Aphasia, the Movie:
Debunking the Myth of the Recovery Plateau

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Jim Gloster, Little Word Films, Inc.
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Nancy Helm-Estabrooks, Sc.D, CCC-SLP, WCU-Asheville, UNC-Chapel Hill
Carl McIntyre: Sole owner (with wife Elizabeth McIntyre) of the rights to and proceeds from Aphasia the Movie, Inc. Travels with film and presents motivational speeches (receives payment for services).

Jim Gloster: Writer and director of Aphasia the movie. Consultant/travel companion for Carl McIntyre and Aphasia the Movie, Inc. (receives payment for services). Former partner, Little Word Films, LLC., production company of Aphasia.

Chuck Bludsworth: Producer and cinematographer of Aphasia the movie. Consultant/travel companion for Carl McIntyre and Aphasia the Movie, Inc. (receives payment for services). Former partner, Little Word Films, LLC., production company of Aphasia.

Denise Caignon: Co-author of assessment tool (L!V cards) discussed in presentation. Speech-language pathologist involved in research study and treatment of first presenter, Carl McIntyre, at UNC Chapel Hill Center for Aphasia and Related Disorders.

Nancy Helm-Estabrooks: Co-author of assessment tool (L!V cards) discussed in presentation. Speech-language pathologist involved in research study and treatment of first presenter, Carl McIntyre, at UNC Chapel Hill Center for Aphasia and Related Disorders. Author of the Aphasia Diagnostic Profiles (ADP) and Cognitive Linguistic Quick Test (CLQT) assessment tools; co-author of Melodic Intonation Therapy (MIT) treatment program.

NOTE:
Carl McIntyre has given his express, written permission for disclosure of and discussion about all aspects of his participation in treatment and research studies.
Aphasia Recovery and the Myth of the “Aphasia Recovery Plateau”

Nancy Helm-Estabrooks, Sc.D., CCC-SLP, BC – ANCDS
Brewer Smith Distinguished Professor Emerita
Western Carolina University
&
Adjunct Research Professor
University of North Carolina – Chapel Hill
The Period of “Spontaneous Recovery”

- Period during which structurally undamaged portions of the brain resume function.

Some factors that resolve during “Spontaneous Recovery”
- Brain swelling
- Blood flow abnormalities
- Metabolic problems

General rule...the greatest amount of spontaneous recovery occurs during... first 6 to 8 weeks after a stroke

Note: Considerable variation may be seen, depending on...
- stroke etiology
- size and location of the lesion
- person’s overall medical state
Myth of the Aphasia Recovery “Plateau”

“No Further Significant Recovery Can be Expected after:
2 months?
4 months?
1 year?
18 months?”

• Retrospective, longitudinal study of...
  • 20 People with Aphasia (PWA)
  • Followed *as long as 15 years* post onset of aphasia.
  • *Confrontation naming skills* of both nonfluent and fluent PWA...

  – Showed Steady Improvement

“chair:
Communication is More than Talking & Listening

Issue of how well PWA recover nonlinguistic communication skills has been largely neglected in aphasias recovery studies.

- Two-year study of 24 people with various forms of severe aphasia.
- Tested over two-year period with BASA at six month intervals
- Finding: 22/24 made notable improvements in communication.
- Two non-improvement cases...
  - One had a history of schizo-affective disorder with major depression.
  - Other had an unstable medical course with probably additional strokes.

- Reviewed all well-controlled published aphasia treatment studies of...
  - PWA who were at least one year post onset (range was from one year to 19 years) when treated.

- Found no relationship between time post onset and response to treatment.

- Well-founded treatments dispute concept of an aphasia recovery "plateau."
Neuroplasticity and Recovery from Aphasia

• “Neuroplasticity” - the capacity of the brain to flexibly reorganize itself and change.

• Brain is a dynamic organ, constantly being modified by interaction with the environment.

• Experiences may change the brain in...
  – Positive ways, e.g., speaking a new language
  – Negative ways, e.g., subjection to continuous psychological trauma, e.g., PTSD

• When there is frank damage to an area of the brain resulting in cell death, remaining healthy areas retain neuroplasticity.

