



## **Together Apart: Optimizing AT for People with Advanced MS During the Pandemic (ATPAP-39)**

Alex Burnham, MS, CCC-SLP, MSCS  
Director of Rehabilitation and TBH Institute  
The Boston Home (Dorchester, MA)

Alex Burnham has **one** Financial Relationship to disclose: salaried employee of the Boston Home, the primary location of clients to be discussed.

Alex Burnham has **one** Non-financial Relationship to disclose: unpaid consultant for National Multiple Sclerosis Society with content to be discussed during this presentation.

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  - ACVREP Start Code: blue179

Participants in this session will be able to:

- 1) identify at least 3 disorder-specific motor, sensory, cognitive, or personalized access needs and considerations in clients with advanced MS for optimizing AT for remote access to family, friends, and caregivers in the context of pandemic-related isolation;
- 2) describe one or more ways to facilitate appropriate feature matching, device/software selection, and accessibility settings modifications to promote independent and functional access for medically isolated clients with multimodal impairments d/t neurodegenerative disorders;
- 3) recommend at least three appropriate funding sources or alternative resources for AT selection newly available or expanded during or following the COVID-19 pandemic for clients with acquired communication and access deficits due to neurodegenerative disorders.

- 96 bed inpatient facility in Dorchester, MA, for adults with advanced multiple sclerosis (MS) and other progressive neurological disorders (PND)
- “Hope over Hardship”
- Offers long-term and outpatient care
- Designated a *Center for Excellence in Long Term Care* by the National MS Society
- Harmon Apartments – 36 accessible IL units opened May 2019



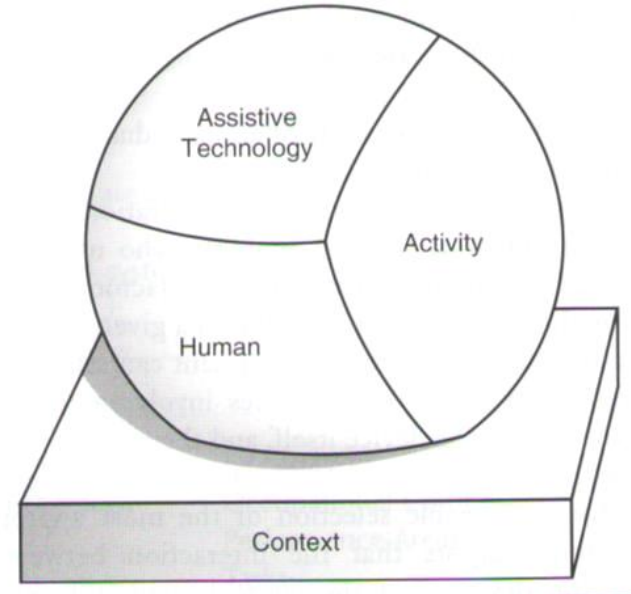
Images: <https://www.thebostonhome.org>

- Offers PT, OT, SLP, seating/mobility, and Assistive Technology design and implementation services
- Integrated technology within facility
  - Customized complex rehab wheelchairs
  - Overhead lifts for transfers
  - AWID elevator call system
  - Reck MUVI assisted exercise systems
  - Sigmacare electronic medical record
  - WiFi for administrative applications and resident access
  - Adaptive computer lab w/ iPad kiosk & desktop magnifier
  - iPad access grant project
  - Apple TV/streaming services/videoconferencing access
  - Multiple resident-centered student projects



The usual TBH hierarchical approach to selecting AT:

- Human
- Activity
- Assistive technology
- Context



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





- Slowly progressive muscle weakness, generally from LE to UE
- Presence of spasticity
- Possible development of ataxia
- Sensory impairments
  - Low vision/optic neuritis
  - Paresthesias
  - Pain/neuralgia
  - Tingling/numbness
- Temperature regulation dysfunction
- Communication impairments
- Cognitive dysfunction
- Behavioral changes
- Fatigue

- Accessibility
- Durability
- Limited or lack of insurance coverage
- Service/upgrade follow-up
- Software of unknown origin/stability
- Confusion over device purpose

## Early pandemic (March-June 2020)

- Residents > staff affected
- 24/96 Covid (+) residents, 1 death
- Set up isolation “Special Care Unit”

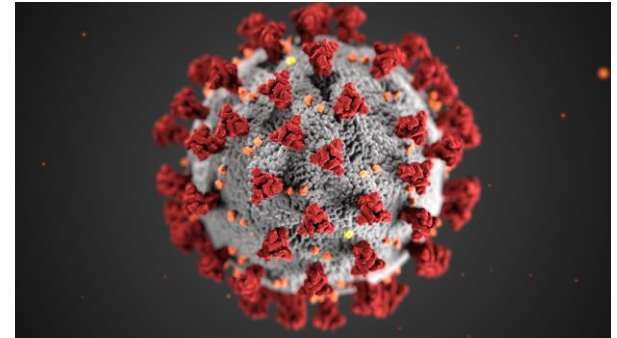
## Pre-vaccination phase (July-December 2020)

- Staff > residents affected
- More consistent testing protocol for vigilance
- Limited supervised family visits

