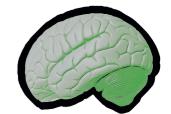
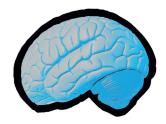




## In this Issue

- $\mathbf{3} \mid \mathsf{Editor's} \ \mathsf{note}$
- **4** | What is aphasia?
- 6 | it takes a village: Caring for a loved one after stroke
- **8** | Needing support: Resources for living well with aphasia
- 10 | Representation in Research
- $12 \mid \texttt{Beyond Words: A conversation with} \ \mathsf{Lindsay Butler, Phd} \ \mathsf{and} \ \mathsf{CCC-SLP}$
- $14 \mid \begin{smallmatrix} \mathsf{Plasticity} \text{ in Parkinson's: Adapting to} \\ \mathsf{speech always possible} \\ \end{smallmatrix}$
- 16 Unlocking communication: Empowerment in Aphasia
- 18 | A peek into the members of the Language and Brain Lab











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### Note from the Editor-in-Chief

This is our ninth issue of *The Spoken Word*—a number that I could not have conceived of when I first launched this modest research digest in the fall of 2018. Sadly, this is also the final issue that I will be Editor-in-Chief for. Although I will miss it immensely, I am also incredibly proud to pass the baton over to Portia Washington, who I know will steer *The Spoken Word* into new heights.

*The Spoken Word* was born out of a simple realization—people are curious about language science. The vast majority of the people that participate in research experiments want to know why we study what we do, what we want to find out, and the final results. Their curiosity is often one of the strongest motivating factors in why they choose to donate their time and gracefully suffer through the boredom and repetition of most of our experiments. Researchers, then, need to meet that curiosity and return what we've learned to the people that were indispensable in learning it. Without our participants, we would know very little about the mind and brain. The Spoken Word seeks to bridge the gap between research and all the curious folks out there that want to know more about language, speech, aphasia, and the rest of the kitchen sink.

All of the articles in *The Spoken Word* are written by a passionate group of undergraduate research assistants who are eager to tackle complex topics in the field of speech, language, and hearing science. For example, this issue has an article about representation in research and how science still has work to do to include everyone's voices. We also have multiple articles on how to support people living with aphasia with specific focus on the experiences of caregivers—an often-neglected group of people that deserve our attention. Our writers spend a year honing their skills and drafting their final articles, and the result of their effort is evident in the quality of the work I am proud to deliver to you, our readers.

Although I say it every year, this issue is one of our best. I hope you can come away with a new perspective on the intricacies of speech and language, and also know that many people care about helping people regain language after it is lost. We are a community united in a common purpose—to know more about ourselves and work together to support those in need.

Best,

Hannah Mechtenberg, Editor-in-chief and Creator of The Spoken Word

## What is aphasia?

by **Portia Washington** 

A phasia is an **acquired** language disorder, meaning that a person may develop this disorder after experiencing a traumatic event such as a **stroke**. A stroke happens when blood flow to the brain is disrupted resulting in the death of brain tissue. The damaged area is also called a **lesion**. Exactly where the lesion is and its size is different from one stroke survivor to the next.

Some stroke survivors have no trouble speaking or listening, but they may have weakness on one side of their body or face. This is called **hemiparesis** and happens when a lesion affects areas of the brain that controls body movement. Interestingly, many motor (movement), speech, and language areas are close to each other in the brain.

So, after a stroke, some people may still be able to think and understand you just fine, but **skilled**, **fine motor movements** (like moving the lips to create speech sounds) are much more difficult. This could manifest as being unable to say words with a lot of consonants (e.g., b, p, t, v), or other difficult speech sounds that require intricate mouth movements. This problem is typically called **apraxia of speech**. Motor difficulties can also manifest as slurred speech due to trouble controlling the muscles in the mouth and throat, otherwise known as **dysarthria**.

