



Assistive Technology Strategies and Solutions for People with Neurodegenerative Disorders

Carolyn Phillips, Tools for Life With contributions from Martha Rust, Liz Persaud & Ben Satterfield www.gatfl.org



AGENDA

- Accessing Tools for Life Your AT Act Program
- Define & Explore the degenerative neurological disease (DND) process:
 - Huntington's disease (HD)
 - Multiple sclerosis (MS)
 - Amyotrophic lateral sclerosis (ALS)
- Considering AAC & matching individuals with AT





"Technology gives me hope & I need a lot of Hope!"

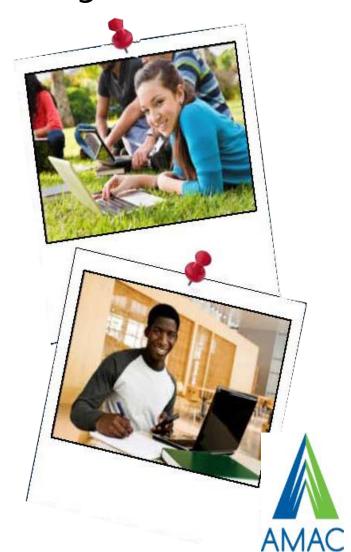
~ Earnestine





AMAC Accessibility

AMAC Accessibility is a social change organization on a mission to create affordable services for governmental, private and nonprofits organization working with individuals with disabilities. Services include e-text, braille, captioning, assistive technology, office management software and consulting.





Tools for Life Mission

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 & TFL Network

- 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 Centers/Outreach Sites
 - Lending Libraries
 - Training and Demonstrations
 - AT Reuse
 - AT Funding Education and Resources
- Online Resources
 - www.gatfl.org 5,000 unique visitors a month

The TFL Network is Growing!





Come Visit Us!



TRAINING
FUNDING
PUBLICATIONS

TFL WIRD

MEET THE TFL TEAM

MEET THE
ADVISORY COUNCIL

DIRECTIONS/MAP

JOIN OUR
MAILING LIST

SCHEDULE A TOUR



accomplish our mission through:





Tools for Life AT Demo Lab

- Tablets
- Vision Items
- DME
- Communication
- Games
- Software
- Switches
- Keyboards







Categories of Acquired Disabilities

Permanent - stable

- Spinal Cord Injuries
- Traumatic Brain Injuries (TBI)
- Cerebrovascular Accidents (CVA/Stroke)

Permanent - degenerative

- Amyotrophic Lateral Sclerosis (ALS)*
- Multiple Sclerosis (MS) *
- Parkinson's Disease
- Alzheimer's Disease
- Huntington's chorea (HD)*
- Acquired Immune Deficiency Syndrome (AIDS)
- Fredrich's Ataxia





TechSage (RERC)

- 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



Scope

- Research (Rogers)
 - R1. User Needs (Rogers, Fain, Jones)
 - R2. Effects of Hearing Loss (Bruce, Echt)
 - R3. Exercise Telerobotics (Mitzner, Beer)
- Development (Price)
 - D1. App Development
 - D1.1. Cognitive Training Game (Gandy-Kennedy)
 - D1.2. Route Planning App (Sanford, Guhathakurta)
 - D1.3. Mobile App to Measure Gait (Jones, Johnson)
 - D2. SmartBathroom Technologies (Sanford, Jones)
 - D3. Intelligent Robotics (Kemp)
- Training (Sanford)
 - T1. Online Education (Phillips)
 - T2. Post Secondary Education (Sanford)
 - T3. UD Competition (Rébola)
- Dissemination (Mitzner)





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Projects

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Development Projects

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App Factory (D1)

The overall purpose of this project is to advance universal design in the wireless community. The objectives of this project are development, deployment, and adoption of software applications ("apps") to enhance the utility and usability of wireless products and services for wireless customers with and without disabilities.

App Factory output will include apps designed specifically to address barriers to wireless access and use by people with cognitive, physical, sensory, and/or speech disabilities. Wherever practical, these apps will incorporate features useful to all customers, with or without disabilities.

A complementary objective of this project is development of a practical model for consumer participation in the process of app development. This process engages the community of people with disabilities throughout the process of envisioning, designing, testing, refining, and disseminating applications.

Latest News

Wireless RERC Researchers Present at CDC Grand Rounds

<u>Last Call for 2013-14 App</u> Developers

<u>Technology Transitions Policy Task</u> <u>Force Workshop</u>

More News

Upcoming Events

September 30, 2013 - 7:00am
STEM Diversity Career Expo



Overview

Georgia Institute of Technology

Opportunities

Human Factors & Aging Laboratory

We are able to implement various methodologies to address many types of research questions -Tracy Mitzner

Publications



Points of Excellence

 Our research advances both science and practice

Projects

- We aim to improve quality of life for adults of all ages
- Students graduating from our lab are very successful

Resources

i Senior-to-Senior Brochure

Sponsors

Overview of the Human Factors and

People

Aging Laboratory



Increase/Decrease Font S



Participant Information (F





News

Science20 featur



What is Huntington's Disease?

