

IF YOU BUILD A MODEL, WILL THEY COME?

Compassionate, dedicated therapists without the proper tools

Because we are in the midst of what scientists call a paradigm shift, there is no integrated biological and behavioral model of aphasia.

Does language get lost after a stroke? Are words, sentences, paragraphs, concepts, and symbols erased from the brain-as-blackboard? Or is access blocked? Like a rock fall in the road? Or a diverted stream? How are the areas in the brain needed to hold words and put them together affected after a stroke? Is attention deficit the problem or simply one of many problems? What about memory? Are we re-teaching language? Or are we digging it out? Are we drilling phrases just so people can “get by” in their life (maybe this is the best we can offer now)? Are we weaving new connections? What happens to the brain during recovery? Can we facilitate the brain’s ability to recruit new neural networks through either specific behavioral therapies or medications? How? What works?

Because we are in the middle of a shift, we need a variety of studies drawing on all the current research approaches. No one can point clearly and say, “*This is what happens. This is how to explain aphasia.*” We need all approaches right now.

Everyone I spoke generally with finds no fault with speech-language pathologists. Speech therapy is an art and a science. Doubtless, speech-language pathologists will remain the major providers of direct therapy to aphasic patients. They will be given new theory and new tools as a model evolves. More science to go with the art. SLPs are the front line, working alongside patients and families. As new concepts are developed, the SLPs need to be given the additional training to integrate ideas into practice. Perhaps certification requirements will need to change. Perhaps a new discipline drawing on multiple fields will emerge to work with aphasic individuals.

Just spit it out!

The wonderfully demented comedy troupe, Monty Python, had a routine in which the tag line was, “*Nobody expects the Spanish Inquisition.*” The Inquisition’s auto de fe, the infamous public burning of a heretic, was an acutely difficult situation, no doubt.

The arrival of aphasia is as unexpected and unwelcome as the Spanish Inquisition. The slow, eternal burn of broken language, aborted comprehension, and a life turned upside down is chronic torture for the aphasic patient. Even those who regain a great deal of function are left scarred with the loss of some

cherished activity or another. Those who do not regain much function often find life lonely and barren.

Aphasia is generally is not the only challenge following a stroke or traumatic brain injury. Patients often have to deal with paralysis, swallowing difficulties, and depression. Then patients have to deal with their families, caregivers, doctors and other health care professionals, employers, and insurance companies. Once they are somewhat out and about, they get to deal with strangers. With the rest of us in the “normal” world.

The valuable role of family and community in assisting aphasic patients is known. Unfortunately, resources are modest and outreach to these groups is minimal. For lucky patients living near major research centers, access to experts and support groups is reasonably good. Most patients and families, however, do not have the resources to seek continued therapy after the token paid by their insurance providers.

Aphasic adults become the proud owners of a chronic affliction (and who can doubt that losing comprehension and communication even to a slight degree is not an affliction?) Once their brief formal, paid-for therapy is over, what next? Researchers and clinicians around the world have found that support groups can provide not only warm and fuzzy support and encouragement, but also concrete coping strategies and that all too infrequent commodity, hope.

What can make life work for an aphasic patient? Certainly not, “*Just spit it out,*” which was the response of one spouse for years to her aphasic husband. Until she learned more about what was wrong and how to help him facilitate communication she was a helpless outsider in the process whose frustration cast a pall on their marriage. Imagine how frustrating it was for the husband who could not even begin to explain.

Clearly there is a place for active family and caregiver training. Who pays for this, however?

Because there is not an integrated model of aphasia, we are largely left holding a big bandage and trying to wrap patients and families in a comprehensive approach that includes, at its center, traditional speech therapy. We must continue to support and increase groups and treatments based on pragmatic communication. We cannot offer more, yet, to most patients. In spite of the dedication and skill of those studying and treating aphasia, the overall outcome for many patients, when all is said and done, is only marginally better than, “*Just spit it out.*”

I have a mind...just can't talk

It is no secret that we Americans are squeamish about brain damage and anything that appears to suggest mental deficiency. Even as we applaud participants in the Special Olympics, we are often kindly condescending.

We are a country of doers and goers and when faced with difficulties often find it easier to evade and avoid than to slow down and learn, or stop judging.

Aphasic adults are blown out of their lives. They open their eyes after a stroke or brain injury and open their mouths and nothing comes out. Or garble comes out (and they think it means something.) Or two or three words come out. Maybe they can understand, maybe they can't. Perhaps all numbers elude them, even though they were math whizzes once. Maybe they can read, maybe they can't. Infinite variations.

I remember Mr. Miller, a loyal patron in the public library where I worked for many years.

He had severe cerebral palsy, was missing one hand, had a swallowing problem, and could only speak slowly and indistinctly. But if I sat down and listened to him, we could not just converse politely, we could communicate. Over the years I have encountered Mr. Miller. He takes the bus, volunteers at a local rehab hospital, got married several years ago, and continues to frequent the library. I am not sure if he has aphasia, certainly dysarthria. But he taught me about endurance and patience.

I know that many people thought he was "slow." His estimation dropped in their eyes. Or they pitied him. Who wants to be patronized? Who wants to be pitied? I don't. Neither do aphasic patients. Yet their forays into the world of talkers is often unpleasant and even painful. They isolate themselves, which makes everything much worse.

We value sharpness, intelligence, and speed in our culture. When one loses his or her edge, can't express his or her intelligence, and slows down: out of the loop! Where are the public awareness campaigns about this chronic condition that effects 1 million Americans? Someone needs to speak up.

While we are asking this, we can ask: What about doctors treating brain injury and stroke? When are more of them going to catch up on their literature and offer support and encouragement to their aphasic patients?

There's nothing you can do

So far I haven't talked to anyone with aphasia whose initial encounter with the medical profession was better than, *"You might get a little better with time. But really there is nothing you can do so don't expect much change."*

That was the positive statement. Often the judgment (remember the Spanish Inquisition) was, *“She will never talk again.”* The husband of an aphasia patient (12 years post-stroke) who was told she’d never talk, put it more bluntly, *“We’ll have to wait until the old guard dies off before aphasia patients get the help they need.”*

Some folks react strongly to being told “never.” They won’t capitulate. They have families and support and that elusive motivation or inner drive. We know that is important but we can’t measure it. We don’t know how to tap into it. Others give up. One caregiver told me that there are two kinds of stroke survivors: those who give up and those who don’t. Can we do anything about those who give up?

