using People First Language is Crucial

People First Language puts the person before the disAbility, and it describes who a person is not what a person has.

Making the Connection

A change in Language and Attitude can change everything!



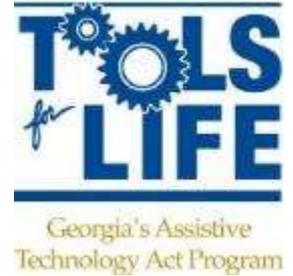
Making the Connection: Be Contagious



- If employers believed adults with disabilities have (or could learn) valuable job skills, we wouldn't have an estimated 70 percent unemployment rate of people with disabilities.
- If merchants saw people with disabilities as customers with money to spend, we wouldn't have so many inaccessible stores, theaters, restrooms, and more.
- If the service system identified people with disabilities as "customers," instead of "clients/consumers/recipients," perhaps it would begin to meet a person's real needs (like inclusion, friendships, etc.) instead of trying to remediate "problems."



Communication Tips



- Don't be afraid to make a mistake.
- Always BE RESPECTFUL.
- Don't make assumptions about what a person can or cannot do. Ask before giving assistance. If you offer help and the person says "no," don't insist. If the answer is "yes," ask how you can best help, and follow directions.
- If someone with a disability is accompanied by another individual, address the person with a disability directly rather than speaking through the other person.
- Treat adults as adults.
- Expect diversity of preferences and opinions.



Communication Tips: Physical Disabilities

- Do not make assumptions about what a person can and cannot do.
- Respect the individual's personal space: personal space includes a person's wheelchair, crutches, or other mobility aid. Never move someone's crutches, walker, cane, or other mobility aid without permission
- Do not push a person's wheelchair or grab the arm of someone walking with difficulty without first asking if you can help.
- When speaking for more than a few minutes to a person using a wheelchair, try to find a seat for yourself so that the two of you are at eye level.
- When speaking with someone with a speech impairment, don't pretend to understand if you do not. Ask the person to repeat what was said.

Communication Tips: Deaf/Hard of Hearing

- Ask the person how he or she prefers to communicate.
- Before you start to speak, make sure you have the person's attention. A wave, a light touch on the shoulder, or other visual or tactile signals are appropriate ways to get their attention.
- Speak in a clear, expressive manner. Do not over enunciate or exaggerate words.
- Unless asked, do not raise your voice. Speak in a normal tone.
- Talk directly to the person who is Deaf or hard of hearing, not to the interpreter.
- If you are speaking through an interpreter, remember that the interpreter may lag a few words behind. Pause occasionally.

Tips: Deaf/Hard of Hearing



- To facilitate speech reading: face into the light, and keep your hands and other objects away from your mouth. Face the person directly and maintain eye contact. Don't turn your back or walk around while talking. If you look away, the person might assume the conversation is over.
- While you are writing a message for someone who is Deaf or hard of hearing, don't talk, since the person cannot read your note and your lips at the same time.
- If you don't understand something, ask the person to repeat it or write it down. The goal is communication; don't pretend to understand if you did not.



Communication Tips: Cognitive Disabilities

- Treat adults with cognitive disabilities as adults.
- When speaking to someone who has a cognitive disability, try to be alert to his or her responses so that you can adjust your method of communication if necessary.
- For example, some people may benefit from simple, direct sentences or from supplementary visual forms of communication, such gestures, diagrams, or demonstrations.
- Use language that is concrete rather than abstract.
- People with brain injuries may have short-term memory deficits and may repeat themselves or require information to be repeated.

Tips: Cognitive Disabilities



- People with auditory perceptual problems may need to have direction repeated and may take notes to help them remember direction or the sequence of tasks. They may benefit from watching a task demonstrated.
- People with perceptual or “sensory overload” problems may become disoriented or confused if there is too much to absorb at once. Provide information gradually and clearly. Reduce background noise if possible.
- Don’t pretend to understand if you do not. Ask the person to repeat what was said.
- In conversation, people with cognitive disabilities may respond slowly, so give them time.



Myth



- It's inappropriate to touch a person's arm lightly to let them know you're speaking to them.

Communication Tips: Vision Impairments

- It is appropriate to touch the person's arm lightly when you speak so that he or she knows you are speaking to him or her.
- Speak directly to the visually impaired person, not through a companion or third party. Visually impaired people can hear and respond for themselves.
- Identify yourself when you approach a person who is blind. If a new person approaches, introduce him or her. Not everyone recognizes voices or remembers them.
- Don't shout. Most blind people have normal hearing. Speak clearly and strongly if you know that an older visually impaired person also has a hearing problem.
- Identify yourself when entering a room and let the blind person know when you are leaving. Don't leave a blind person talking to an empty room, or standing alone in empty space.