- Huntington's Disease(HD) is a devastating, degenerative brain disorder for which there is, at present, no effective treatment or cure. HD slowly diminishes the affected individual's ability to walk, think, talk and reason.
- Eventually, the person with HD becomes totally dependent upon others for his or her care. Huntington's Disease profoundly affects the lives of entire families: emotionally, socially and economically. This hereditary disorder in 1872, HD is now recognized as one of the more common genetic disorders.
- More than a quarter of a million Americans have HD (40,000) or are "at risk" of inheriting the disease from an affected parent. HD affects as many people as Hemophilia, Cystic Fibrosis or muscular dystrophy.
- info gathered from HDSA



Stages & Symptoms for HD

- Early Stage Symptoms of Huntington's Disease may affect cognitive ability or mobility and include depression, mood swings, forgetfulness, clumsiness, involuntary twitching and lack of coordination.
- Mid-Stage As the disease progresses, concentration and short-term memory diminish and involuntary movements of the head, trunk and limbs increase. The most common involuntary movement is *chorea**. Walking, speaking and swallowing abilities deteriorate.
- Late Stage Eventually the person is unable to care for him or herself. Death follows from complications such as choking, infection or heart failure.
- info gathered from HDSA



More info about HD & HOPE!

- HD typically begins in mid-life, between the ages of 30 and 45, though onset may occur as early as the age of 2. Children who develop the juvenile form of the disease rarely live to adulthood. HD affects males and females equally and crosses all ethnic and racial boundaries. Each child of a person with HD has a 50/50 chance of inheriting the fatal gene. Everyone who carries the gene will develop the disease.
- In 1993, the HD gene was isolated and a direct genetic test developed which can accurately determine whether a person carries the HD gene. The test cannot predict when symptoms will begin. However, in the absence of a cure, some individuals "at risk" elect not to take the test.
- info gathered from HDSA



What is Multiple Sclerosis (MS)?

- Multiple sclerosis (MS) is a life-long chronic disease diagnosed primarily in young adults. During an MS attack, inflammation occurs in areas of the white matter of the central nervous system (nerve fibers that are the site of MS lesions) in random patches called plaques.
- Physicians use a neurological examination and take a medical history when they suspect MS. Imaging technologies such as MRI, which provides an anatomical picture of lesions, and MRS (magnetic resonance spectroscopy), which yields information about the biochemistry of the brain. No single test unequivocally detects MS. A number of other diseases produce symptoms similar to those seen in MS.
- This and More info found at the MS Society web site.



Symptoms of MS

- Symptoms of MS may be mild or severe and of long duration or short and appear in various combinations. The initial symptom of MS is often blurred or double vision, red-green color distortion, or even blindness in one eye. Most MS patients experience muscle weakness in their extremities and difficulty with coordination and balance. About half of people with MS experience cognitive impairments such as difficulties with concentration, attention, memory, and judgment.
- The cause of MS remains elusive, but most people with MS have a normal life expectancy. The vast majority of MS patients are mildly affected, but in the worst cases, MS can render a person unable to write, speak, or walk.
- This and More info found at the MS Society web site.



More Info about MS & HOPE

- There is as yet no cure for MS.
- Until recently, steroids were the principal medications for MS. While steroids cannot affect the course of MS over time, they can reduce the duration and severity of attacks in some patients.
- The FDA has recently approved new drugs to treat MS. The goals of therapy are threefold: to improve recovery from attacks, to prevent or lessen the number of relapses, and to halt disease progression.
- This and More info found at the MS Society web site.



What is Amyotrophic lateral sclerosis (ALS)

- Amyotrophic lateral sclerosis (ALS) is a fatal, neurodegenerative disease
 that attacks nerve cells and pathways in the brain and spinal cord. When
 these cells die, voluntary muscle control and movement dies with them.
 People with ALS in the later stages of the disease are totally paralyzed, yet
 in most cases, their minds remain sharp and alert.
- ALS struck Yankee Hall of Famer Lou Gehrig in 1939. He died two years later, but ALS is still commonly known as Lou Gehrig's disease.
- This & more info can be found at www.alsa.org

Home About ALS

About Us

Our Research

In Your Community

Advocate

Get Involved

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THE ALS ICE BUCKET CHALLENGE



WHAT IS ALS?

WHAT WE DO

DONATE



FACT CENTER.....

The ALS Association is incredibly grateful for the outpouring of support from people all over the world. We thank you for participating in the Ice Bucket Challenge and for making donations to support our fight against this disease.