Perhaps not telling them nothing can be done would be a good start.

We do know that over 50 percent, perhaps as high as 70 to 80 percent of aphasic patients will have depression. Oh, they are sad. Who wouldn’t be after stroke? I am going out on a limb here to say that very few people, including so-called experts, have a clear understanding of what depression is.

Let’s look at this so-called mood disorder more closely. Depression is one of the unruly stepchildren of mind-body medicine. A stepchild that has been kept relatively controlled by a variety of medications. Seemingly guided by, *“Oh, this seems to help even if we don’t know why.”* The neurochemical basis for depression is still unclear. Serotonin, much beloved by theorists, is not the whole answer. It might not even be an answer for some kinds of depression.

Depression is not merely a bad or sad mood. Mood can change with depression and is often the outward signal of something wrong, but it is simply a symptom of a more profound, far-reaching physiological sea change that has ramifications throughout the body and brain.

For some, mood itself governs the course of their depression. For others, with chronic pain and other conditions, mood may be secondary to physical symptoms. In other words, mood itself is not a reliable indicator of depression.

What simple thing have we learned about strokes and depression? The incidence of depression in aphasic patients, with no ancestral history of depression, is related to the area affected by the stroke. This is important.

We now are getting into the brain and zeroing in on changes in neural network. Depression is not randomly distributed among the patient population after a stroke. You’re sad and I’m not. He’s depressed. She’s not. It is highly correlated to the site of damage. Right front quadrant has zero incidence of depression. Right rear quadrant, 13 percent. Left rear quadrant, 17 percent. And left front has 60 percent! (Based on work done by Jeffrey Evans, Ph.D. at the University of Michigan.)

If depression in an aphasic patient is not controlled, little progress regardless of other therapies can be expected. And maybe the presence of depression is giving us important information about neurochemistry that we are not in a position to understand yet.

We know from other studies of illness and depression that this will be an uphill battle. Depression's role in exacerbating or even producing symptoms is generally misunderstood at best, at worst not well applied or ignored in the real world of patients and doctors.

Computers (not covered in detail in *Research Summary*)

Computers can be used as an augmentative aid in aphasia, a substitute, in a sense, for the patient's own language. Although being able to communicate basic needs and concepts is a boon to someone who previously could not, it is a pale replica of conversation and comprehension.

Malcolm McNeil (University of Pittsburgh) summarized:

Computers will not facilitate a bad treatment and they are not likely to provide a treatment that cannot be done in their absence. They could help deliver an otherwise theoretically sound and experimentally validated treatment.

Perhaps the greatest potential for computers is in conjunction with therapeutic assessment and treatment. Surely being able to vary exercises for patients to use at home, being able to manage endless repetition and feedback can allow motivated aphasic individuals more practice than is possible now. With the current climate of minimal insurance reimbursement of speech therapy, being able to take the proper practice home could make a huge difference. The goal is to provide easily administered, efficacious treatments that can be delivered cost-effectively.

The use of computers, however, is limited in the same way as other current therapeutic interventions. The best exercises are not experimentally validated. The model that allows treatment is still rooted in childhood education. The rapidly growing body of knowledge regarding brain function and recovery has not been incorporated into an integrated model of aphasia.

Michael Weinrich (Departments of Neurology and Rehabilitation at the University of Maryland in Baltimore) is one of the pioneers in computer-assisted therapy. At the Aphasia Research Center in Boston, Errol Baker and Marjorie Nicholas are showing "modest but real" with C-ViC. (icon based computer-assisted visual communication.) Work is being done to predict which patients are the best candidates for C-ViC by mapping lesions and looking at the patients' success using C-ViC.

Speech recognition technology based on natural language understanding (MossTalk) has shown promise for rebuilding communication skills. The program provides feedback on whether patients are building sentences correctly. MossTalk is being developed with the assistance of Unisys Corp. (Marcia Linebarger) at the Moss Rehabilitation Institute in Philadelphia (Myrna Schwartz.)

Myrna Schwartz is currently studying the effect of using a specialized email system to help aphasic patients form social bonds using communication groups, email, and a PC-based augmented communication system (CS.) Eventually, vocal messages will be able to be sent via the Internet. Will the combination of conversation groups, Internet communication, and CS have a positive effect on language performance, functional communication, and psychological well-being? One hopes so.

A study in Scotland of a computer-based communication system called TalksBac (University of Dundee, Department of Applied Computing) concludes that "TalksBac has the potential to augment the communication abilities of nonfluent adults with aphasia, who have not been able to develop their own compensatory strategies."

A study at Frenchay Hospital in Bristol, UK looked at whether potentially harmful behavior patterns might be adopted when computers were used at home. They found no evidence of harmful habits being developed.

Leora Cherney (Rehabilitation Research Institute Corp. in Chicago) is using her reading aloud treatment as the basis for a computerized approach to aphasia therapy. Oral Reading for Language in Aphasia (ORLA). She has found in preliminary work that her approach produces improvement not only in reading comprehension, but also auditory comprehension and oral expression.

At the Department of Veterans Affairs Medical Center in Phoenix researchers concluded that a computerized reading treatment for aphasic adults was efficacious. Improvement was generalized to non-computer language performance.

Several programs (C.H.A.T. and software from Bungalow) were mentioned to me by aphasia patients mentioning the hope these might help them.

Follow the money

The National Institute of Deafness and Communication Disorder is the lead National Institutes of Health agency funding aphasia research. In 2000, 4.1 percent of its budget went to aphasia research. That was slightly over 9 million dollars.

That's the big piece of the aphasia research pie. The leading advocacy group for aphasia, the National Aphasia Association, doesn't providing research funding. I received no response from my inquiries about research funding from the American Speech and Hearing Foundation. The Department of Veterans Affairs also funds aphasia research. I do not have a figure for that.