• The neuroplasticity that contributes to the recovery from aphasia may occur either...
  – spontaneously
  – in response to well-founded and carefully administered treatments.
### Correct Content Units

<table>
<thead>
<tr>
<th>Content Unit</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cookie</td>
</tr>
<tr>
<td>Girl</td>
</tr>
<tr>
<td>Mommy</td>
</tr>
<tr>
<td>Wash</td>
</tr>
<tr>
<td>Dishes</td>
</tr>
<tr>
<td>Spill</td>
</tr>
<tr>
<td>Water</td>
</tr>
<tr>
<td>All the floor</td>
</tr>
</tbody>
</table>

### Totals: 8

Cookie … (unintelligible) … air puh boom, oh … yair 'bout move over … Cookie, cookie j- girl. Mommy wash dishes. Spill water all the floor … are (unintelligible).
Boy is trying the … boy is trying to get cookies and give them to … a girl, but da ’tool is about to /i/ fall.

Woman is washing dishes. She let the sink overflowing in water. And is a fire outside the window. See trees.

7- one hour, twice weekly sessions of SPPA
Task: Draw as many animals as you can before and after CDP

Task: Tell me what you did over the weekend.
Task: Make a Grocery List for Yourself

**Breakfast**
- Egg
- Bacon
- Coffee
- Toast

**Dinner**
- Ice Cream

**Supplies**
- Canned Fruits
- Lettuce
- Cucumbers
- Parsley
- Meats
- Spaghetti
- Cheetos
“One on One” – Intensive Individualized Aphasia Therapy

University of Central Florida “Aphasia House”

Rehabilitation Institute of Chicago Intensive Aphasia Therapy Program
Aphasia Groups for Communication Therapy and Support

Aphasia Center at MGH Institute of Health Professions

Boston University Aphasia Community Group

Asheville Aphasia Support Group
Conclusion

• Significant (albeit slowed) recovery from aphasia can continue indefinitely if PWA continue to have ...
  – Dynamic interactions with their environments
  – Incur no new brain damage

• Recovery can be enhanced by...
  – Well-founded aphasia treatment programs even many, many years post onset.

• Given the flexibility of the human brain and its capacity for positive change, it would be silly to think otherwise.
Carl McIntyre

Beyond the recovery “plateau”

Denise Caignon, M.S., CCC-SLP
Clinical Speech-Language Pathologist,
Adjunct Clinical Instructor
University of North Carolina – Chapel Hill
Case background

• Sept 2005: Large L-MCA stroke

• April 2007: Carl & wife contact Dr. Helm-Estabrooks at UNC

• Shattered life: former actor/salesman, sole breadwinner, wife & 3 young children

• Exhausted therapy benefits paid for by insurance

• Doctors: “You’ve plateau’ed.”

Brain MRI (May 20, 2012) showing extensive damage to left hemisphere, sparing of motor strip area for right limb movement
Aphasia Diagnostic Profiles (ADP)
- Auditory comprehension: 84th percentile
- Lexical retrieval 37th percentile
- Nonfluent—Broca
- Overall aphasia severity: 61st percentile

Cognitive Linguistic Quick Test (CLQT)
- WNL: Executive function, memory, attention, visuospatial skills, cognitive flexibility

Raven’s Progressive Coloured Matrices (analogous reasoning): 95th percentile.

Weaknesses/Strengths

• Typical Broca: agrammatic, telegraphic speech
• Phonological (deep) alexia, agraphia
• Significant apraxia of speech/articulatory struggle
• Trouble w/numbers/dates—particularly via auditory channel

• Good auditory comprehension
• No limb, ideomotor, or buccofacial apraxia
• Grossly intact nonlinguistic cognitive skills
• Excellent use of gesture, drawing, facial expression, reading/writing high-content words (mostly nouns)
• Good self esteem, outgoing personality
• Motivation/tenacity—used to rehearsing and working hard
Life Interests and Values Cards
based on the Life Participation Approach to Aphasia (LPAA)

Enrolled in L!V card pilot study + speech-language therapy in UNC Center for Aphasia and Related Disorders

Worked with SLPs, OTs, PTs on self-determined goals

http://www.livcards.org
http://www.asha.org/public/speech/disorders/LPAA.htm

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Carl’s self-chosen goals

- **L!V goals**: Many interests and hobbies, including political conversations, golfing, gardening, painting, *BUT*...

- His PRIMARY functional goal was to find PAYING (not volunteer) work to support his family.

- **Therapy goals**: Work on agrammatism, anomia, articulatory struggle/apraxia.

- For “working for pay” goal, intensive contacts made with vocational rehabilitation, & several avenues were explored...
That hill looks awfully steep....