Please visit our Frequently Asked Questions for important information about our mission, structure and finances. We also want to provide you with information about our plans to put the Ice Bucket Challenge donations to work, supporting our short-term



More Info about ALS & HOPE

- The facts about ALS are sobering: Every day, an average of <u>15</u> people are newly diagnosed with ALS more than <u>5,600</u> people per year. As many as <u>30,000</u> Americans may currently be affected by ALS. The average life expectancy of a person with ALS is two to five years from time of diagnosis.
- There is no known cause or cure, but with recent advances in research and improved medical care, many patients are living longer, more productive lives.
- In keeping true to the spirit of the game Gehrig loved best, ALSA seeks to covers all the bases - research, patient and community services, public education, and advocacy - in providing help and hope to those facing the disease.
- This & more info can be found at www.alsa.org



Toward Evidence-Based Practice

 Medical students do the wrong things in a clinical setting not because of a deficiency in knowledge, but because they don't make good decisions. They know a lot, but they don't think systematically.

(Arthur Elstein, Ph.D, University of Illinois, presenting a lecture at University of Washington, April 27, 1999).



Staging

 . . . the sequencing of management so that current problems are addressed and future problems anticipated.

Voice Archiving!



No Detectable Speech Disorder

. . Diagnosis has been made, but often speakers do not yet exhibit speech symptoms in those with spinal presentation.



Obvious Speech Disorder with Intelligible Speech

.. both the speaker and listener notice changes in speech - speakers may perceive extra effort needed for speech.



Reduction in Speech Intelligibility

... changes in speaking rate, articulation, and resonance are all evident.



Natural Speech - Supplemented

... natural speech is no longer a functional means of communication in all situations.



No Functional Speech

... speakers with advance bulbar ALS have lost functional speech due to profound weakness.

Consider: "I am effective at conversing with:

- 1. familiar persons in a quiet environment.
- 2. strangers in a quiet environment.
- 3. a familiar person over the phone.
- 4. young children.
- 5. a stranger over the phone.
- 6. while traveling in a car.
- 7. someone at a distance.
- 8. someone in a noisy environment.
- 9. before a group.
- 10. someone in a long conversation (>1 hour)."



Techniques for Improving Comprehensibility (Speaker)

- Provide listener with context
- Don't shift topics abruptly
- Use turn-taking signals
- Get your listener's attention
- Use complete sentences
- Use predictable types of sentences
- Use predictable wording
- Rephrase you message
 - Yorkston, Beukelman, Strand, & Bell



Techniques for Improving Comprehensibility (Speaker)

- Accompany speech with simple gestures
- Take advantage of situational cues
- Make environment as friendly as possible
- Avoid communication over long distances
- Use alphabet board supplementation
- Have a handy backup system



Techniques for Improving Comprehensibility: (Listener)

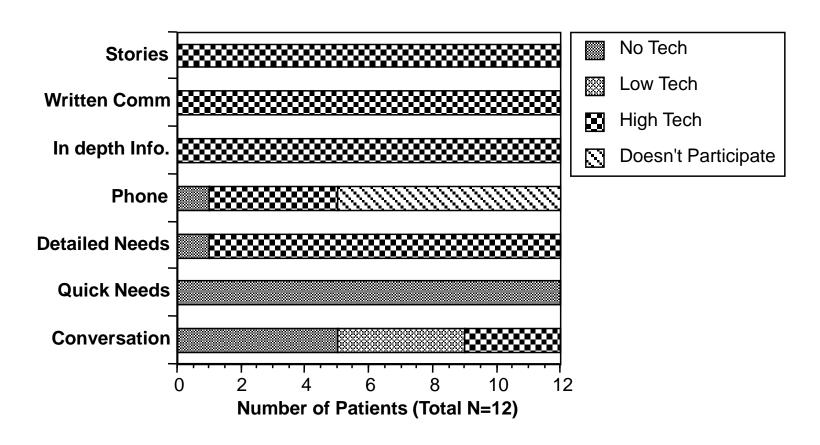
- Know topic of conversation
- Watch for turn-taking signals
- Give your undivided attention
- Choose time and place to talk
- Watch the speaker
- Piecing together the cues
- Make the environment work for you
- Avoid communicating over long distances



Techniques for Improving Comprehensibility (Listener)

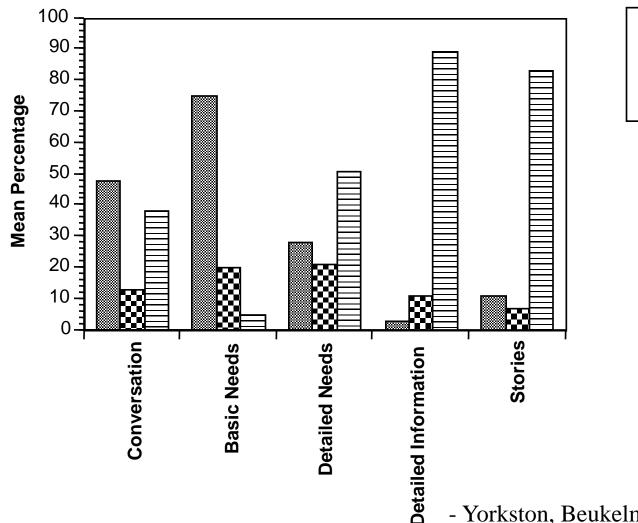
- Make sure
- your hearing is as good as possible
- Decide on and incorporate strategies for resolving communication breakdowns
- Establish some rules of the game
- Facilitate communication with others