Assuming (really wildly) that DVA also spends about 9 million dollars on aphasia, it gives one pause to think that **\$20 dollars per aphasia patient would more than double (probably actually triple) monies spent on aphasia research in the United States.**

Although some medications are being researched, the often mixed-blessing relationship between industry and research is lacking with aphasia research. If some pill or another proves successful that will increase the amount of money available for pharmacotherapy.

This is not a solution, however, to funding aphasia research.

The only other major industry collaboration potential is with software and computer engineering firms. Because the role of computers in treating aphasia is still relatively unproven, there are not huge opportunities for co-research. Again, if a particular system or approach proves successful, those funding opportunities will increase. Again, hardly a systematic solution.

Research universities and institutions are able to process private donations for research so that they are tax deductible. It would be possible to assemble an informal advisory board and contribute money without the infrastructure of a foundation or organization. This might be one approach to supporting research on a case by case basis without restricting future options.

Hot off the genome

Finally, the first research directly linking a speech and language disorder with a specific gene, the FOXP2. Scientists now have a locus, once a locus, then more individual genes and the proteins they code for. This is how breakthroughs are born.

It is difficult to anticipate how the recent research on the FOXP2 gene will influence research in aphasia. Identifying this gene, one that causes a severe speech and language disorder, is the first step, perhaps, in unraveling the overall genetics of speech and language. Undoubtedly, research into the neural circuits for speech and language will get a boost from this very specific study. Are some people at greater risk for poor recovery due to an underlying genetic strength or weakness in speech and language? We don't know and we need to find out!

What I think is most important

- Public awareness of aphasia as a chronic condition must be increased!
- Ditto
- Educational programs for caregivers and families need to be packaged and distributed. The Internet is now a major tool for health care information. Let's exploit that.
- Education of doctors and insurance companies on aphasia as a chronic condition in which improvement can be seen over time is vital.
- Support for support groups needs to increase: educational materials, advice on finding sponsorship that kind of thing, small grants to community groups.
- Research that involves brain imaging to track changes in neural anatomy needs to be encouraged. Regardless of the therapies being tried, brain imaging studies should accompany them.
- Research borrowing from constraint-induced therapy and other behavioral approaches not apparently directly tied to language may be important to integrate.
- Research in neurochemistry is important, although pay-offs are likely to be many years off.
- Efforts to find a useful pharmacological adjunct need to continue.
- Further developing our social model of aphasia treatment using groups and social support in a setting that can provide comprehensive help is important until a cure is found.

RESEARCHER STATEMENTS

The following statements are a mixture of verbatim and paraphrased dialogue. I integrated email, phone interviews, and published works to capture the essence of what each researcher had to say. If I inadvertently mis-stated an opinion or fact, I alone am responsible for that error. When in doubt, assume I did it, not the researchers who generously assisted me. More detailed information about several of the interviewees can be found in the Appendix.

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Dr. Holland emphasized the value of increasing aphasia awareness through public education and awareness campaigns. She also underscored the vital role that family members, caregivers, and the community at large can have in helping patients cope with their aphasia and learning how to communicate more effectively.

She pointed out one of the real roadblocks: the attitude of many doctors that there "isn't much you can do about it."

Aphasia is a chronic condition that can be ameliorated to some extent throughout a patient's life time. Skills can be improved through a variety of strategies. When patients accept that their life has changed, there is no going back, then they can devise ways to communicate their basic needs. Basic needs are not simply requests for food, water, and shelter, but the needs of an individual who had a life full of activities and interests prior to the condition which lead to aphasia. Pointing and grunting are not satisfactory substitutes for human communication and interaction. Sometimes, however, the choice is that bleak: being held incommunicado or learning to point to pictures. For more fortunate patients, language skills actually return to some extent.

Almost always, however, loss is present. Some activity is beyond reach even for those whose cognitive and conversation skills are close to their pre-stroke levels. Aphasic patients are dealt a blow to their quality of life, to their self-esteem.

The question posed by the University of Arizona team is, "What would you like to do that you can't because of your aphasia?" If the patient has accepted the fact his or her life is now different, is now transformed, a strategy of living that takes aphasia into account can be designed using a comprehensive psychosocial

approach. With individual and group therapy, some semblance of a satisfactory life can be re-constructed.

We lack a coherent theoretical model that explains aphasia, thus we lack concrete experimental evidence that indicates which therapeutic intervention might surpass another. A psychosocial approach toward functional communication at least allows patients to achieve some degree of relevant conversational, reading and comprehension skills. “What can we do now to improve the quality of life for aphasic adults?” summarizes Audrey Holland’s approach to this challenging problem.

What are the current gaps between aphasia research knowledge and field application of that knowledge? How do we reach practitioners and patients with relevant information? Are there any good models for this?

There are huge gaps, and two big reasons for them. First of all, most aphasia research focuses on the language disorder, and what can be learned about normal language processing by studying disordered language. This means that for much of this work, its clinical application is limited. Even though most researchers give lip service to clinical implications, those of us in the trenches can’t often find the implications, and those who do the language processing research often don’t know very much about the persons with aphasia, just about the exotic language.

Second, research that directly focuses on the value of clinical intervention and the development of new treatment approaches is notoriously difficult to do, extremely time consuming and seldom looked on with favor by federal funding sources. For example, the use of qualitative methodologies, many of which are very appropriate to treatment research, are basically anathema to the NIH. Thus many studies that have purported clinical value end up using methodologies that are so tightly constrained as to make the behaviors of their focus (for example, obscure syntax, or word retrieval devoid of context) almost trivial in relation to the big picture of living with aphasia.

In terms of reaching practitioners, I don’t see reaching practitioners as the big problem. Rather, I see their being able to use some of the available, cutting-edge techniques as a bigger problem. The limitations imposed by the current healthcare climate, where quality of life seems to have gotten lost in the shuffle, is the culprit.

