ASSISTIVE TECHNOLOGY FOR PEOPLE WITH NEURODEGENERATIVE DISORDERS

CLINICAL ASSESSMENT, INTERVENTION, AND ACCESSIBILITY CONSIDERATIONS

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Encompass Health Rehabilitation Hospital of Braintree
40th Annual Neurorehabilitation Conference
November 17, 2019

Disclosure Statement

Alex Burnham receives a salary from the Boston Home SNF (discussed in this presentation) and has been a past pilot research grant recipient from the National Multiple Sclerosis Society (not discussed here).

Objectives of this presentation

- Describe AT & service delivery process
- Identify funding opportunities and limits
- Highlight specific technologies that we have had some success with
- Consider adaptations to improve access to technologies
- Case study review
- Provide some local and national resources

AT Process & Funding

Assistive Technology defined:

"any item, piece of equipment, or product systems, whether acquired commercially off the shelf, modified, or customized, that is used to increase, maintain, or improve functional capabilities of individuals with disabilities"





Images: soetalk.org, alimed.com, nuance.com, permobil.com, nedisabledsports.org

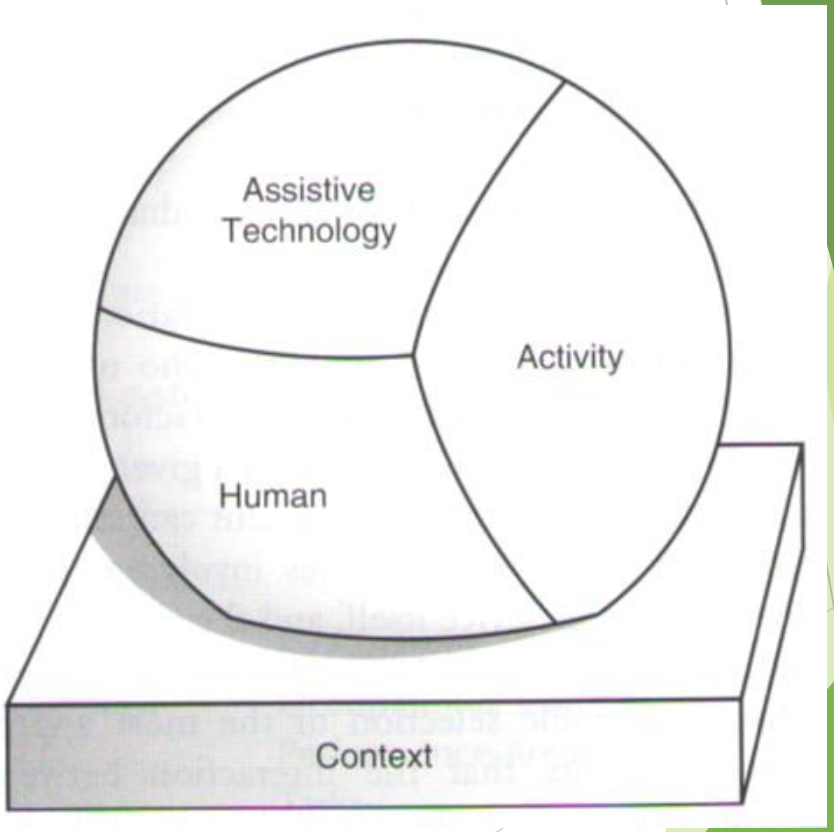
Assistive Technology Act Amendments of 2004. Pub. L. 108-364. 118 STAT. 1707.

What's the difference between AT & augmentative & alternative communication (AAC)?

- AAC is included here under the umbrella of AT
- Almost all forms of AT require communication and cognition supports to optimize access
- OT's, SLP's, ATP's, etc can be involved in many facets of design & implementation of AT for clients with and without communication disorders

Human Activity Assistive Technology (HAAT) Model

- Human
- Activity
- Assistive Technology
- Context



Cook, A.M. & Polgar, J. M. (2015). Cook & Hussey's Assistive Technologies: Principles & Practice. 4th edition. St. Louis: Mosby.

Hierarchy of AT Selection

Adapt activity or task

Commercially available mainstream tech

Commercially available rehab tech

Combine/modify commercially available products in an innovative way

Design/fabricate custom equipment

Cook, A.M. & Polgar, J. M. (2015). Cook & Hussey's Assistive Technologies: Principles & Practice. 4th edition. St. Louis: Elsevier.