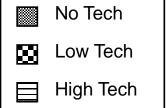
Category of AAC Method(s) Used "Most of the Time" by Communicative Activity





Overall AAC Method Use Breakdown by Communicative Activity (N=6)

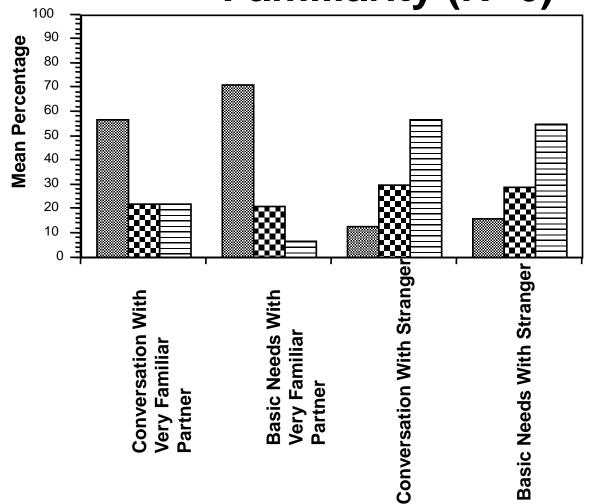


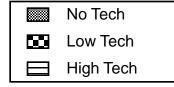


- Yorkston, Beukelman, Strand, & Bell



Use of AAC Methods by Partner Familiarity (N=6)







Considering Assistive Technology: What Works for the Individual



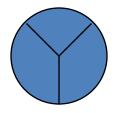


Assistive Technology Matching:A TEAM APPRAOCH

- The Person with the disAbility
- Circle of Support Family of Choice
- "Case" Managers
- Speech & Language Pathologist
- Occupational Therapist
- Physical Therapist
- Engineers



Human Activity Technology (HAAT) Model



- Human: represents the skills and abilities of the person with a disability
- Activity: a set of tasks to be performed by the person with a disability
- <u>Context</u>: the setting or social, cultural and physical contexts that surround the environment in which the activity must be completed
- Assistive Technology: devices or strategies used to bridge the gap between the person's abilities and the demands of the environment



AAC evaluation – Educate the Individual

- Needs and environmental assessment
 - Communication partners
 - Communication locations
 - Communication modes
 - Message needs

Hangout with intent

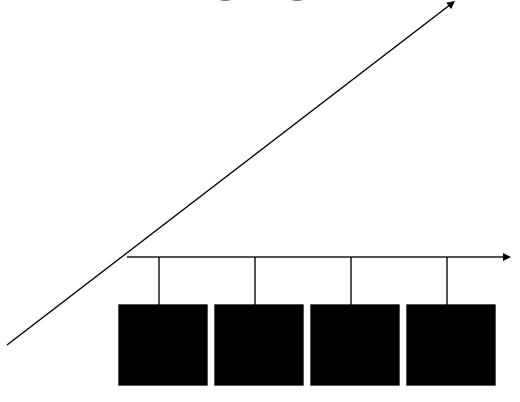


4 Purposes of Communication

- Express needs and wants
- Information exchange
- Social closeness
- Social etiquette



Promoting Strengths & Managing Weaknesses





The AAC Evaluation

- Language abilities
 - Language comprehension
 - Language production (vocabulary, grammar, morphology)
 - Spelling and writing abilities
 - Mechanics of writing
 - Speech function
- Speech function

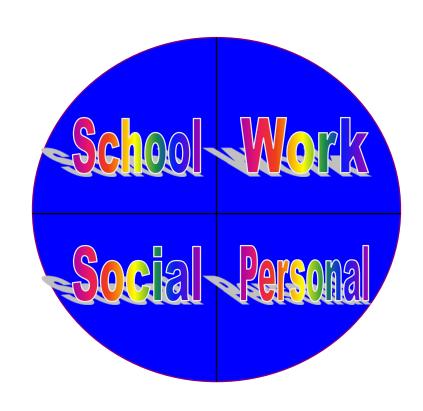


MAC Factors influencing AAC strategies

- Word retrieval/semantic breakdowns
- Auditory comprehension difficulty
- Reading comprehension difficulty
- Reduced ideational skills
- Memory impairment
- Spelling/phonological processing impairment



A Holistic Approach





Selection of an AT Device

Depends on an analysis of the following conditions:

- Prior experience or knowledge, and interests;
- The individual's specific strengths, weaknesses;
- The specific device (reliability, ease of operation, technical support, cost)
- Usefulness across settings
- Usefulness over time as symptoms manifest!