I spend a lot of my time doing workshops and seminars that teach new methods and stretch the wings of clinicians. Attendance is always good, and responses are very positive. But the underlying complaint never varies, *“How can we apply these approaches in the places we work? Under the current rules for reimbursement?”*

What are the current gaps between aphasia therapies and access to therapies? Is this an insurance issue? Education of physicians? Are patients being enthusiastically and appropriately referred to therapists? Who is doing this well?

I think I got into this question in the preceding paragraph to some extent. It certainly is an insurance issue, but it also reflects the medical culture in which aphasia therapies were born. Doctors are skeptical—the Cochrane report to which you referred is an excellent example of overstatement in the extreme, but reflects the problem. Thank you for quoting my counter position to it as balance. And the medical model is frankly outdated in its relevance for the treatment of aphasia. The model has moved into the social, interactional realm. But it is the medical model that controls access to treatment. And patients run out of funding long before they run out of appropriate treatment possibilities.

Under these circumstances, it is hard to think of “enthusiastic and appropriate referral patterns.” We have a very large aphasia clinic here at the University of Arizona and because we focus on group therapy and cost effective individual treatment of a functional nature, we are relatively cheap. We have sold this notion to local hospitals and rehab centers, and we get tons of referrals from them when their patients run out of benefits because we provide an affordable alternative. I think this is an expandable model.

A second model is that embraced by the Connect Program in London, which is sponsored by a private foundation. Its goal is to serve aphasic patients, develop treatment methods, and to spread itself across the English healthcare system. (Sally Byng at Connect, 16–18 Marshalsea Road, Southwark, London, SE1 1HL, UK.)

What are the levels of research funding? Are there any significant clinical trials that need funding?

Aphasia treatment research per se is not sexy at the NIH, for reasons described earlier. It looks a lot better on paper from say NIDCD, than it actually is because of the factors listed under question 1.

My sense is that there is a lot of relevant research that fails to make the funding cut for most agencies, and my own thinking is that private foundations really need to be made more aware of the aphasia community’s needs in this regard.

Clinical trials are always welcome. But as you know randomized controlled trials are designed for pharmacological and surgical (medical model again) treatments. When they get applied to behavioral changes, they become very complex and extremely expensive. For example, dose-

response curves are easy with pills. Imagine trying to do them well with sessions and focus of language therapy.

Are computer programs helpful in regaining speech? Who are the experts in this area?

I think computers have a role in aphasia treatment. I do not think they substitute for clinicians, nor are they appropriate for all problems in aphasia, but they certainly are useful adjuncts. I think the most knowledgeable persons in this regard are Marcia Linebarger (associated with Myrna Schwartz at Moss Rehab in Philadelphia. MossTalk) and the C-Speak group at the Boston VA.

What about the great enthusiasm in some quarters for use of fMRI in therapeutic interventions?

As for therapies based on fMRI, I am leery, except in the most general senses. I see the potential for fMRI as being able to find out how and if the brain might be altered physiologically BY therapy, and for tracking changes over time, but it basically leaves out the neurochemistry—and I think we're a long way off from building treatment on it. In fact, there are huge gaps in knowledge that fMRI might never touch. Mind you, I am a great advocate of learning what we can from this powerful tool, but guiding therapy? Not now.

Research on neural plasticity, some of which can be demonstrated using the fMRI as an observational tool, is hot stuff. But we are just beginning to understand the implications of this.

What do you think is the greatest difference between your “supported conversation for adults with aphasia approach” and that of the cognitive neuropsychologists?

First, there is a difference in focus from strengths (us) versus weaknesses and areas of deficits (them), in a nutshell. Please note that neither of these approaches is right or wrong, and there is overlap at many times, too. Second, groups have a central role in our treatment, not a peripheral one.

There are a couple of big structural differences: first, we target very different behaviors to work on. Cognitive neuropsychologists tend to target more linguistic and structural elements than we do (unless, of course a patient clearly WANTS to do that sort of work). Second, our clinic and our research base is clearly centered on learning to live as well as possible with aphasia. This means we have an opportunity almost daily to see the effects of what works and what doesn't work in lessening aphasia, and although we are concerned with the impairment of aphasia, we are perhaps even more concerned with its effects on limiting normal activities and societal participation (World Health Organization's terms). So our designs for treatment research are not limited to single-subject

designs, but are often pre-post treatment comparisons, group studies, and in some cases, derived from qualitative methodologies as well.

On a more philosophical level, involvement of aphasic person/family in setting treatment goals is central to what we do. So are a couple of issues, like planning and promoting work to be done at home, not only to make up for lost time under current reimbursement plans, but clearly illustrating the necessity of personal/family responsibility in lessening aphasia (and of course, thereby playing havoc with tight treatment designs).

We also focus more on the development of strategies for compensating for language problems (for use by both aphasic people and their families) as well as approaches that focus on attempts to eradicate language problems. The chronicity of aphasia is what people have been ignoring when in fact, understanding its chronicity and working within it to improve the aphasic condition is a key to management.

Indeed, paradigm differences are at the heart of all of this—and I agree that both approaches need to be supported. I cannot imagine, regardless of our functional thrust for example, saying to a patient, *“We can’t work on your word retrieval problems.”* Or, *“Forget the little words. They don’t contribute much to transmitting meaning.”*

We have plans for expanding our aphasia clinic here at Arizona. I am going to be spending most of my time next year developing a residential program to complement our current day clinic, concentrating predominantly on chronic aphasic patients, and evaluating a holistic approach to learning to live successfully with aphasia, rather than curing it. There is a groundswell of enthusiasm in the US, Canada, Australia and England for such approaches.

What are the major differences in assessment tools that you use and the strict neurolinguists use for aphasia?

There are practically no differences. We all use a range of different tests for different purposes (in our case, some functional measures are added that are not used by “strict neurolinguists”.) But almost all of us use tests such as the Western Aphasia Battery or the Boston Diagnostic Aphasia Examination to gain a clear picture of someone’s aphasia, and as a baseline measure, and selected subtests of, say, the PALPA (Psycholinguistic Assessment of Language Processing in Aphasia), when we are going about attempting to delimit a patient’s particular neurolinguistic deficit at the single word/phrase/contextual level.