Job ideas pursued... & ultimately abandoned:

- Hardware store stocker/clerk?—trouble w/ aud comp of numbers
- Chauffeur?—addresses, numbers
- Back to college to retrain?—reading, writing, number problems
- Graphic artist?—needed further training
- Florist/nursery worker? — reading plant labels
Voc Rehab and his therapy team were supportive, but recession & Carl’s move from big city to small town (over 10% unemployment) made it hard to find training programs or entry-level jobs...

Any job requiring reading, writing, math, speaking....!?!?

What’s left?
Definitely not this!
Treatment approaches

• Integrated with L!V/functional goals
• Always evidence-based, but sometimes adapted/hybridized
• Some delivered over Internet (Skype)
UNC-Chapel Hill
Aphasia conversation group

• Allowed Carl to practice skills learned in therapy
• Leadership skills via group facilitation
• Vital support from peers
• Reduced social isolation
2 most helpful treatment approaches

Visual paired associates

* Susan Lott et al*

- Phonological alexia tx adapted to work on trouble with grammatical functors in *spoken* language
- Pairs (picturable words + functors) of homophones/near-homophones trained with visual stimuli

Carl frequently uses this compensatory strategy to self-cue grammatical functor words when speaking.
Treatment of Underlying Forms (TUF)

*Cynthia Thompson & Lewis Shapiro*

- Complexity Account of Treatment Efficacy (CATE)-based treatment for agrammatism

- Treatment of complex syntactic forms generalizes to simpler forms and overall more complex syntax in everyday conversation

“Pete saw the mouse who the cat chased” = object-relative structure

In several published studies, generalizes to: “Who did the cat chase?” (wh-movement) and/or “It was the mouse who the cat chased.” (object cleft)

For Carl, treatment primarily generalized to more (though not always correct) use of functors—pronouns, past/present tense, prepositions, etc.
**What “plateau?”**

Over 16 months, steady gains made on Aphasia Diagnostic Profiles (ADP)

<table>
<thead>
<tr>
<th>Initial eval 5/10/07</th>
<th>Re-eval 01/24/08</th>
<th>Re-eval 9/29/08</th>
</tr>
</thead>
<tbody>
<tr>
<td>Aud comp: 84\textsuperscript{th}</td>
<td>Aud comp: 95\textsuperscript{th}</td>
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<tr>
<td>Lexical retrieval 37\textsuperscript{th}</td>
<td>Lexical retrieval: 50\textsuperscript{th}</td>
<td>Lexical retrieval: 75\textsuperscript{th}</td>
</tr>
<tr>
<td>Nonfluent—Broca’s</td>
<td>Borderline fluent</td>
<td>Borderline fluent</td>
</tr>
<tr>
<td>Severity: 61\textsuperscript{st} %ile</td>
<td>Severity: 73\textsuperscript{rd} %ile</td>
<td>Severity: 77\textsuperscript{th} %ile</td>
</tr>
<tr>
<td>Years post-onset: 1,8</td>
<td>Years post-onset: 2,5</td>
<td>Years post-onset: 3</td>
</tr>
</tbody>
</table>
Spontaneous speech samples
(from session notes)

**May 07:** “Work and ah... pain... all day... but still... and Elizabeth and Grace... **was**... Brownies... and I... Liza and Sawyer and me home...”

**December 07:** “Well um... **went to** office and pain... head pain and really strange but... **went driving** home... and Elizabeth and Grace **need to** Brownies... and I **babysit** Liza and Sawyer.”

**May 08:** “Liza growing up, I think .... I think Monday, Tuesday, I’m going to vote

**May 09:** I **was** outside **picking** weeds.... I **never thought** one year ago I’m speaking **almost good** .... never thought.... but still I’m **need** work....
First career break: Aphasia class presentations

April '09: “Little Word” Trouble

2008-09: Guest speaker in UNC-CH aphasia classes

2010: Expanded to neurology & nursing classes, conventions

Now: Gives polished speeches (which he scripted and continually refines) for university classes, medical conferences, and other venues

Carl presenting to SLPs and the aphasia community at Northwestern University, July 2012
Aphasia the Movie premiers May 2009
UNC Chapel Hill

Carl & friends/collleagues
(Writer/Director Jim Gloster
and Cinematographer Chuck Bludsworth, many others) create the award-winning film
in compressed 2-week shooting schedule in 2009