Most Effective Technological Products

- Able to level out the playing field
- Work in cross-settings
- Portable
- Easy to maintain
- Affordable to replace and/or maintain
- Good and reliable technological support
- Accessible training format



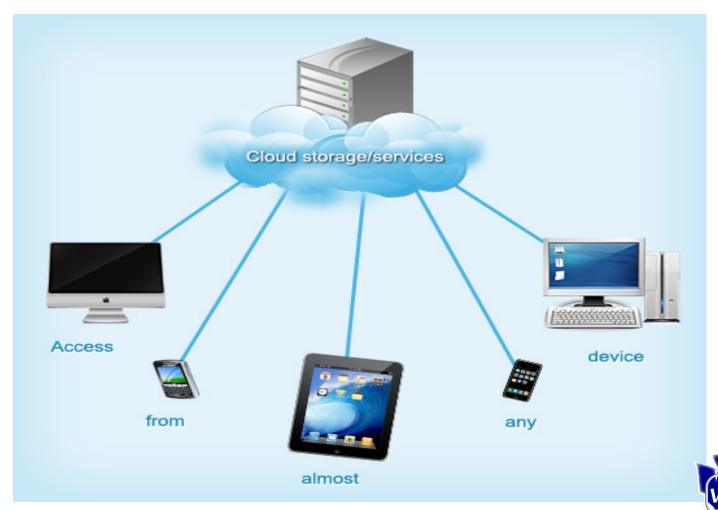
Future

- Level out the playing field
- The Future is Contextual
 - -GPS apps
 - Ads on Internet
 - -Smart watches
 - -Social Media





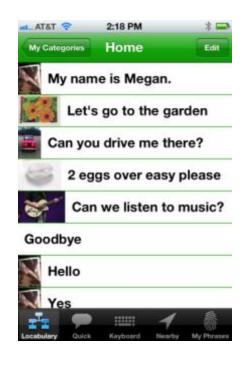
The Cloud is Here to Stay

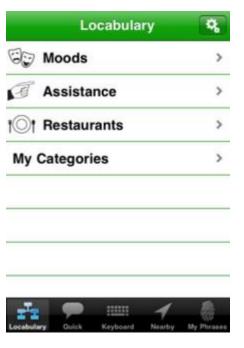




Locabulary







- Uses GPS to track user location and suggests appropriate vocabulary based on location
 - ie: McDonald's,Starbucks
- A keyboard to type for textto-speech
- User can tag their own locations and create vocabulary for each location

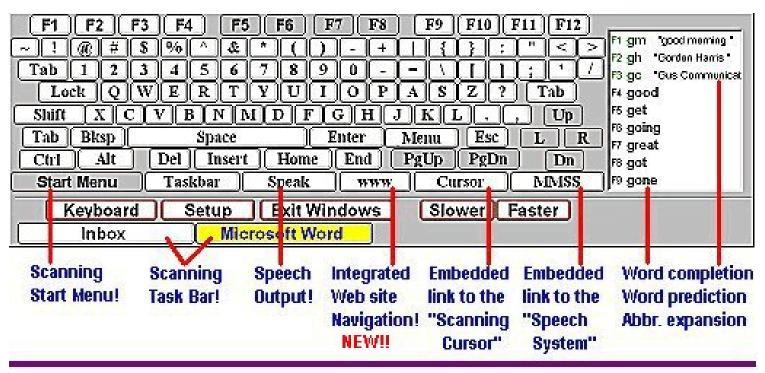


Alphabet + Semantic Topic Board

Small Talk	Food	Church	Health	Schedule
Family	ΔΒΟΙ	D E F G	Yes	Wait
Personal		L M N O	No	Not done
Transportation	P Q R S			Please stop
Trips			Start over	Not finished
Weather	WXYZ		Forget it	
Sports	Will spell words	Please repeat	Maybe	
Shopping	Point to first letter		Don't know	



On screen keyboards





Morse Code

2 switch option

```
INTERNATIONAL MORSE CODE
   TIME OF DASH EQUALS THREE DOTS
```