To this mix, we add other measures specifically related to other variables of interest. For example, I might decide I want to put the aphasia into its overall cognitive context, so I might opt for a measure such as the Test of

Nonverbal Intelligence, or use another test, on which we should not expect to see change as a result of treatment, as a control test. I think this is probably true of most research programs, as well.

If you were to go with a strictly cognitive/neurolinguistic approach, where is the best work (from the point of view of developing tools for treatment) being done?

This one is the tough one. Work by Pelagie Beeson here at the University of Arizona is particularly strong using a cognitive neuropsychological approach to reading and writing in severe aphasia, although she gives it a lovely functional twist as well. Rita Berndt at Maryland is excellent at both lexical and syntactic issues from this point of view, and so is the MossRehab Group in Philadelphia (Myrna Schwartz and Marcia Linebarger et al) although they seem to grow more functional by the moment.

Finally, in a direct cognitive tradition, not cognitive/neuropsychological, there is Nancy Helm-Estabrooks at the Boston Aphasia Research Center, and (while not terribly practical in the real world of patients) Cynthia Thompson works impeccably within a Chomskian linguistic tradition. (Example of current funded study: Linguistic Specific Treatment in Aphasia.)

Do you think there is value in endowing a university chair to support aphasia research?

I have doubts about that as a way to go, primarily because, as you sit in one of those, you still have the same academic responsibilities and I suspect that that fact makes it easier to forget how and why you were endowed. Research grants, clear expectations, funding of specific projects, and deadlines strike me as a sounder approach. That is, the research itself takes the money, paying for an endowed chair fails to address the issue. An alternative in that ballpark might be a grant with some strings attached, to, say, conduct research on treatment—something like a MacArthur grant. Also, this would not limit recipients to academic institutions.

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First, I think it is extremely (I would like to find a stronger word, like exceptionally or supremely) important for those of us who are trying to help persons with aphasia to understand the degree to which their limitations with communication can be stressful.

It is not unusual for me to hear aphasiologists say, “so-and-so has made a good recovery,” and for me to find that “so-and-so” is still trying to come to terms with the residual communication difficulty. Consequently, I find your statement about a patient who “is doing extremely well, but remains frustrated...” to be the rule, rather than the exception.

Is there any particular research or programs that you would like to see funded? Are there any significant clinical trials that need funding?

What is lacking more than anything else in this field, in my opinion, **is** funding for clinical trials. These are expensive. Support from NIH is excellent, but is generally limited to research that is highly likely to succeed. Thus, there is a conservative streak in NIH funding which ends up yielding publishable results of often derivative research.

Money is needed for what could be called ‘high risk, high return’ research. That is, it could provide a funding boost to original, creative ideas that may not pan out but which, if they did, would make a big difference to the world of aphasia therapy. An example of this would be to fund projects similar to one I have been working on for a number of years in pharmacotherapy, but have difficulty getting NIH to fund because it is not clearly a ‘winner.’

I have been working on a project, with assistance from researchers in Paris and Japan, to examine the role of certain neurotransmitters. We have gross results that need to be further supported experimentally: language output abnormalities have been linked to dopaminergic system deficiencies and anomia and auditory comprehension disorders have been linked to cholinergic deficiencies. We have had some remarkable results with a small pool of single-case studies in which patients served as their own controls.

I am involved with the National Aphasia Association (NAA) which has struggled with a modest budget for over ten years. It is the first and major U.S. group devoted to active advocacy for aphasia patients and their families. As little as \$50,000 could make a big difference. Obviously, more money could enable NAA to perhaps emulate the successes of organizations like the National Head Injury Foundation (NHIF) and the Alzheimer’s Association. These groups have local chapters and are active in influencing major funding decisions as well.

Interestingly, when looking at numbers, according to the NHIF, 30,000 to 50,000 of the 400,00 to 600,000 people who sustain traumatic head

injuries are left with noticeable physical, social, and cognitive deficits severe enough to prevent them from returning to their former levels of function.

Compare this to the approximately 80,000 out of 500,000 stroke victims each year who become aphasiac. Even though 1 million Americans are aphasiac, diseases such as multiple sclerosis (250,000 to 300,000 in the US) and Parkinson's (600,000 to 1 million in the US) are much better known due to active public awareness and education campaigns, televised programs, and grass roots events.

Nearly 4 million Americans have Alzheimer's disease, according to the Alzheimer's Association. This is clearly a problem that needs to be addressed in a comprehensive fashion, as they have been doing, with an active international organization. It is a useful model for aphasia.

According to a survey by NAA, 90 percent of those with aphasia believe that public knowledge about aphasia is minimal. We have a lot of work do!

Are there promising researchers that might not be as well known as some I have mentioned?

If you have not run across him yet, I'd like to mention David Caplan at Massachusetts General Hospital. Two of his current funded projects are "Sentence Production in Aphasia," and "An Investigation of the Trace Deletion Hypothesis."

His research on sentence production aims to gather basic data currently unavailable, with the goal of improving aphasic patient's sentence production abilities. As you know, producing sentences in conversation would go a long way in improving the quality of life for aphasic patients.

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We are looking at brain change with aphasia research. Although we can change the context of communication and assist aphasic adults in learning how to leverage their skills so as to participate more fully in their life, the goal needs to be understanding where the deficits are in the brain so we can fix them.

I don't think that language is lost after a stroke. It becomes difficult or impossible to retrieve language because of brain damage. We aren't trying to re-teach

language with therapy and treatment, we are trying to help aphasic patients find out where the lost words and symbols are and regain full access to them.

Is there an non-research activity that you think could be valuable to support?

I think funding a small conference of some sort where leading experts could convene to discuss these important issues and perhaps realize a set of priorities and a set of strategies for their resolution. If you are interested, I might be interested in organizing (or helping) such a summit. A possible model for this kind of summit might be one in which I am participating in February, 2002 on *Apraxia of Speech*.

The Academy of Aphasia, for example, provides a valuable international forum supporting shared research and expertise.

What are the current gaps between aphasia research knowledge and field application of that knowledge?