Funding Assistive Technology

- **No** universal funding for Assistive Technology
- **Yes** funding for specific classes of devices to meet specific needs for specific individuals
- Funding can differ based on location, age, function, diagnoses, roles, goals, etiology, effort . . .
- Creates frustrating experience for the ***Client***, family members, caregivers, AT professionals, and other service providers

Public Funding

- *Medicare*: >65 or total disability, medical nec., DME
- *Medicaid*: income dependent, medical nec., DME
- *Veterans*: Must have service related injury
- *Voc Rehab*: Must have disability & voc goals
- *Worker's compensation*: Workplace injury
- *Schools*: Must have IEP, <22, differs by district
- State specific *AT Act programs*: MassMATCH.org

Private Health Insurance

- Varies by provider, plan, & employer
- Deductibles, prior authorizations, co-pays, & caps
- May dictate which provider/supplier can be involved
- May cover features that Medicare/Medicaid may not cover (i.e. mobility outside of home, mechanical standers)

Other sources

- Service clubs
- Private foundations
- Nonprofit organizations

Kiwanis Club, *Rotary Club*, *National MS Society*, *Muscular Dystrophy Association* *Travis Roy Foundation*, etc.

- Family/community fundraising efforts, GoFundMe, etc.

Opportunities may vary based on economy and giving trends

Assistive Technology services that are often funded (in pink)

- Evaluation of the technology needs of the individual (Assessment, trial, etc.)
- Acquisition of AT (report, funding, etc)
- Coordinating (ordering, delivery)
- Setup (adapting, fabrication, configuration)
- Training
  - Training client in use of technology
  - Training client in setting up/directing setup
  - Modifications
- Follow up/Follow along

Cook, A.M. & Polgar, J. M. (2015). Cook & Hussey's Assistive Technologies: Principles & Practice. 4th edition. St. Louis: Mosby.

Who funds equip & services for…

- A 62 year old with advanced MS in a SNF who wants to **operate lights & TV**
- A 17 year old with a spinal cord injury who wants to be able to **open the front door**
- A 43 year old with ALS who needs to access a computer to **Skype with family**
- A 82 year old with spinal stenosis who wants to **stay at home** and not move into a facility
- *How are AT devices and services funded in your treatment context?*

AT for Communication & Cognition

Low tech options

Dedicated devices as AAC options

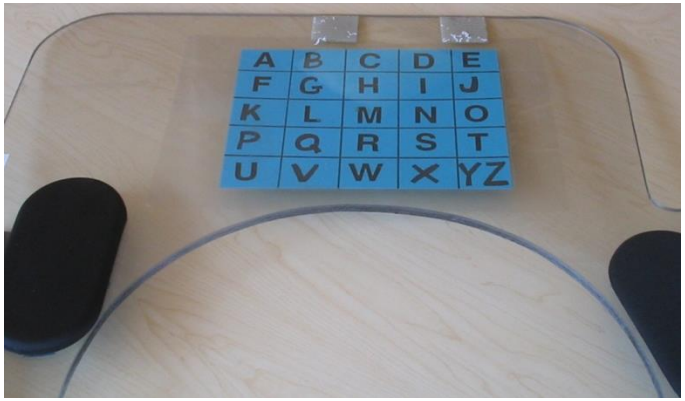
Mainstream technology as AAC options

Preparing to Implement

- PLEASE, please, please consider low tech first!
- Determine the communication goals BEFORE you select the equipment
- Thoroughly assess cognition, language, vision, and sensory feedback with input from PT/OT and medical specialists
- Identify funding sources upfront
- Include caregivers/family to the greatest extent possible during device setup and programming – they will act as personal trainers with the device users more than you!

Low Tech Options

- Voice and speech compensation
  - Text-based cues
  - Visual cues
  - Staff education signs
  - Electrolarynx



Low Tech Options

- Cognitive-communication aids
- Organizational tools
- Memory *resume* (instead of book format)
- Orientation pages (high-contrast sample:)

Designing Low Tech Options

- Visual access
- Motor access
- Consideration of target audience
- Available materials
- Sanitation considerations

Dedicated Communication Devices

- "High-tech" AAC options
- Accessible by individuals with nearly any type of motor, visual, language, or cognitive deficit
- Designed for most clinicians to program
- More readily integrated with wireless technology
- Most likely to be reimbursed by insurers