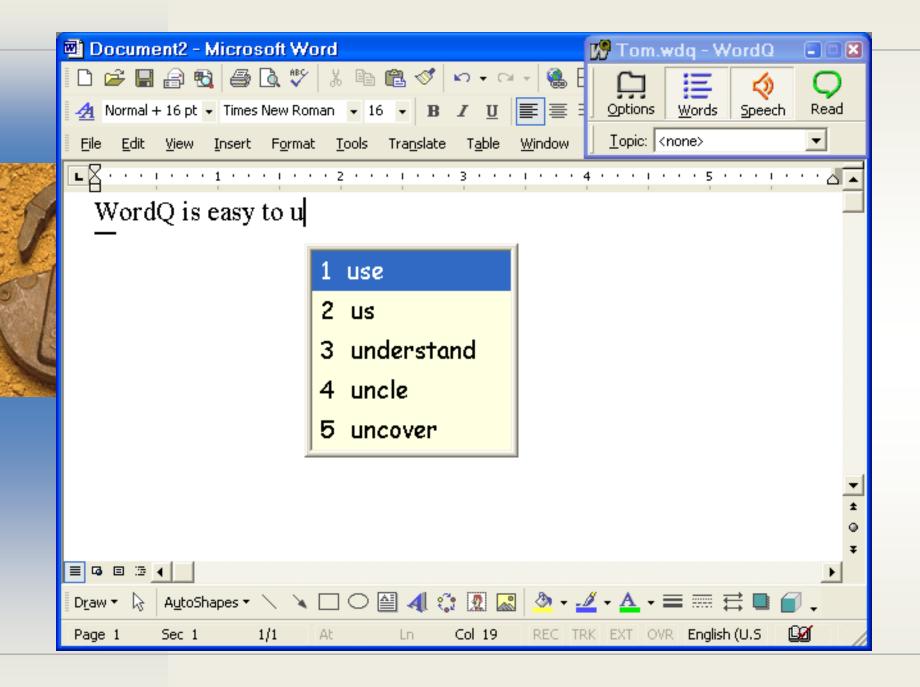
Rate enhancement techniques

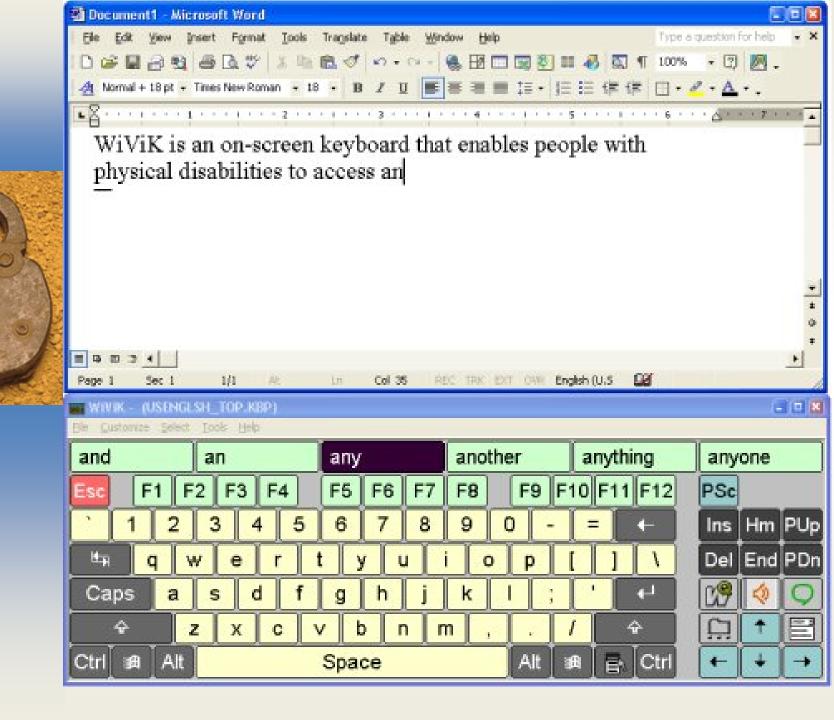
Generating text with these techniques is

• S...L...O...W...

Two techniques to enhance rate of production:

- Word prediction
- Abbreviated expansion







Abbreviated expansions (macros)

- AAC = Augmentative and Alternative Communication
- 3S = 3 spades
- 3C = 3 clubs
- 3H = 3 hearts
- 3D = 3 diamonds



Attention Getting Devices

Bicycle horns

Cow Bells



Battery Powered Doorbell





Voice Amplification Options



ChatterVox voice amplifier





Headset Mic



Transdermal

Mic



Microphone attachments





Voicette and Mini-Vox from Luminaud



Keyboard modifications





Keyboard labels





Access





Mouse Devices

- Smaller mouse options can help with control
- May need device that is switch accessible
- Or device that requires no hand or wrist movement & light touch







Big Track; www.infogrip.com;\$80

Tiny Mouse; http://www.chestercreek.com/TinyMouseOptical.html; \$15



DXT Fingertip Vertical Wireless Mouse

- Ergonomic Relaxed Neutral Wrist and Hand Position
- Precision Grip for Accurate Navigation
 - Small muscles and joints of the fingers have higher processing abilities
- Instantly Switches Between Right and Left Hand
- Video

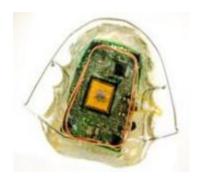


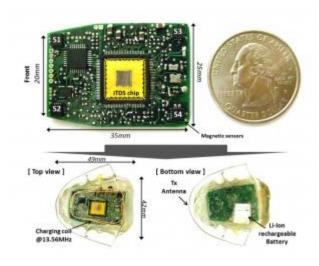




Tongue Drive System

- Wireless device that enables people with high-level spinal cord injuries to operate a computer and maneuver an electrically powered wheelchair simply by moving their tongues
- dental retainer embedded with sensors
- detect movement of a tiny magnet attached to the tongue
- Testing with iPods and iPhones





- GA Tech
- Shepherd Center and Rehab Institute of Chicago



HOME PRODUCTS TECHNICAL SUPPORT COMPANY EDUCATION MEET OUR CLIENTS FUNDING

Products / New Products

ASL brings innovative products to our clients! We are here to help each client reach their full potential – our team creates products and designs as a direct result of the needs of those we serve. Our goal has always been independence and equal rights for those we work with....