Sometimes, people have lesions that affect the motor part of speech more than language. **Broca's aphasia** is one example of this, where someone may be able to understand you well, but struggle to respond with more than a few words at

a time. As lesions get farther away from motor areas, we see disorders like **Wernicke's aphasia** where the person can move just fine, but struggle with more complex use of language like stringing together sentences or responding appropriately to questions. In our lab we tend to study people that primarily have lesions in the language areas of the brain, meaning that they probably experience some degree of trouble understanding or using language. We broadly refer to this group as **people with aphasia (PWA)**.

In the LAB lab, we also study how people that have not had a stroke can arrive at meaningful words and sentences from individual speech sounds. Our lab is one of many in the world that is working to map language functions to different parts of the brain in people without traumatic brain injuries. We also work backwards by connecting the lesions that people with aphasia have to the type of language difficulties they experience. The hope is that studying the way *all* people use language will help us understand how **different areas of the brain work together to make speech and language possible**.

It will take many people many years to conclusively identify which areas of the brain are responsible for language use. Unfortunately, this leaves those living with aphasia without all of the answers and help they need. One day, a person with aphasia may be able to remember the names of things around their house, and the next they may genuinely struggle to recall those same words. Some days are riddled with more confusion than



Ischemic Stroke



**Hemorrhagic Stroke** 

Two types of stroke. In an ischemic stroke (left), blood flow is cut off from the brain leading to tissue death (dark shadow). In a hemorrhagic stroke (right) blood spills out into the brain also resulting in tissue death (red area). Both types of stroke can result in aphasia **Source:** https:// www.scientificanimations.com/, CC BY-SA 4.0 <https:// creativecommons.org/licenses/ by-sa/4.0>, via Wikimedia Commons others, and it is very likely that recovery will feel like an eternity of taking forward and backward steps. Because of this, many people with aphasia have been led to believe that they will never speak again, or never understand speech or language again.

The truth is that aphasia recovery is **nonlinear and dynamic**, and for many stroke survivors the hours in speech, physical, and occupational therapy truly add up. The disorder is **chronic**, meaning that people with aphasia will likely always have to use strategies to aid them during conversations, reading books, or writing because aphasia can affect **all modalities of language**.

In this primer, there is very little mentioned about how aphasia actually affects the person with aphasia's life. It is always important to remember that we are more than our brain activity. Luckily, our student writers care about the intersection of aphasia and everyday life, and they filled this issue with answers as to how people with aphasia are able to navigate multiple facets of life after surviving a stroke or other neurological conditions. So, as you read through the articles I urge you to consider the context of the participants in these studies.

For most of their lives, people with aphasia had complex relationships, fulfilling experiences, and nuanced opinions. In a matter of moments their ability to communicate ceased to exist, not them as a person. For people with aphasia or their family members that may read this magazine please know that there are hundreds of researchers and other professionals that spend their days thinking specifically about the difficulties you face. Many of my own days at work are infinitely better when I have the pleasure of giving a person with aphasia a listening ear, and I know so many people that share this sentiment.

On the next page we share a list of resources that may benefit anyone living with aphasia, those helping people with aphasia, or others curious about aphasia.

Please feel free to reach out to me (Portia Washington: portia.n.washington@uconn.edu) if you want to learn more!

### More resources

### **Public Health**

• F.A.S.T (Face, Arm, Speech, Time). Recognize the signs of a stroke and intervene early: www.stroke.org/en/help-andsupport/resource-library/fastmaterials

## Statistics and resources on stroke and aphasia

• American Speech Language and Hearing Association (ASHA): https://www.asha.org/ practice-portal/clinical-topics/ aphasia/

• The National Aphasia Association: https:// aphasia.org/what-is-aphasia/

### Fun!

• Aphasia Access: https:// www.aphasiaaccess.org/

• Interact-ABI-lity, Online Communication Partner Training: https://abicommunicationlab.sydney.edu.au/courses/ interact-abi-lity/

• Aphasia choirs around the world: https:// singaphasia.com/aphasiachoirs/

• Find aphasia groups near you: https://aphasia.org/ stories/support-all-states/

• Aphasia affinity groups (connect with people with the same identities): Black Americans: https:// aphasia.org/series/blackamerican-aphasiaconversation-group/