Setting and Client Factors Which Impact Device Selection

- Premorbid cognition
- Likelihood of device usage in daily routine
- Amount of caregiver access
- Social acceptance of device
- Client vs family expectations
- Cultural considerations

Accessing Communication Devices

- Touch enter/exit (manual/mouthstick)
- Capacitive stylus
- Switch-activated scanning
- Speech recognition
- Head/facial tracking
- Eye gaze tracking

Voice Amplification

- Designed to increase loudness with minimal change in quality for users with dysphonia
- Considerations
  - Rechargeable batteries
  - Microphone mounting configuration
  - Dexterity of user/caregivers
  - Cost

Selecting Mainstream AT for Communication Disorders

- Conventional computer access
- iDevices/Tablet computers
- Smartphones
- Speech recognition technology

Challenges with Mainstream AT

- Accessibility
- Durability
- Lack of reimbursement
- Service/upgrade follow-up
- Software of unknown origin/stability
- Confusion over device purpose

AAC Apps: A Few Field-Tested Examples

- Tobii SonoFlex
- Assistive Xpress
- Verbally
- Lingraphica SmallTalk/TalkPath
- iOS Notes
- Dragon Dictate
- SoundingBoard
- Scene Speak
- SayIt!
- JABTalk (Android)
- SpeechAssistant
- Jabberwocky (head-tracking access)

Speech Recognition

Speech Recognition Computer Access

- Nuance Dragon suite
  - Dialectical variations
  - Military spelling option
  - Specific vocabulary training
  - “Code words” for public area data entry
- Video conferencing options (eg, FaceTime, Skype, Hangouts) for moderate+ dysarthric speakers

Speech Recognition on Multiple Platforms

- PC: Dragon Naturally Speaking/Dragon Professional Individual, Windows Speech Recognition, Google Docs Speech Recognition
- Mac: Dragon Dictate for Mac/Dragon Professional Individual, Mac OS Dictation, Google Docs Speech Recognition
- iOS: Siri, Dragon Anywhere service, Dragon Dictation App
- Android: OK Google, TalkType Voice Keyboard, Speechnotes
- Plus others . . .

“Ideal” Characteristics for a Speech Recognition User

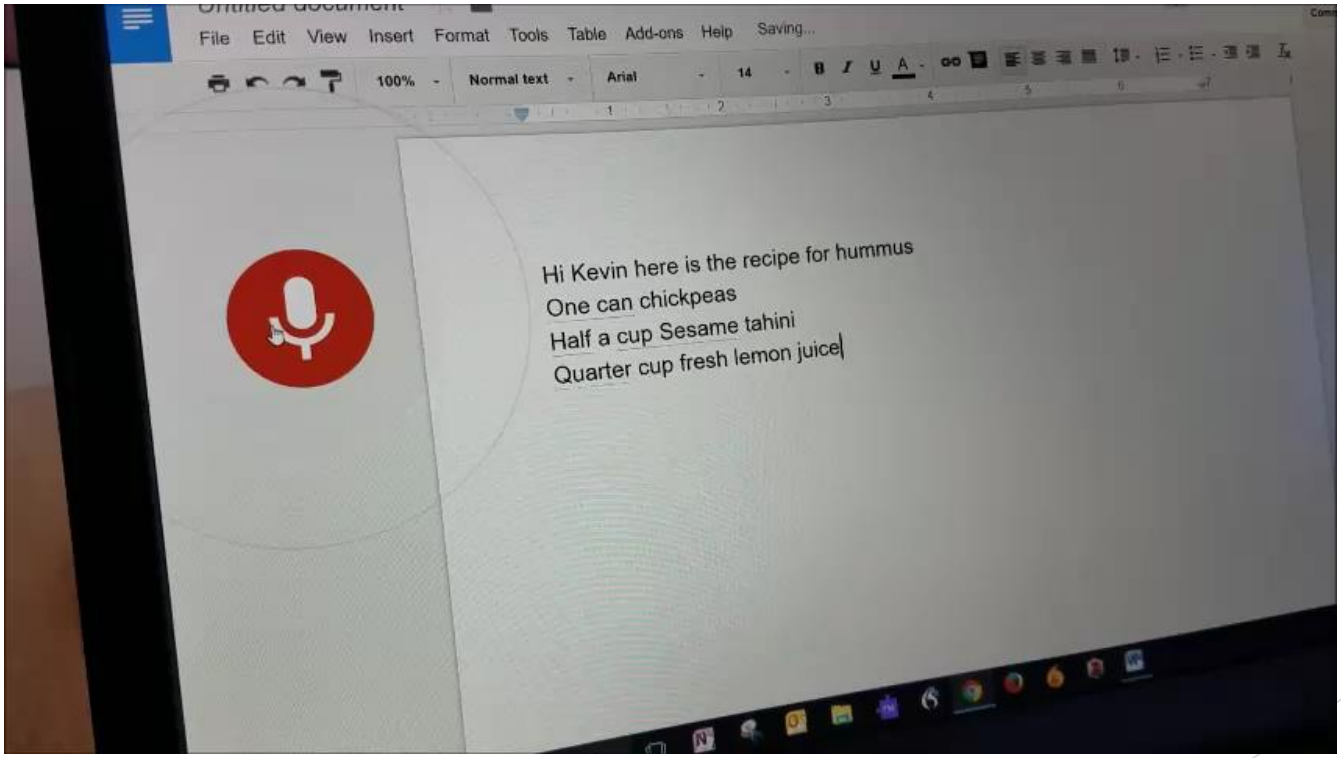
- Excellent articulation
- No accents: Foreign or regional
- Outstanding language skills
- Skillful with dividing attention
- Exceptional executive function
- Deep, consistent monotone voice
- Strong respiratory system
- High frustration tolerance

