

“I Have a Hope” – Finding a Voice after 20 Years

Abstract:

Little is known about the effectiveness of using portable electronic devices for those with long-standing acquired brain injuries. This case study follows one client who acquired an injury at age 40 and sustained global aphasia. For 20 years, the client refused the majority of rehabilitation; however repeated, “I have a hope.” As a result, few gains were achieved, negatively impacting relationships, activities of daily living, and managing change.

Using his sole goal of re-establishing communication, a Dynavox M3, and later, an iPad with Proloquo2go was introduced. The client attained new skills, made a successful transition to supportive living, reconnected with family members, and participated in the community. He also demonstrated a renewed motivation for rehabilitation and a willingness to take risks. This presentation will demonstrate the client’s journey through video clips, outcomes reporting and interviews. The past five years of individualized, multi-trial training provided him with strategies and bestowed him with new hope for his independence.

Adults who have suffered a brain injury may be left with ongoing speech, language and communication difficulties. Some individuals may recover all or most of their speech and language, but many will be left without functional communication. Augmentative and alternative communication methods may provide tools, techniques and strategies to improve functional communication. In addition to the difficulties in communication, these individuals may have associated deficits in cognition and memory, as well as problems with higher executive functions.

As adults, all individuals have a need to (cited in: Condeluci, 1995; Halpern, 1993; Wagner, Newman, Cameto, Garza and Levine, 2005; all cited in McNaughton and Beukelman, 2010, p. 4):

- Have a safe place to live
- Participate in meaningful activities
- Maintain a reliable source of income and access to needed services
- Develop friendships and intimate relationships

These goals are equally important for individuals with brain injury, and can provide structure for the delivery of rehabilitation services. In order to attain these goals, the development of communication skills and strategies will assist and facilitate them. Through the progression toward these life goals, positive enhancements will be seen in self-determination and self awareness, and ultimately, in Quality of Life.

There are many factors which have potential impact on the success in the implementation of augmentative communication. The individual’s skills and communication needs, social supports, motivation, barriers in the environment, access to training, communication facilitators, and the match of the person to the technology all have bearing on the degree to which a communication system will be integrated into day to day activities. The “overall intervention goal is to assist persons with aphasia to be functional communicators who can participate in ways that enhance their autonomy and maintain or even expand their social networks” (Beukelman et al, 2008 -1, p. 263).

During the course of several years of rehabilitation, and the introduction and implementation of speech generating devices, several factors contributed to success, and made significant strides towards independence and autonomy.

1. Case Facilitator – provided training, practice, problem-solving, programming and technical support; identified vocabulary (Beukelman et al, 2008 – 1, p262); primary lead in developing goal areas, barriers, and strengths; sought out additional assistance and supports; coordinated services.

2. AAC Specialist – provided assessment, recommendations for equipment, strategies for vocabulary organization; strategies for visual supports (Beukelman et al, 2008 – 1, p.263)
3. Introduction of the iPad with Proloquo2Go – this mainstream technology made the AAC application more acceptable to the client, his family, and his community. The wide variety of low cost applications allowed him to not only communicate, but to share photos, email, access the Internet, Skype, use Face Time, make grocery lists, play online games, etc. (McNaughton and Light, 2013, p.209)
4. Use of the device in daily life situations – this was essential to provide motivation to the client (Johnson et al, 2008, p.278)
5. The use of multi-modal supports – the use of traditional grids, visual scenes, word based cues, auditory feedback, high quality speech synthesis, schedule displays, pain scales, calendar programs, etc. provided a rich language environment to enhance comprehension (Beukelman et al, 2007, p.236)

Notes:

1. The iPad is a registered trademark of Apple Inc., 1 Infinite Loop, Cupertino, CA, 95014, USA
2. Dynavox M3 is a registered trademark of the Dynavox Mayer-Johnson Company of Pittsburgh PA
3. Proloquo2Go is a registered trademark of AssistiveWare Technologies
4. Resident Apps used on the iPad: Camera, Contacts, FaceTime, Photos, Videos, Mail, Safari
5. Purchased Apps used on the iPad: Skype, Grocery Store
6. Accessibility Features used on the iPad: VoiceOver
7. 200+ iOS Apps for Adult Speech-Language Therapy: This link provides over 200 Apps descriptions to use with adults with disabilities; not only speech-language apps, but other therapies, daily living activities, games, scheduling, calendars, story telling, and many more. <http://tactustherapy.com/adultapplist.pdf>

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Brain Injury Services (BIS), Hamilton, Ontario

Brain Injury Services offers services from supervised 24-hour-a-day complex residential care, to transitional living arrangements, to independent living supported by an extensive community services program.

Mission: Brain Injury Services offers individuals with a brain injury increased independence through innovative services, education and community integration

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Technology Access Clinic (TAC)

The **Technology Access Clinic** is an Augmentative and Alternative Communication (AAC) Service, authorized by the Ministry of Health, Assistive Devices Program; TAC is positioned within Developmental Pediatrics and Rehabilitation (DPR), McMaster Children's Hospital, Hamilton Health Sciences. TAC provides service to individuals of all ages and diagnoses with complex communication needs.