There certainly are gaps between research supported clinical evidence and practitioner's implementation of this information. Among the most prominent reasons I believe are: a culture among practicing clinician to not keep up on the literature and insurance (3rd party payers) coverage limitations that absolutely and categorically prevent "best practices" when they are available and known.

What are the current gaps between aphasia therapies and access to therapies? Is this an insurance issue? Education of physicians? Are patients being enthusiastically and appropriately referred to therapists? Who is doing this well?

There are always issues of getting appropriate referrals from PCPs because of misinformation, lack of information, disciplinary arrogance and bias. Our ability to get appropriate referrals is probably considerably higher than the average because of our procedures in the Pittsburgh Aphasia Treatment, Research and Education Center and because of the circumstances with the VA hospital (a portion of the PATREC). Another factor is the relatively high profile and perceived competence of the co-directors of PATREC (myself, Dr. Patrick Doyle and William Connors) due to our clinical successes and because we do research on these issues that the referring physicians (and others) know about and respect.

The psychosocial approach is important. We use a comprehensive approach here, but that is not sufficient to address what I believe to be the underlying problems that result in aphasia: attention deficits, memory and resource allocation problems. We need to get at those kinds of issues before we can see any real, substantial improvement in the kinds of therapies we can provide.

The team we have at Pittsburgh and Carnegie Mellon is well positioned to do research in aphasia. Endowing a university chair, which incidentally costs \$1.5 million here at Pittsburgh, often has magnet effect and attracts additional money along with top researchers.

What are the levels of research funding? Are there any significant clinical trials that need funding?

The levels of research funding are relatively low compared to many other less prevalent and handicapping conditions. This is due to a couple of factors: few qualified persons doing this research; an emphasis on “randomized controlled trials” as the only source of evidence, a standard that the field is not yet ready to undertake; and, we have not had a public figure with aphasia to draw attention to aphasia (possible exception of Kirk Douglas) the way that Parkinson’s Disease (Michael J. Fox) or Alzheimer’s Disease (former President Reagan) has.

There are a thousand clinical trials that need to be funded! They are all (or nearly all) pre-RCT paradigm. We need more applications of small-scale studies. We need to find funding for the right small scale work in order to justify the larger, multi-site clinical studies so beloved by NIH.

Lobbying for federal funds for the “right kind” of research is very important. Other solutions to funding pinches are also appropriate and possible with support from well-endowed private foundations, direct support of post-doctoral candidates, endowing a university chair, or even hiring an executive director for programs like PATREC that require researchers’ time to administer and run.

How sufficient are the assessment tools neurolinguists use for aphasia?

For the most part, the assessment tools are OK. The measures are pretty good. Some of the more specialized assessments do require additional training. They are not off the shelf for the majority of speech-language pathologists. We do provide specialized training at Pittsburgh with this assessment tools.

Are computer programs helpful in regaining speech?

There are experts in the implementation of computers in aphasia treatment and computers clearly should have a place in the treatment armamentaria of SLP’s, however, the problems of good aphasia treatment are not due to computer applications research or development.

Computers will not facilitate a bad treatment and they are not likely to provide a treatment that cannot be done in their absence. They could help

deliver an otherwise theoretically sound and experimentally validated treatment.

MARCEL A. JUST, Ph.D..

D.O. Hebb Professor of Psychology
CCBI Center Co-Director
Center for Cognitive Brain Imaging
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Carnegie Mellon University
Pittsburgh, PA 15213

We discussed the importance of having access to a sufficient pool of candidates for research. Obtaining subjects for human research is a challenge in of itself. For some researchers access to subjects is more restrictive than lack of funding.

Dr. Just is completing work on a paper that is not ready for public release. He sent me the paper which appears to be a useful model for continued work in aphasia treatment. The work is based on a neurocognitive approach using fMRI to determine whether the therapy produced a task-specific change in patterns of brain activation. The research was a collaborative effort with researchers at the University of Pittsburgh, in addition to the professionals at Carnegie Mellon. This relationship, which includes access to the VA system, as well as a number of hospitals, permits a great deal of research on aphasia to take place.

It is important to recognize that improvements can continue for a number of years post- stroke. Aphasia is a chronic condition. Insurance companies treat it as an acute situation and do not support efforts to continue therapy. Some of Dr. Just recent work has been with patients more 5 years after their stroke. It appears that old function doesn't return, but new networks are established. The brain has a remarkable capacity for recovery through recruitment of new areas and we need to learn to exploit that with appropriate therapies.

Dr. Just mentioned how moving the theatrical production of *Wings* (Arthur Kopit) about the struggles of a person with aphasia was.

<http://endeavor.med.nyu.edu/lit-med/lit-med-db/webdocs/webdescrips/kopit826-des-.html>:

In the well-written preface, Arthur Kopit describes how he came to write Wings, a play about stroke and language disorder. And he explains there how his fictional account of strokes and their aftermath, "is a work of speculation informed by fact." One fact important to Kopit was that his father suffered a major stroke seven months before Kopit was commissioned by National Public Radio to write an original radio play. Wings, (which has been successfully staged as well) however, is not

based on Kopit's father, but on the life of a character, Emily Stilson, who is an amalgam of people, both stroke victims and their stroke-recovered caregivers, from the rehab center caring for Kopit's father. The title of the play refers to an early career of Emily Stilson--she was an airplane wing-walker. Kopit deftly employs the sounds of an airplane in the scenes in which Emily is experiencing a stroke. In fact, the sounds and sights inside and outside of Emily as well as her private dialogue are combined masterfully by Kopit to bring about a high degree of verisimilitude to the chaos produced by stroke.

STEVEN SMALL, MD, Ph.D..

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MC-2030
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Dr. Small asks, "Can we cure aphasia?" Although he understands that we now regard aphasia as chronic condition, he sets his bar high: cure it. To cure aphasia, we need to change the brain. That's where the work is.

He suggests that we change the current, standard definition of aphasia:

"...an acquired impairment of language performance produced by damage to the brain."

He thinks this definition is more applicable:

"Aphasia is a result of a stroke and other brain injury which is characterized by difficulties with language use, signified by language, memory, motor, visual spatial and affectual disorders. Aphasia is chronic but gradually improving over months to years, often accompanied by social problems for both the afflicted person and their communication partners."