DVD released May, 2012

www.aphasiathemovie.com
Motivational speaker

• Presentations—sometimes as keynoter speaker—in more than 50 audiences, worldwide

• Medical centers, professional and student education, stroke and other conferences

*Carl at the Stroke 2012 conference, Sydney, Australia*
Partial list of venues

- UNC-Chapel Hill
- Northwestern University, Evanston, IL
- Goshen College, IN
- University of South Carolina, Columbia, SC
- American Association of Neurological Nurses Convention, Seattle, WA
- Indiana Speech Language Hearing Association Convention, Indianapolis
- Stroke 2012 conference, Sydney, Australia
- Vanderbilt University, Nashville, TN
- Portland State University, Oregon
- Rapid City Regional Hospital, SD
- Carondolet Hospital, Tucson, AZ
- University of So. California, Irvine
- Rehabilitation Institute of Chicago

and many others
Film festivals

Carl at The Other Film Festival, Melbourne, Australia September 2012

- Big Bear International Film Festival Audience Award for Best Short Film
- Fort Lauderdale International Film Festival Official Selection
- Foyle Film Festival Official Selection
- Radar Hamburg International Film Festival Official Selection
- Prince Edward Island International Film Festival Official Selection
- Feel Good Film Festival Audience Award for Best Short Film
- Reel Abilities Film Festival Official Selection
- USA Film Festival Finalist

Latest wins:
The Other Film Festival
- Best Collaboration
- The Film That Left Me Wanting More
Carl’s life = “Carryover” …on steroids

- Gives speeches before large audiences
- Takes questions in noisy, distracting environments
- Self-scripted speech, constantly revised and refined
- Salesman: Selling the story that having a stroke ≠ giving up on life
- Self cuing—gestures, “picture” words
- Use of more complex syntax
Improvements noted in informal conversation since *Aphasia* was filmed

- More use of past and future tenses

- Still errors (e.g., you/I pronoun confusion, verb agreement) but more *overall* use of functors

- More complete sentences; less telegraphic

- Makes phone calls, talks with strangers. *Always* lets new listeners know his condition at conversation outset
What’s next for Carl and Aphasia?

• Possible book project with wife Elizabeth
• More bookings for Aphasia, speaking engagements
• Northwestern University study based on CATE, w/functional MRI (fMRI) component.

fMRI studies will show effects of neuroplasticity in real time as Carl performs language tasks...
In aphasia recovery (as in all things) the journey...

The road of life twists and turns and no two directions are ever the same. Yet our lessons come from the journey, not the destination.
--Don Williams, Jr. (American Novelist and Poet)

....is the destination
Addendum
Clinical applications
Synergy between therapy & *functional* goals

- Choose and adapt therapy program(s) that leverage spared strengths and target pt’s life interests and values.
- Grounded in pt’s everyday life, no matter how limited—hobbies, volunteer activities, topics of conversation--even favorite TV programs.
- For some, this could just mean functioning at home; for many, it will mean activities that involve the world outside.
- Efficiency and functional relevance of therapy will become more important as “ObamaCare” implemented, with emphasis on QUALITY over QUANTITY of therapy.
- “Carryover” to real life starts ASAP—in 1st session if possible
Recipe for functional improvement

• Use a *functional* assessment tool and initial interview with pt and/or family to determine what pt cares about and will work on.

• Cognitive-linguistic assessment to determine pt’s spared strengths as well as weaknesses.

• Non-linguistic cognitive skills are critical for success in therapy—particularly cognitive flexibility and self-monitoring of errors.

• The mind must be nimble enough to choose what spared skills to use, and you can’t improve if you don’t know what needs improving.
Recipe for functional improvement

- Pediatric therapists work with children in the context of play. Adults also want to “play” and don’t like being forced to struggle through tedious therapy that has no personal relevance to them.

- Example: Help a pt plan a fun outing—conversational scripts, “googling” points of interest, map reading.

- “Improvement” can mean better functioning in ADLs, and/or improvement on standardized test measures. It doesn’t ALWAYS mean both.

- Better quality of life (in the patient’s opinion) should be the gold standard
Other treatment approaches used successfully with Carl McIntyre

• Melodic Intonation Therapy (MIT): Increase in utterance length and reduction of apraxia of speech

• Oral Reading for Language in Aphasia (ORLA) w/virtual therapist: Alexia/length of utterance)

• Luria: Sentence schemata for agrammatism/alexia

• Response Elaboration Training (RET): Expansion of pt utterances in context of conversation