Specialty Products & Adaptors

Specialty Products & Adaptors

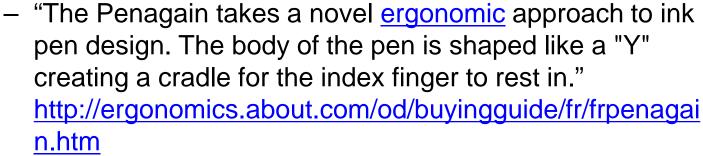
Specialty Products & Adaptors



Ergonomics









 Wide barrel pens can make it easier for some people to write due to their contoured shape. With a Fat Ergonomic Pen there's more surface area to grip which makes it easier to write.





Live Scribe Pen

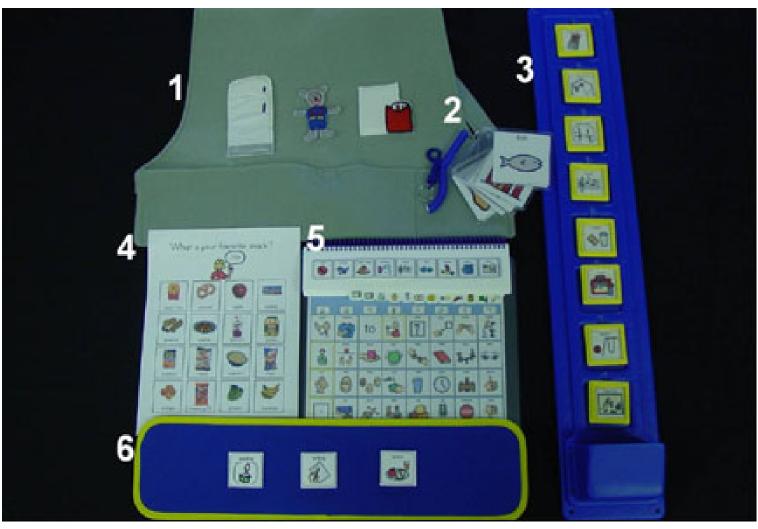
- Records what it hears and what you write
- Uses specific paper for playback
- Connects to computer by USB for saving
- Tap on note and playback from there
- Jump forward and back in notes
- Dictionary
- Translation Apps
- Purchase Apps online
- Demo







Light-Tech AAC Options





Mid-Tech AAC Devices





Which One???





LET'S TAKE A LOOK AT SOME OPTIONS



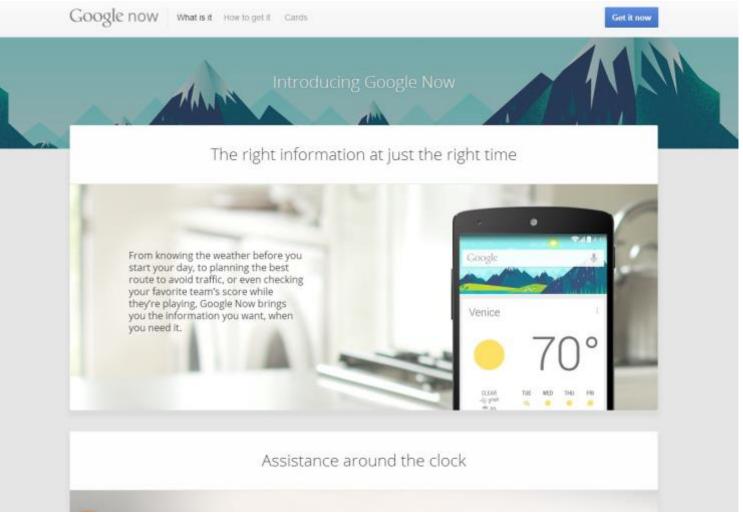








Google Now





Tasker



Tasker is a phone automation application that allows you to really unleash your android device's capabilities.

Tasker in a nutshell is a program that tells your device "When this happens, do this!"

- "When something is plugged into the headphone jack, open my music app"
- "When I open the navigation app, turn GPS on"
- "When my phone is connected to this cell tower, turn on wifi and connect to my home wifi"



Z Wave Modules

Z Wave modules differ from X-10 in that they work over a proprietary wireless network instead of existing wiring. Furthermore, instead of each module having to directly talk with the gateway, modules can communicate with each other.

This means that a command sent to the gateway is sent to all modules within range and each of those modules relay the command to all modules within their range, and so on, until the appropriate module receives the command.

This allows your network of modules to extend far out beyond the reach of the gateway itself making multiroom, multilevel, and exterior/interior implementation all on one network a possibility

Shown at right is a dimmable 3 prong lamp switch.