- Does anyone have all of these?

Comparing Platforms

Platform	Must Train Device?	Customize Vocab	Works Offline	Control Device by Voice?	Cost
GoogleDocs Dictation	None needed	✗	✗	✗	Free
Mobile Devices (Siri, OKGoogle)	None needed	✗	*Some* functions	✗	Free
Dragon	Yes	✓	✓	✓	$74.99-$300
Mac OS OSX Mavericks v10.9 or later	None needed	✗	✓	✗	Free

Non Native Speaker Using Google Docs Speech Recognition



AT for Addressing ADL & IADL

Electronic Aids to Daily Living

- Also referred as Environmental Control Units
- Control items in context of ADL
  - Infrared: Fans, lights, media devices
  - X-10: Fans, lights, media devices
  - Direct access: Nurse call, phone, hospital bed
- Variety of control interfaces
  - Direct select: physical/voice
  - Switch scanning

X-10 & Insteon

- Use home wiring *and/or* radio frequency
  - Keypads
  - Installable outlets
  - Motion detectors
  - Cameras
  - Mobile phone control
  - Hub available
- Some modern tech signals interfere with x10 (Bluetooth, Wifi, audio equipment, etc)

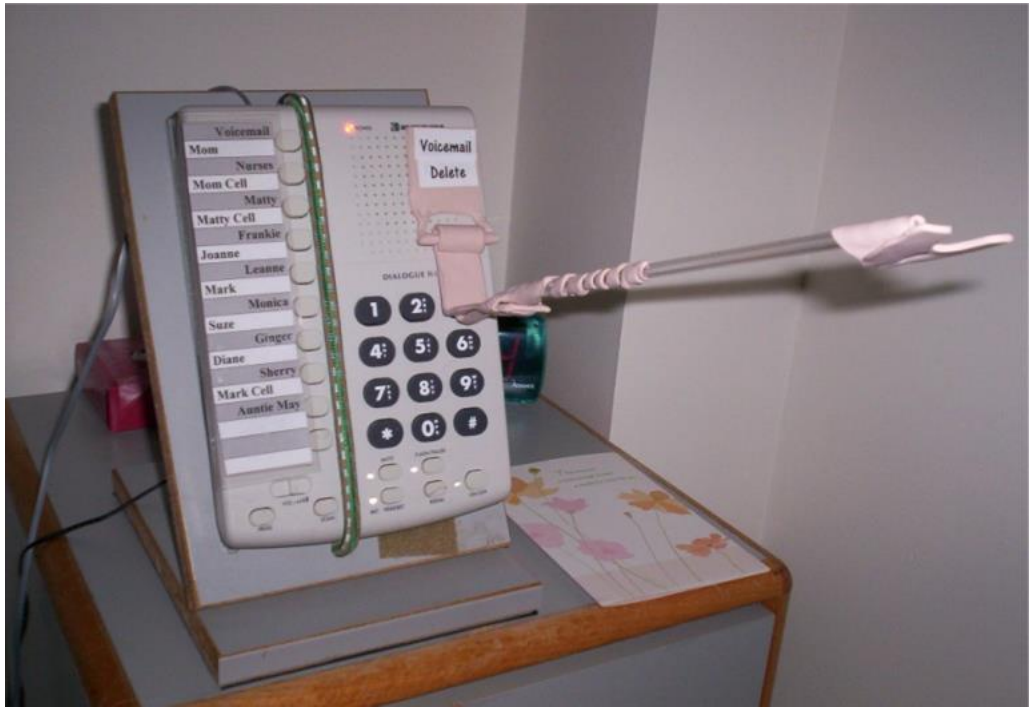
Adaptive Landline Phones

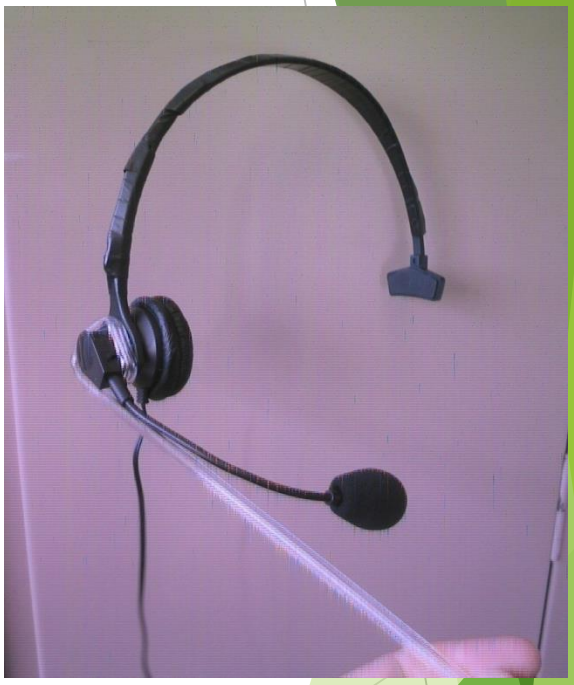
- **Serene Innovations HD 40-P**
  - Large Single button speed dial
  - Speakerphone
  - Operates off modular phone jack

