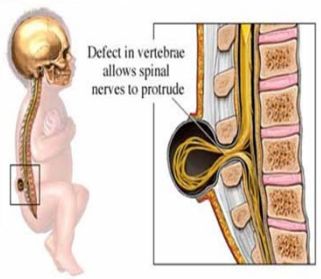
AAC Following Brain Herniation: Supporting Long-Term Recovery

Carole Zangari, Ph.D., CCC-SLP
zangaric@nova.edu
Nova Southeastern University, Fischler School of Education
Linda Parras
Levi Parras
levihp@aol.com

Case History

- Born with spina bifida @ 44 weeks following normal pregnancy
  - Labor of 16-18 hours, then induced
  - Presence of meningocele, club feet
  - Surgery to close back w/in 24 hours
- Spina bifida type: Arnold-Chiari II malformation
- Hydrocephalus

Spina Bifida



- Myelomeningoscele is the most serious type of Spina Bifida.
- Spina Bifida type II: Arnold-Chiari II, a malformation of the hindbrain
- Incompletely formed spinal cord causes lack of motor control in lower extremities

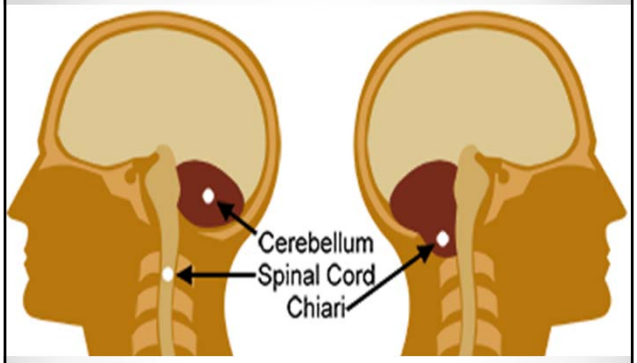


Image: MountSinai.org

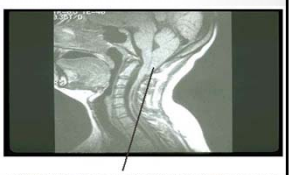
Ages 0-16

- Per parental report, speech-language development WNL
- Multiple back surgeries (closure, fusion, rod placement); foot surgery
- 2 shunt replacements
- Wheelchair user with voluntary movement of upper extremities
- Received OT for fine motor skills
- Attended school; Socialized w/ peers

Brainstem Herniation at Age 16

- Pressure from the brain herniation moved brain tissue, blood vessels, and cerebrospinal fluid away from their original position.
- Diminished blood supply and pushed structures through the foramen magnum causing damage to the nervous system.
- 8th nerve was damaged resulting in auditory dyssynchrony.
- Absent auditory brainstem responses associated with normal function of his outer hair cells of the cochlea but poor neural synchrony of the 8th nerve.

Image from *The Hyman-Newman Institute for Neurology and Neurosurgery* at *Beth Israel Medical Center*, NY



LOWER CEREBELLUM WEDGED INTO UPPER SPINAL CANAL

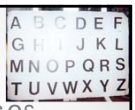
Immediately Following Brain Herniation

- Coma for 4 weeks
- 6.5 week hospitalization followed by 3 months of rehab
- Following the coma:
  - Mechanical ventilation
  - Tracheostomy
  - Auditory Dyssynchrony
  - Aspiration Pneumonia
  - Tube Feeds via PEG
  - Aggression & self-injurious behavior
  - Movement, and sensation were also affected
  - Corneas were damaged during this period

Initial Recovery Period

- Reduced fine motor ability and tactile sensation
- Ongoing health problems
- Severe hearing & vision impairments
- Cognitive and behavioral issues
  - Self-injury, aggression
- Tracheotomy and a G-tube
- Anarthria
- Change in cognitive functioning (memory loss, cognitive decline, flexibility)
- Anxiety, sleep disorder, depression, reduced self-confidence, change in temperament

Communication



- Home-bound educational services
- Approximately 9 months after CVA, began attempting to communicate
  - Expressive: vocalized /a/ on command; all other communication via gestures, body movement, attempted writing, pointing to alphabet board
  - Receptive: reading paragraphs (large font), interpreting manual signs, intermittently attending to environmental sounds and conversational speech at louder intensities

Public School AAC Services

SGD Trials Prior to University AAC Evaluation

- Public School AAC/AT Evaluation considered several SGDs.
  - Device 1: Super Hawk
  - Device 2: Macaw
  - Device 3: Say It All Plus (w/ 4 pictures)

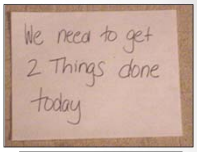
Family Priorities and Concerns

Poor communication contributing to:

- Depression
- Challenging behavior
- Limited access to opportunities
  - Lack of access to meaningful education
  - Little/no socialization

University AAC Evaluation

- Communicated most effectively with mom
- No functional hearing
- Vision functional for 2" bold letters
  - Minimal/no tolerance for other graphic symbols
  - Task instruction delivered through writing brief instructions
- Functional reading at phrase level, although attention to task was problematic
- Delta Talker with customization was recommended as first SGD.