Amazon Echo

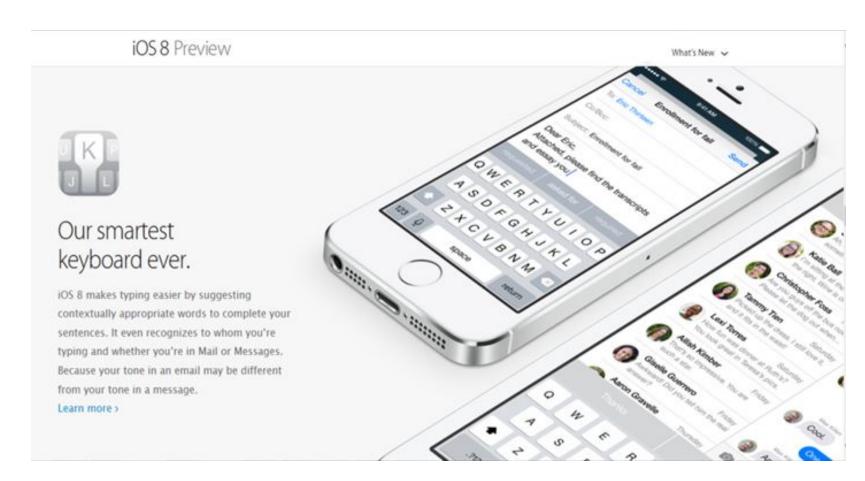




- Speech-controlled speaker system
- Voice recognition further distances
- Timers, news, information
- Invitation only
- \$199, \$99 Prime members



iOS 8: Typing made Easier





iMovie





- Share information via Facebook, Twitter, Email, or SMS
- Upload photos



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





Talkitt

- Enables people who have motor, speech, and language disorders to easily communicate using their own voice
- Translates unintelligible pronunciation from any language into understandable speech
- http://www.talkitt.com/

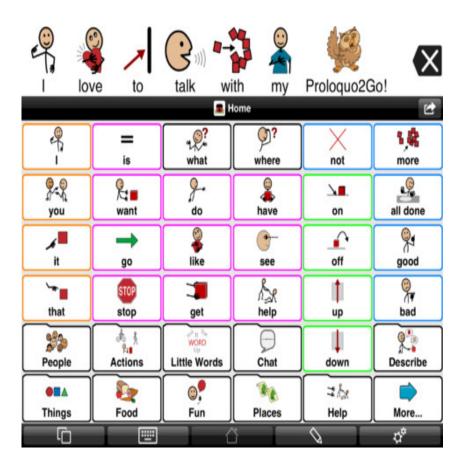












- 24 location max
- SymbolStix (default)
- Scrolling possible
- Side navigation remain constant
- Intuitive editing and creating
- Keyboard with picture/word prediction
- Price now \$79.99

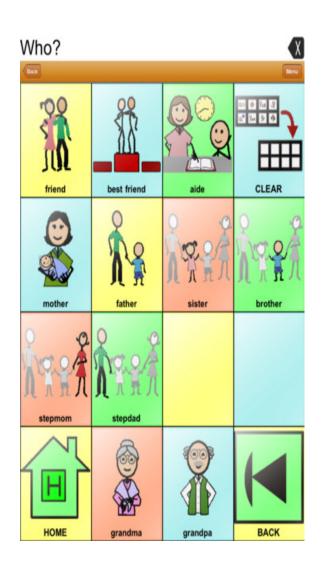








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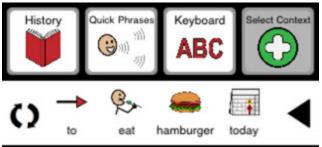








Tobii SonoFlex





- Available for the iPhone, iPad, Android, Kindle Fire, PCs and SGDs
- Combines core, quick- hits
 & situational vocab.
- 50 pre-made context packages
- Intuitive programming
- Structure w/ flexibility
- Full App: \$99.99
- Lite vers.: Free





Tap to Talk

- For emergent communicators
- For Android, Kindle & Nook
- Library of 2K symbols
- Player: Free (comes w/ sample albums)
- Designer: \$99/yr or \$179
 lifetime
- Create/ modify w/ Designer









Speak it!

- Copy emails, documents, web pages, PDF files, and more; paste them into Speak it!, and have the text spoken back to you.
- Email text to speech files
- Make announcements over PA system
- Endless phrases and possible uses
- \$1.99





Apps for Relaxation





Breathe2Relax



- Portable stress management tool
- Detailed information on the effects of stress on the body
- Instructions and practice exercises to learn the stress management skill called diaphragmatic breathing









Pandora



- Free internet radio
- Create custom stations based on genre, song, artist







iZen Garden





- Choose from 100s of objects, plants and creatures to place in your garden
- Rake the sand and share your creations
- Helps you to center your mind, relax your psyche and relieve your stress



VGo Telepresence Robot

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









Our Question to You: What have You Learned today?





The Tools for Life Team



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