- **Serene Innovations RCx-1000**
  - Speakerphone
  - RF remote button, 3.5mm jack for switch
  - Single switch scanning, auditory & visual cues

Images: sereneinnovations.com

Client-centered Adaptations to Landline Phones





Infrared ECU Control

- Mini Relax
  - Infrared remote
  - Learnable from another remote
  - Performs single switch scanning
  - Does 6 functions
- InVoca
  - Infrared speech-recognition remote
  - Self-learning, so can be used with speakers with dysarthria
  - Up to 25 functions
  - Limited functionality for newer TV/device models

Infrared, x-10 & Special Devices

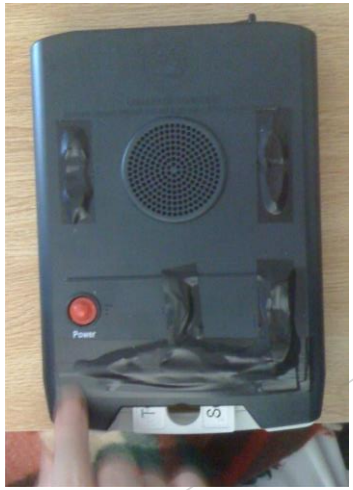
- Quartet: All In One System
  - Learns IR signals
  - Can use voice or switch activation (voice very OLD technology)
  - Operates x-10 Devices
  - With programming & equipment, can operate TV, bed, phone, nurse call, lights, peripherals, and other automatic environmental devices
  - Good reliability, very pricey

Smart Speakers

- Uses Speech recognition/AI
- Must be connected to Internet
- No “training” required
- Familiar to caregivers
- Compatible with connected home tech (WeMo, ITTT, Media, Hue)
- Compatible with web services (Calendars, To-do lists, messaging, etc)
- New features added regularly