Tips: Vision Impairments

- Face the person and speak directly to him or her. Use a normal tone of voice.
- Don't assume that help is needed. Always ask before providing assistance.
- Never push, pull, or grab a blind person. This can be frightening and it's often embarrassing
- If you are offering direction, be as specific as possible, and point out obstacles in the path of travel.
- Alert people who are blind or visually impaired to posted information.
- Never pet, talk to or otherwise distract a service dog unless the owner has given you permission.
- Don't hesitate to use words like "see" and "look."
- Don't use hand signals or gestures.

Communication Tips: Communication Disabilities

- If you are having trouble understanding what is being said, **ask the person to repeat** rather than pretend you understand. The former is respectful and leads to accurate communication; the latter is belittling and leads to embarrassment.
- In conversation, people may respond slowly, so give them time.
- Don't try to finish sentences or guess what the person is saying.

Myth



- It's best not to shake or grasp someone's hand.

More Communication Tips



- Shake hands or hand over business cards. If the person cannot shake your hand or grasp your card, they will tell you. Do not be ashamed of your attempt, however.
- It is okay to feel nervous or uncomfortable around people with disabilities, and it's okay to admit that. It is human to feel that way at first. When you encounter these situations, **think "person" first instead of disability; you will eventually relax.**



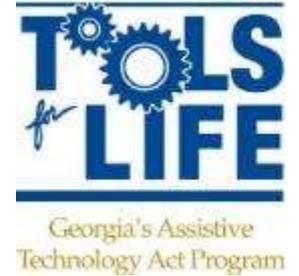
Exploring Tips for Researchers

- Produce all information in plain language and a minimum type size of 12 to 18 point font.
- Use a clear, easily recognizable, sans serif font. Do not print sentences and block capitals.
- When requested, provide information in alternative formats such as large print, audio, braille, and e-text.
- Use interpreters for people who need to communicate with sign language.
- Make sure your website is developed and designed with accessibility in mind.

Tips for Researchers

- If possible, provide services in a flexible way: home visits, phone calls, videoconferencing, alternative schedules, etc.
- Make sure your facility is fully accessible to individuals with mobility disabilities.
- Have a good working relationship with other service providers who can help and provide referral services.
- Provide your staff and others working on your projects disability awareness training.
- Involve people with disabilities and service planning and training delivery.

Myth



- People with disabilities always need help.
- Taking the time to assist them in getting acclimated to various environments.



Fact

- Many people with disabilities are independent and capable of giving help as well as receiving it.
- AT Helps!

AT Helps!



- Assistive Technology strategies and solutions can help support individuals with a variety of disabilities in the workplace. AT helps to bridge the gap and provide solutions to problems with:
 - speaking
 - hearing
 - seeing
 - moving around
 - getting places
 - memory
 - cognition (thought processes and understanding)
 - daily living activities, such as dressing and preparing meals
 - socializing



Automatic Feeder

- Mealtime Partner
- Different mounts
- Battery operated
- Bowl tops controls amount of food
- Control Pause time between spoonful
- Adjustability of the spoon



VGo Telepresence Robot

- Enables a person to replicate themselves in a distant location and have the freedom to move around as if they were physically there.
- Reduces travel costs
- School
- Hospital
- Work Remotely



Kubi



- Dock your tablet for remote pan and tilt controls
- See and interact with people during a conference call
- Use any Video Client: Skype, FaceTime, Google Hangout, etc.
- Cloud Control

TFL AppFinder

Search by:

✓ **App Name**

✓ **Categories**

- Book
- Education
- Environmental Adaptations
- Hearing
- Cognition, Learning, Developmental
- Navigation
- Personal Care and Safety
- Productivity
- Communication
- Therapeutic Aids
- Vision



Questions

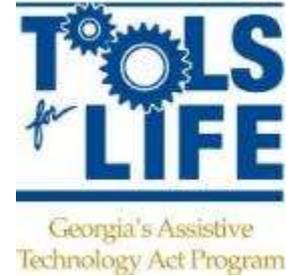


Hope

Hope begins in the dark, the stubborn hope that if you just show up and try to do the right thing, the dawn will come.

Anne Lamott

Contact



Carolyn Phillips

Director and Principle Investigator, Tools for Life

Carolyn.Phillips@gatfl.gatech.edu



Liz Persaud

Training and Outreach Coordinator

Liz.Persaud@gatfl.gatech.edu



Thank you



www.techsage.gatech.edu

This research and contents of this presentation were supported in part by the grant from the National Institute on Disability and Rehabilitation Research (Department of Education) Grant H133E130037. However, those contents do not necessarily represent the policy of the Department of Education, and you should not assume endorsement by the Federal Government.