Although there is no question that aphasia therapy helps, no method has been proven superior to any of the others. There is no integrated model of aphasia, but that doesn't mean we can't help people with aphasia. Right now, a comprehensive approach similar to that used in Alzheimer's clinical centers is a reasonable model. But we can't stop there!

There are a number of important issues to address, even in the absence of an integrated biological and behavioral model of aphasia. We need to know what medications can interfere with stroke recovery. Over 80 percent of people are

taking medicine at the time of their stroke. We don't need to make matters worse. What inhibits recovery?

Also, we need to identify remedies for specific biological problems in the brain. We know that people with strokes have decreased cerebral perfusion; they have decreased glucose metabolism globally; and, they have decreased catecholamine concentrations in particular regions. We also know that catecholamine, monoamine and cholinergic receptors are found throughout brain regions involved in language and memory. Let's move ahead and study these concepts.

Clearly, the problem of depression and other so-called affective disorders needs to be addressed. We find that 70 to 80 percent of people with aphasia probably have depression. We don't know what anti-depressants are most efficacious for aphasics because we don't know what isn't working (neurochemically) post-stroke.

We have seen the importance of motivation in stroke recovery. We cannot quantify motivation, but clearly one of the things that correlates best with patient recovery, perhaps more so than injury size or site, is how driven the patient is to get better. What can we do to maximize motivation? Can we learn to measure it in a clinically useful way?

We need interventions that are biological and behavioral, and then establish the correlation between biology and function. For effective therapies of any kind, we need to monitor their biological effects. We have to keep looking at the brain until we can cure aphasia.

Dr. Small's Mary Law Lecture 2000, "*The Future of Aphasia Therapy - is it just a dream?*" provides excellent insight into aphasia research. Perhaps he would not be too offended if I summarized his approach, in an ideal world, as "*It's the brain, stupid.*"

LEORA CHERNEY, Ph.D.

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Chicago IL 60611-4496

Dr. Cherney is one of a handful of researchers trying to tap the potential of technology in treating aphasic adults. She is developing a computerized treatment program, Oral Reading for Language in Aphasia (ORLA), based on her approach for improving language skills in aphasic individuals through reading aloud.

She uses techniques originally designed for reading-disabled children and modified them to work with her aphasic patients. Her approach is graduated: beginning with 3 to 5 word sentences, increasing the complexity to 8 to 10 word sentences, and then to 20 to 30 word paragraphs. Of necessity, there is a great deal of repetition. Improvements in verbal expression and reading comprehension are seen.

Part of her study will be to remove the "personal" influence with clients to see whether the approach itself is successful and not dependent on the therapist-patient bond. Additionally, she is going to monitor brain changes with her therapy using brain imaging studies on the study subjects.

If a computerized ORLA system is effective, it will be used in conjunction with a SLP who will do assessments and evaluations of individual patients. The program can be distributed to professionals as stand alone software or via the Internet. In light of the limited amount of therapy that is reimbursed by insurance companies, having cost-effective software available for ongoing training could make a big difference for patients. Rural areas are under-served by SLPs and this program could easily make therapy available to many that have no access to ongoing treatment.

Information received from the NATIONAL INSTITUTE ON DEAFNESS AND OTHER COMMUNICATION DISORDERS at the National Institutes of Health

Prevalence of aphasia: approximately 3.5 per 1,000 adults in the United States; approximately 1,000,000 Americans have some form of aphasia.

Extramural Research Funding: In 2000, the most recent year with actual figures, extramural aphasia research spending represented 4.1 percent of the NIDCD budget.

Funding Levels of Extramural Research on Aphasia at NIDCD ¹

Fiscal Year	Amount
2002 est.	\$11,328,000
2001 est.	\$10,244,000
2000	\$9,195,000
1999	\$5,910,000
1998	\$5,956,000
1997	\$5,735,000

General State of Science Concerning Aphasia: Aphasia research is providing new ways to evaluate and treat aphasia as well as to further our understanding of the function of the brain. Brain imaging techniques are helping to define brain function, determine the severity of brain damage, and predict the severity of the aphasia. These procedures include PET (positron emission tomography), CT (computed tomography), and MRI (magnetic resonance imaging) as well as the new functional magnetic resonance imaging (fMRI), which identifies areas of the brain that are used during activities such as speaking or listening.

Using imaging technology, NIH-supported scientists recently have documented reorganization of brain activity after treatment for acquired reading disorders following stroke. The neuroimaging performed during a reading task before and after treatment indicated a shift in brain activation from one area to another, showing that it may be possible to alter brain activity patterns with therapy for acquired language disorders (Steven Small, FUNCTIONAL NEUROANATOMY OF NORMAL AND IMPAIRED LANGUAGE).

For future studies, functional brain maps of individuals with brain injury performing cognitive tasks will be compared to those of uninjured individuals to determine how damage affects normal brain function. To characterize the impact

¹ NIDCD is the lead NIH agency funding research on aphasia; total awards made by NIDCD in FY 2000 equaled \$226,151,629; for the same period, total NIH awards equaled \$14,791,024,329.

of rehabilitation on the brain, functional brain maps will be acquired for individuals with brain injury performing cognitive tasks before and after rehabilitation. (Leslie J. Gonzalez-Rothi, TREATMENT OF APHASIA AND RELATED DISORDERS).

The central goal of aphasia therapy is to improve an individual's ability to communicate by helping the person to use remaining abilities, to restore language abilities as much as possible, to compensate for language problems, and to learn other methods of communicating. Treatment may be offered in individual or group settings. NIH-supported scientists are designing and studying the efficacy of behavioral treatments for agrammatisms, anomia, aprosodia, and attention disorders associated with aphasia. The impact that these behavioral treatments may have on the quality of life of the participants and their caregivers will also be monitored (Leslie J. Gonzalez-Rothi, TREATMENT OF APHASIA AND RELATED DISORDERS).

In-depth testing of the language ability of individuals with the various aphasic syndromes is helping to design effective treatment strategies. The use of a computer-assisted visual communication system to assist aphasics who are unable to produce or comprehend language is being studied (Martha W. Burton, PROCESSING DEFICITS IN APHASIC PATIENTS.)