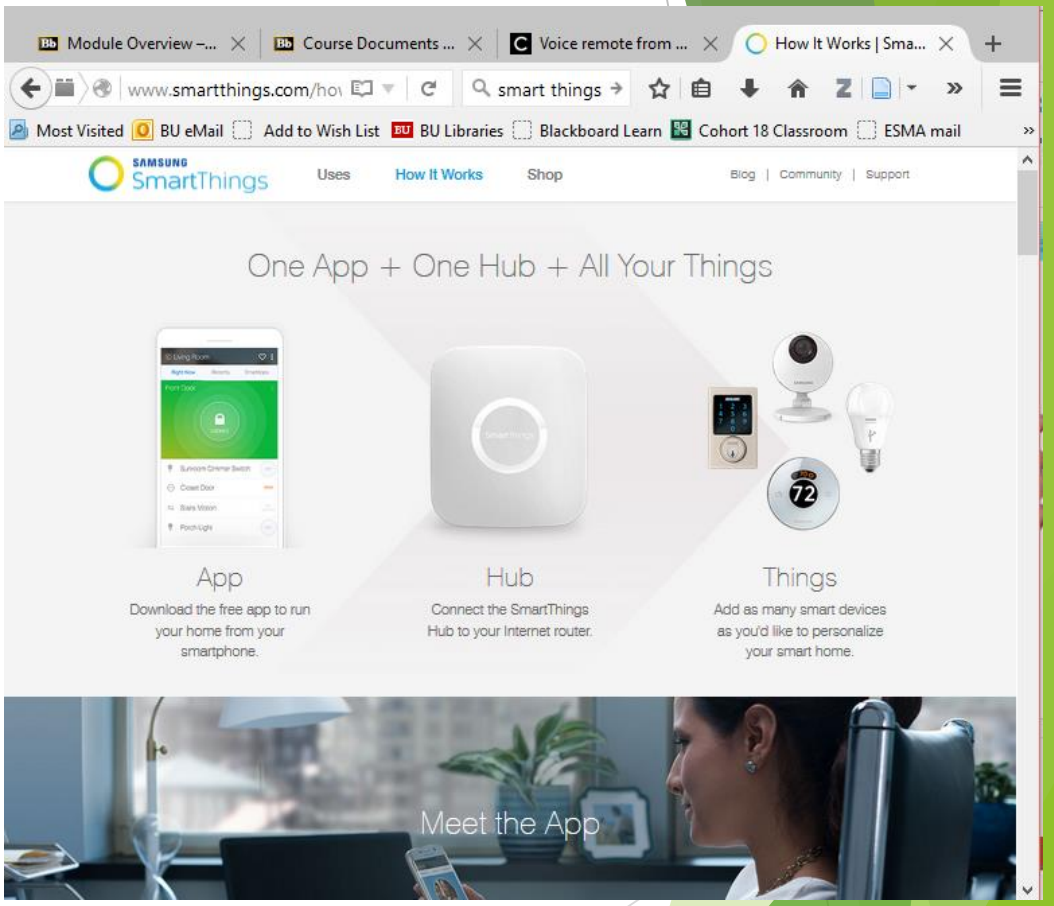
Talking Book Program

- Free for qualifying individuals through National Library Service
- Can adapt with alternative input
- Wireless remote and hands-free operation available
- https://www.loc.gov/nls/



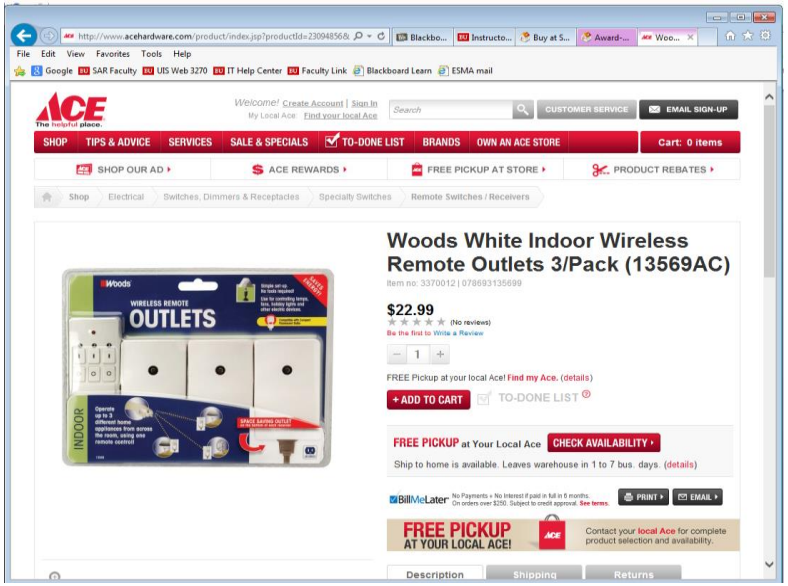
Internet of Things

- Home automation apps/devices gaining popularity
- Some use WiFi control, some x-10



Smart Home Devices in Action!