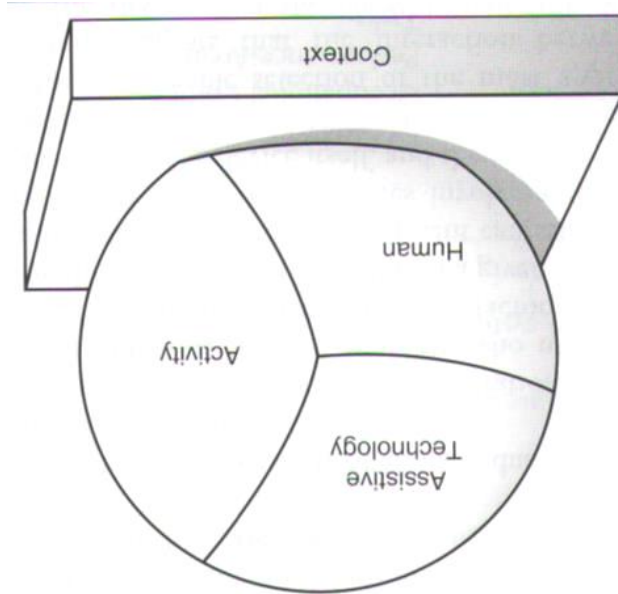
## Post-vaccination phase (January-July 2021)

- Slow reopening of group activities, gym access, communal dining
- Reopening more consistent and less structured family visits
- 98% resident vaccination acceptance by March 2021 (87.3% nationally)
- 80% staff vaccination by July 2021; mandatory after Oct 2021 (79.7% nationally)

## Vicious variants! (August 2021-present)...



1. Initial attempts to reduce Covid entry/transmission
2. Isolation of single-resident (+) Covid cases
3. Development of isolation unit for multiple-resident (+) Covid cases
4. Evolving best practices to minimize second-wave Covid entry/transmission
5. Ongoing surveillance/outbreak staff/resident testing
6. Transition to increased cognizance of social distancing & PPE utilization
7. Expansion of rehabilitation service delivery and MD access via telepractice



Our world flipped upside down to prioritize instead:

- Context (Covid+ or not)
- Assistive technology
- Activity (mostly external communication)
- Human

Inventory existing resident AT and ID gaps/needs



Select dedicated AT for isolation rooms and unit



Create routine sanitization protocols and schedules



Identify staff who can set up, operate, and modify AT for critically ill residents



Close communication with family/caregivers to establish AT access routines



Design/fabricate easily cleaned/disposable auxiliary materials (e.g., mounts)

Still considering pre-Covid criteria such as:

- When vocal communication or neurotypical access is becoming less efficient, functional, or effective
- When the person with PND or close caregivers request it
- When future decline in neurotypical access and vocal communication is anticipated in near future

New considerations:

- Where AT can be positioned with minimal supports
- What mainstream tech families/caregivers possess externally
- How staff can be trained to set up, operate, and troubleshoot AT even under mountains of PPE!



- Almost all residents = Medicaid recipients, which suspended more stringent reviews for critical DME
- Seeking donations (\$/old devices) from families, friends, and other sources to repurpose for residents
- Bulk purchases of tablet/EADL control devices which could be added to existing family accounts for ease of connectivity
- Upgrade WiFi to support onboarding of more & “smarter” devices
- Non-profit grants from disorder-specific and disability services





- Expanded appreciation for resilience in people with advanced MS
- Mainstream technology is not so fragile or inaccessible after all
- Accessibility and connectivity is more vital to QOL and service delivery than ever before
- External communication partners can learn new tricks too
- Video education to prepare for alternative caregivers to facilitate AT implementation
- Telepractice can be effective and efficient independent of Covid infections

# Marie: A Case Study in Client-centered Solutions & Iterative Design for Communication AT During Covid

- 50-something female with advanced SPMS (Initial Dx ~age 20)
- Early onset bulbar symptoms c/w spastic dysarthria in addition to BUE ataxia and weakness, progressing to quadriplegia
- LTC resident x 12 years, seeking accessible AAC options for most of this time as motor symptoms worsened and device(s) evolved
- Photography enthusiast -- always wants a good camera on her SGD!
- Son, mother, and stepfather unable to visit face-to-face for 4 months d/t facility quarantine (Mar-June 2020), then on limited basis until mid-2021

# Future Directions for AT Assessment and Development – Covid or Not!

- Increase integration of IoT into complex rehab tech to permit more client autonomy with EADL and environmental control
- Plan for unexpected changes in service delivery models
- Create redundancies in education, data storage, and functional capacity in case of loss of access to caregivers or device functionality
- Help residents help themselves by explaining AT to unfamiliar providers
- Develop emergency offline or simple portable AT tools that can travel with clients to hospitals, isolation wards, alternate care facilities, etc
- Place password/passcode lists in secure but retrievable status

Demo of VoiceITT app for dysarthric speech-speech synthesis:  
<https://apps.apple.com/us/app/voiceitt/id1212106553/>

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

<https://data.cms.gov/covid-19/covid-19-nursing-home-data>. Accessed 1/12/22 with data updated as of 12/26/21.

All other uncited images/videos are provided by the author.

Ask an MS Expert: Assistive Technology for People with MS (livestreamed 6/4/2021):  
[https://youtu.be/b76P2qD\\_8R0](https://youtu.be/b76P2qD_8R0)

National MS Society Clinical Bulletin: AT & AAC for People with MS:  
[https://nmsscdn.azureedge.net/NationalMSSociety/media/MSNationalFiles/Brochures/Clinical\\_Bulletin\\_Assistive\\_Technology.pdf](https://nmsscdn.azureedge.net/NationalMSSociety/media/MSNationalFiles/Brochures/Clinical_Bulletin_Assistive_Technology.pdf)

*THANK YOU FOR YOUR TIME!*

*aburnham@thebostonhome.org*  
*<https://www.thebostonhome.org>*

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