Promising new drugs that may improve the rate of language recovery administered shortly after some types of stroke are being investigated as ways to reduce the severity of aphasia (Delaina Walker-Batson, PHARMACOLOGIC MODULATION IN THE TREATMENT OF APHASIA.)

The NIH supports a multitude of programs that are designed to prepare individuals to become active and responsible members of the scientific community. Some programs provide research training for individuals who are interested in aphasia. For example, an NIDCD-supported Institutional Training Grant provides research training to individuals interested in communication sciences and disorders. Hands-on apprenticeship training is provided in speech production, development and disorders across the lifespan with special attention to sensorimotor processes in speech and speech disorders from development to aging; language structure, development and disorders, including studies of aphasia; and peripheral and central processing of speech and non-speech acoustic stimuli.

A primary purpose of the training program is to provide intensive interactive research experience, leading toward the establishment of successful independent clinical investigators.

Another pre- and postdoctoral program is based at the Aphasia Research Center in Boston and has produced 36 post-doctoral trainees, with a high proportion who have gone on to careers in research and research training in the area of adult communication disorders. In addition, there are opportunities across NIH that

provides support to individual postdoctoral researchers to prepare them for careers in research in aphasia or other cognitive disorders.

NIH Intramural Research on Aphasia: Functional imaging techniques are being used to characterize brain activation patterns in normal subjects and individuals with neurological disorders affecting human communication in the Voice, Speech and Language Branch of NIDCD's Division of Intramural Research.

A goal of the branch is the development of neuroimaging methods to study aphasia in individuals recovering from stroke. The branch is involved in 1) longitudinal fMRI-EEG/ERP (electroencephalogram/event related potential) studies of speech production in the course of recovery and 2) development of neurochemical PET methods as indices of neuroplasticity.

Images of the living brain as it re-acquires the ability to speak provide valuable information on the physiology of language recovery. In addition, the use of neuroimaging technology to show functional reorganization of the brain during spontaneous recovery will be an effective tool to evaluate treatment of aphasia. To further research in this area, the NIDCD is establishing collaborations with major regional stroke centers at The Johns Hopkins University, National Rehabilitation Hospital, The University of Maryland, George Washington University, and Suburban Hospital, and has also begun a pilot study using MR/EEG paradigms in control subjects. (Allen Braun, IN VIVO NEUROCHEMICAL IMAGING STUDIES and PET AND fMRI ACTIVATION STUDIES.)

Collaborative NIH Efforts and Future Initiatives on Aphasia: Biomedical research has become complex and involves multidisciplinary approaches. Research on aphasia is currently being supported by the NIDCD, NICHD, NINDS, NIMH and NIA with NIDCD serving as the lead institute. When research opportunities overlap the mission of several institutes, collaborative efforts will be fostered. As the primary Institute conducting aphasia research, the NIDCD has cosponsored over the past year a symposium series, "New Perspectives in Language Research," with the NICHD, NINDS, NIMH and NIA.

The development of language across the lifespan and the effects of brain injury on language performance were major themes of this symposium. The March 2001 symposium on "Developmental Disorders of Language" also included scientists involved in aphasia, language development, spatial cognition and underlying neural systems.

The NIDCD is in the planning stages of two initiatives related to aphasia. Both activities are related to treatment and rehabilitation of adult aphasia. One initiative is a Request for Applications, co-sponsored with NICHD, that is focused on augmentative and alternative treatments relevant to adult aphasia. The other initiative being planned is a planning workshop to formulate research

recommendations on aphasia intervention and use of neuroimaging techniques. Other NIH institutes conducting aphasia research will be invited to participate in the workshop. The NIDCD was invited to present at the annual conference of Clinical Aphasiology; in addition, NIDCD will be presenting at the Academy of Aphasia's annual meeting in October 2001. Presentations by NIDCD staff at these two major meetings highlight research and funding opportunities for researchers and clinicians in adult aphasia.

The NIDCD Strategic Plan states that research that focuses on the perceptual and cognitive processing in normal and disordered communication is a major priority of the Institute. In particular, NIDCD recognizes the need for additional research to investigate the perceptual and cognitive consequences of disordered communication and to determine how these processes change with treatment. In addition, the NIDCD Strategic Plan emphasizes research that develops and improves devices, pharmacologic agents, and strategies for habilitation and rehabilitation of human communication disorders as a high priority.

Specifically, research is needed to:

- Capitalize on emerging technologies to design and improve devices that enhance communication.
- Use clinical trials and other clinical studies to evaluate the efficacy of newly developed devices, drugs, and other therapies for individuals with communication disorders.
- Develop and refine diagnostic criteria and capabilities to facilitate early diagnosis of hearing, speech, or language disorders.
- Use clinical trials and other clinical studies to develop and assess medical and behavioral interventions for infants and children who have a hearing, speech, or language disorder.
- Develop cost-effective techniques for the assessment of speech/language development and disorders in the broad range of languages currently used by residents of the United States, taking into account all cultural and ethnic groups.
- Use molecular genetic, electrophysiological, imaging, and other approaches to precisely define the phenotypes of communication disorders as a basis for optimizing clinical diagnosis and intervention.

Regarding clinical trials on aphasia: one has to have a defined therapeutic protocol, validated outcome measures, and sufficient pilot data to show justification for the major expenditure of dollars involved in a typical clinical trial.

It is questionable if there are sufficiently specified treatment programs and substantial efficacy data currently, to serve as the basis of a trial for aphasia intervention. However, smaller-scale studies of treatment efficacy are underway and additional studies are needed.

NIH Institutes, with contact persons, that conduct aphasia research:

National Institute on Deafness and other Communication Disorders:
Judith Cooper 301.496.5061

National Institute of Child Health and Human Development:
John McGrath 301.496.5133

National Institute of Neurological Disorder and Stroke:
Marian Emr 301.496.5924

National Institute of Mental Health:
Clarissa Wittenberg 301.443.4513

National Institute on Aging:
Jane Shure 301.496.1752