Oldie but goodie mainstream solutions



Mainstream Tech Adaptations

Adaptaions: Tools/Orthoses

Will the client require splinting, tools or positioning equipment to access the device?

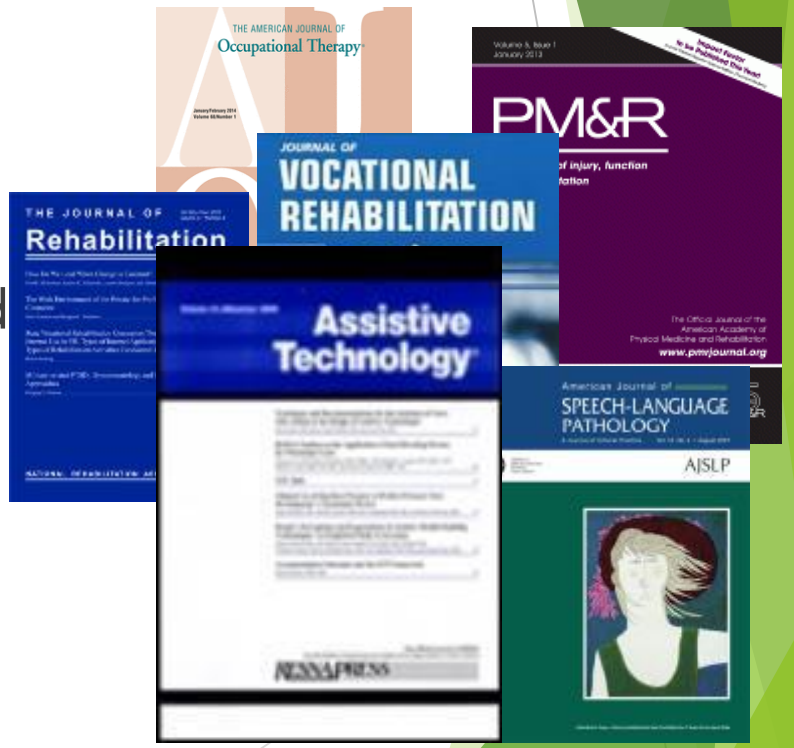
Evidence & Literature

Literature: Limitations

The *AT literature* has a **lack of quality evidence** related to best practices, assessment, intervention & outcomes measurement

Why?

- Tech changes rapidly
- Dependence on context
- Solutions must be individualized
- Client needs vary



(Lenker & Paquet, 2004; Anttila, et al., 2012)

Research Into AT for Communication Among People with PND

- Ball et al (2004). Acceptance of Augmentative and Alternative Communication Technology by Persons with Amyotrophic Lateral Sclerosis. Augmentative and Alternative Communication. 20(2): 113-122.
    - Excellent stability in acceptance of AAC options among 50 people with ALS regardless of when introduction of tech occurred during disease progression
- Baylor et al (2010) . Variables associated with communicative participation in people with multiple sclerosis: a regression analysis. American Journal of Speech-language Pathology. 19(2):143-53.
    - Demonstrates multifactorial rationale for facilitating improved communication (potentially using AT) for people with MS for social, vocational, and QOL purposes.
- Blake and Bodine (2002). An overview of assistive technology for persons with multiple sclerosis. Journal of Rehabilitation Research and Development, 39(2): 299-312.
    - Despite age, good overview of feature matching, funding, and device implementation process.
- Johnson et al (2009). Use of cognitive aids and other assistive technology by individuals with multiple sclerosis. Disability and Rehabilitation: Assistive Technology, 4(1): 1-8.
    - >50% of respondents to cross-sectional survey of n>1000 people with MS used electronic memory aids, with factors positively correlated with this approach including younger age, higher education, and increased fatigue.