Mission: To facilitate the communication of individuals who are not able to write due to a long-term disability and /or whose speech does not meet all of their communication needs

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McMaster Children's Hospital
Technology Access Clinic


"I Have a Hope"
Finding a Voice After 20 Years

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Principles and Goals of Rehabilitation



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Brain Injury and AAC

- AAC strategies not widely or consistently implemented with persons with severe chronic aphasia
- Overall goal is for persons to "become functional communicators, and participate in ways that enhance their autonomy and maintain or expand their social networks"

(Beukelman, Ball and Fagar, 2008)

- "The use of AAC is not a goal in and of itself;** rather the use of AAC is the means by which successful communication is obtained and all of these other valued goals of adult life are pursued"


(Williams, Kresman and McNaughton, 2008)

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Introduction to AI

- Everything was effortless for AI
 - Family
 - Successful career as an Metallurgical Engineer on track for senior management
 - Financial security
 - Full of life – active recreation, social & leisure participation
 - Celebrated 40th birthday (August 1988)
- October 1, 1988, sustained an acquired brain injury at a baseball game



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AI's story - video

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AI, 1993 –
Six years
post injury

Video

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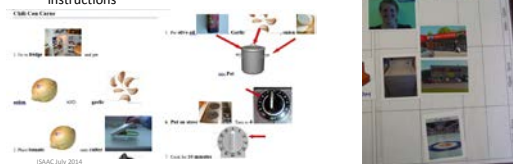
Communication Strategies

Cookbook

- Occupational Therapy students developed cookbook
- Used photos, step-by-step instructions

Scheduling

- Used pictures
- Consistent & predictable meetings

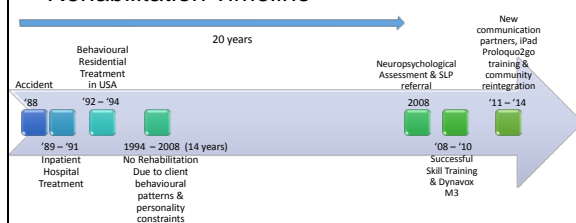


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Rehabilitation Timeline



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2008 Communication Abilities

- Poor comprehension of auditory information
- Attempted to communicate naturally with speech ("boom boom", a few words, "yes" – nod, "no" – sign)
- Could initiate messages, but needed partner support (written choices, key words written to assist in comprehension)
- Aware of communication breakdowns, but unable to repair successfully



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Learning How AI Learns

- Neuropsychological Assessment, Dr. Lad, Hamilton Health Sciences (2008)
 - Strategies to enhance learning were recommended:
 - Giving time
 - Chaining
 - Sequencing and breaking tasks into component parts
 - Using visual memory aides (i.e., pictures)
 - Scheduling, rehearsal and informing of transitions
 - Recommendation of referral for Speech-Language Pathologist
 - Technology Access Clinic Referral for augmentative communication



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Outcome of AAC Assessment

- Dynavox M3™ speech-generating device: Provided dynamic display, touch screen capabilities with the ability to:
 - Retrieve whole messages with touch of one button
 - Use words, letters, phrases; adjust font size
 - Use photographs and clear / familiar line drawings on buttons
 - Use photographs for visual scenes, to enhance comprehension and facilitate conversation
 - Accommodate page and button characteristics for visual, physical, attention and cognitive abilities
 - Provide high quality recorded speech

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M3 videos

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iPad video

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Introduction of iPad, Proloquo2go - 2011

- 2011 Re-assessment: M3 adequate for training; but bulky, and he was only using it during treatment – no carry-over
- Trial with iPad, Proloquo2go
 - More portable
 - Screen brighter, easier to read / see
 - No longer needed recorded speech, adjusted well to synthesized speech
 - Re-created M3 vocabulary on iPad/Proloquo2go, so little training regarding vocabulary
- Built-in features of iPad, not available on M3
 - Camera, photo, videos
 - Internet, email, contacts
 - Multitude of Apps available

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Review of Communication Abilities

- Significant gains in his communication abilities
- Not quite independent, but:
 - Independently combines a variety of methods to get message across
 - With minimal prompting, navigates to multiple locations to retrieve messages
 - Produces more and more spoken words and phrases
 - Initiates communication without support
 - Using communication device with health professionals
 - Reduction in frustration regarding communication

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Goals for Service

- iPad:
 - Learn basic operation and familiarize to vocabulary
 - Learn the iPad keyboard
 - Send an email
 - Identify and use Apps within iPad; added on other Apps
 - Learn good day vs. bad day vocabulary
 - Practice learned vocabulary
 - Inform staff of upcoming activities
 - Ask questions
 - Communicate health needs to medical professionals

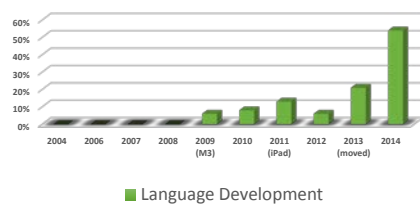


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Adaptive Behavioural Scale: Residential & Community, Version 2 (ABS:RC-2)



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Factors Contributing to Communication Success

- Case Facilitator
- AAC Specialist
- Introduction of iPad with Proloquo2go
- Use of the device in daily life situations
- Use of multi-model support



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Al's wedding speech

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Quality of Life, 26 years later

- Al "is generally successful in getting what he wants most out of life, getting his needs met and achieving his goals in most, though not all, important areas of life."
- Al "identified a high level of satisfaction in the areas of health, goals and values, money, friends, children, relatives and community."

Quality of Life Inventory (QOLI), June 19, 2014

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Thanks!

Any questions?



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