Receptive communication is mostly through reading partner messages

Delta Talker

- Delta Talker: Based on Minspeak, or semantic compaction
- Unable to see Minsymbols so it was customized with letters and words.
- Had both digitized speech and synthesized speech.
- Used successfully for several years.

Initial Intervention Goals

- AAC therapy was initiated 25 months post incident
- Receptive communication: Increase attention to written communication
- Expressive communication
  - Enhancements to alphabet board use
  - Begin use of SGD
    - Develop operational skills
- Expand educational opportunities

Delta Talker with Alpha Overlay

Speaker from head phones is disassembled and used as a vibro-tactile aid. When he holds it in his palm, he can feel the vibration and knows he has typed a letter.

Return to School

- Returned to school approximately 3 years post injury to VI classroom
  - Very part-time, increased time in school slowly
  - Initially, did not qualify for school SLP services
- Nursing support for health needs
  - Nurse transcribes teacher messages using a dry erase board
- Graduates high school

Communication Status

- Attends to all written messages
- Follows simple gestures (e.g., thumbs up) presented within his visual field
- Begins to construct sentences with appropriate language content, form and use

Communication Goals

- Continue to develop operational & social competence w/ SGD
- Begin using pre-stored messages
- Improve oral motor status
- Build pre-vocational skills
- Trials with various AAC devices, E.g.,
- Light Writer

Transition to Pathfinder

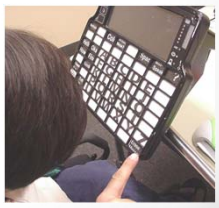
- Larger screen, better contrast
  - On good vision days he put with his face up close to the display window & he could see what he spelled.
- Alphabet overlay
- More pre-stored message capabilities.

Goals

- Improve operational competency of SGD
- Increase auditory awareness
- Improved ability to utilize auditory skills
- Increase oral motor strength to facilitate resting posture
- Improve operational competency of computer skills

Pathfinder Period

- Began with a 32-location overlay but as his automaticity and visual memory improved, he transitioned to a 64-key overlay



Pathfinder Period

- Primarily communicated with this device through pre-stored messages and an alphabet page.
  - Preferred spelling over other methods
- Examples of Pre-stored Messages: “Hello,” “Thank You,”., “How are you?” “Good bye,” “What’s new?”

Improvements

- Consistently attended to written messages
- Improved spontaneous communication with familiar partners
- Improved use of pre-stored messages
- Increased interest in pre-vocational training
- Increased acceptance of auditory intervention
- Improved oral motor strength for healthier resting posture

Trial Auditory Intervention

- Focused on
  - Increasing awareness of sound
  - Increasing ability to identify non-speech sounds, such as car honking, phone

Process

- Purchased CDs of environmental sounds
- Standardized the loudness levels
  - Phase 1: Discriminate between sound & no sound
  - Phase 2: Identify the sounds from photo choices
  - Phase 3: Label the sound

Transition to Tellus 3+

- Clearer, high resolution scre
- Static navigation button
- Interest in the capabilities of a an integrated device
  - Chosen for ease of emailing, cell phone access, and better internet capabilities.
- Received and sent text messages to friends and family.

Improvements

- Improved spontaneous communication w/ familiar partners
  - Constructs sentences with appropriate language content, form & use
  - Uses more pre-stored messages
- Increased awareness of sound
- Increased discrimination of sounds
- Client reports: “It is easier to talk with!” “It was just like a computer.”

Transition to COMLINK LT

- Persistent technical difficulties with email and texting led Client to explore new options.
- ComLink LT was customized to meet individual needs
- Wireless keyboard replaces the need for a white board

Transition to COMLINK LT

- Communication Status
  - Uses SGD on a daily basis
  - Good ability to formulate appropriate sentences
  - Initiates, maintains, and terminates interactions
  - Learning to use SGD for email and social networking (Facebook)

Back-up SGD

- iPad with The Grid Player

AAC Considerations for Individuals with Auditory Dyssynchrony & Vision Impairment

- Because the feedback loop is impaired, it is difficult for the client to monitor what they are communicating.
  - Consider vibro-tactile aids for training purposes.
- Make changes gradually.
  - Introduce new vocabulary, screens, strategies, and devices slowly.
- Improvement may be slow, but with continued intervention, there may be significant progress.
- Continue to re-evaluate needs in light of new and emerging technologies.

Additional AAC Considerations

- Keep instructions clear and concise.
- Be prepared for communication rate to be slow. It takes time for the client to read your messages and then respond.
- Respect the client's learning pace.
- Expect fluctuation in performance, particularly at the start of intervention. Over time, they may become more consistent.
- Repetition is important. Set the topic, discuss, and then summarize.
- Help the client develop new interests and pursue new life experiences.

Resources

- Downloadable Environmental Sound Files for auditory re-training
  - http://www.cofc.edu/~marcellm/confrontation%20sound%20naming/zipped.htm
- Oral Motor Program
  - Gangale, D.C. (2001). The source for oral-facial exercises: Updated and expanded. East Moline, IL: LinguiSystems, Inc.
- Email Program for the Visually Impaired
  - ICanEmail by: RJ Cooper http://www.rjcooper.com/icanemail/index.html
- Big Keys Plus Keyboard
  - http://www.bigkeys.com