Synthesis of Literature: AT Practice

- Natural context better than clinic for AT
  (Burke, et al., 2013; Gentry, 2008; Gentry, et al., 2015; Harvey, et al., 2013; Raghavendra, et al., 2013)

- Outcomes best assessed by client satisfaction and acceptance of AT *after* customization
  (Demers et al, 2002: QUEST 2.0)

Synthesis of Literature: Specifics

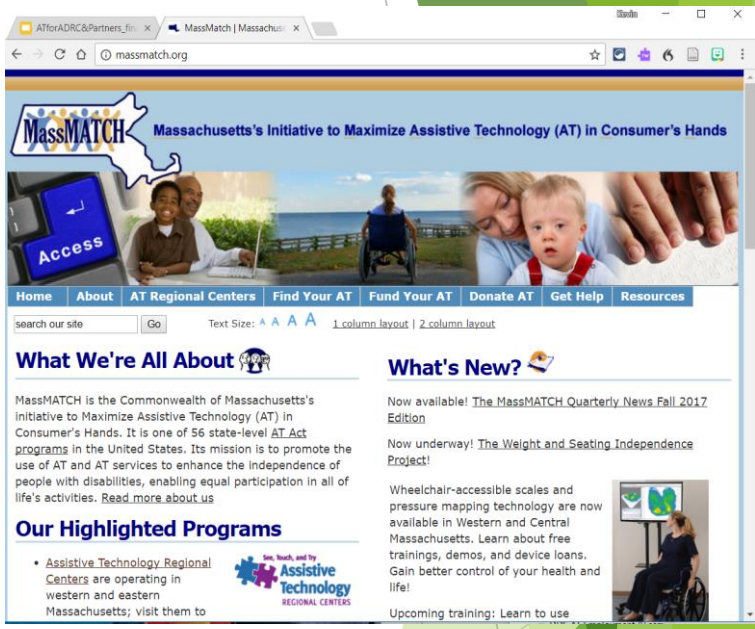
- Mobile devices improve **events & task recall** for adults with:
  - Chronic neuro conditions
    (Gentry, 2008; LoPresti, et al., 2008; Lindqvist, et al., 2015)
  - Autism Spectrum Disorder
    (Gentry, et al., 2010, Gentry, et al., 2015)

images: wikipedia.com

AT Funding & Support Resources

AT Act Programs: Find Statewide Resources

- Assistive Technology Act of 2004: improved coordination of AT services
- Each state has programs: i.e. device loan, alternative financing, DME re-use, etc.
- Find yours: ataporg.org/programs
- In MA: massmatch.org/



ATRC: Assistive Technology Regional Centers

- Try out AT for free!
- Compare: Hundreds of devices in stock
- Borrow devices up to 4 weeks
- Open for all to borrow: Individuals with disabilities, caregivers, professionals, etc.
- Three locations in MA:
  - Boston & Worcester: Easter Seals MA atrc@eastersealsma.org
  - Pittsfield MA: United Cerebral Palsy cmcconnell@ucpbershire.org

See, Touch, and Try Assistive Technology REGIONAL CENTERS

Resources

- State AT Centers funded by AT Act: https://www.ataporg.org/programs
- The International Society for Augmentative and Alternative Communication: https://www.isaac-online.org/
- The Rehabilitation Engineering and Assistive Technology Society of North America: http://www.resna.org/
- The Assistive Technology Industry Association: https://www.atia.org/
- Podcast: Assistive Technology Update http://Assistivetechnologyradio.com
- MA Telecom Equipment Distribution Program Landline adapted phones https://mass.gov/eopss/agencies/massedp/
- National Library Service: Talking Books http://www.loc.gov/nls/

Marie: Client Centered Solutions & Iterative Design

- 40-something female
- Advanced SPMS (Initial Dx ~age 20)
- Early onset bulbar symptoms inc. spastic dysarthria in addition to BUE ataxia and weakness
- LTC resident x 10 years, seeking accessible AAC options
- Photography enthusiast; always wants a good camera with her AT!

Future Directions for AT in Communication Disorders

- Implantable devices that indirectly improve voice and speech or directly allow for access
- Closer consideration of client preferences and premorbid characteristics in communication output (eg, VocalID)
- Continued increase in seamless integration into mainstream technology

Future Directions for AT in ADL/IADL

- Improvements in environmental control using computer/tablet/smartphone
- Improvements in speech recognition and other hands-free access technology
- Evidence and literature without "tech expiration"
- Evidence, smart learning, and support literature for clients of all abilities
- Reduction in price/availability of funding

THANK YOU FOR YOUR SUPPORT AND TIME!

- EXTREMELY special thanks to Kevin Berner, OTD, OTR/L, ATP, (Canton Public Schools, Canton, MA) whose input, research, and inspiration were instrumental in composing earlier drafts of this presentation.
- Questions? Thoughts? Concerns?

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