Spanish speaking aphasia group: https://www.biav.net/ resource-directory/grupo-deafasia-para-hispanoparlantesspanish-speaking-aphasiagroup/

• The aphasia community: https://www.aphasia.com/

• Aphasia Recovery Connection: https:// aphasiarecoveryconnection.or g/arc-board/

• International Aphasia Movement (IAM): https:// aphasianyc.org/iam-on-zoom/ Jennifer L.Mozeiko Deborah S.Yost Editors

# Caring For a Loved One with Aphasia After Stroke

A Narrative-Based Support Guide for Caregivers, Families and Friends

✓ Springer

\*\*

# it takes a village

by Erica Croxford

**C**aring for a loved one post-stroke can be an incredibly difficult task, and especially so if they have aphasia. Caregivers commonly feel like everything was thrown at them at once: their loved ones' diagnosis, navigating doctor's appointments, continuing therapy at home, and juggling financial responsibilities. In the healthcare field, sometimes there is a lack of acknowledgement, support, and education for care partners as they make the enormous transition into their new roles.

In the span of only a few days, care partners are expected to understand the implications of the diagnosis enough to advocate for their family member in the hospital. Simultaneously, they continue the management of their personal lives while trying to keep their loved one motivated. After being discharged from hospitals or rehabilitation centers, many families decide to continue outpatient speech therapy services. Athome practice is one of the leading factors driving language success during the journey with chronic aphasia. Allowing our caregivers to feel supported and properly educated can help diffuse the sense of feeling overwhelmed and promote better recovery for their loved one.

Thankfully, many caregivers are open about their experience, and share wisdom with others to help alleviate this burden.

The University of Connecticut Caregiver Support Group wrote a book containing inspirational stories from seven women who became caregivers after men in their lives acquired aphasia. These women discuss their lives pre- and post-aphasia onset. Their stories are raw and inspiring, highlighting the many challenges they faced throughout this life-changing event. *Caring For a Loved One with Aphasia After Stroke* shares advice the authors wish they knew before they started their journeys, and I have chosen to share some of my favorites with you.

Dr. Deborah Yost is a caregiver to her husband and the co-editor of *Caring For A Loved One with Aphasia After Stroke*. She offered insight into the world of caregiving and made it clear that as a caregiver, you should not feel alone. Joining a support group changed her life, giving her the ability to exchange advice with other women experiencing the same thing. Groups like these allow people to feel supported from the onset and through the whole process.

Yost stated, "It was so stressful because I didn't feel confident that I could do all these things. You do feel totally isolated and alone (. ...) you just feel like it's your burden that nobody else in the world has your burden."

Talking with other people going through similar things can alleviate these feelings and can make you more confident in your decisions. Yost pushed the importance of support groups stating, "They can find some solace in the fact that there are others out there." Unfortunately, there is no manual telling you what to do, but these groups can offer suggestions from those who really understand.

Caregiving is not an easy task, it can easily consume you and make you feel inexperienced and doubtful of your abilities. However, the trust you build between you and your loved one is unmatched. To know that they trust you to take care of them can create a beautiful bond. You are bound to uncover new and surprising things about each other in the process of caregiving.

Yost mentioned that her relationship actually became stronger because she realized the kind heart her husband had. In the midst of challenges and uncertainties, the journey of caregiving creates a remarkable bond of trust and resilience; fostering a sense of gratitude and comfort in knowing you have provided the best care possible.

### **Advice for Caregivers**

• Set aside a small amount of time for yourself each day, away from your caregiving duties.

• Be confident and be kind to yourself. Know you are doing the best you can.

• Stay in touch with your friends and family, and find humor in them. Ask them for help when you need it.

• Set a dedicated time to address finances, which will allow you to approach bills with a fresh mind.

• Take cues from your loved one. Observe what their needs are, but be careful not to push your own goals onto them.

• Accept that some people in your life will step up, and others will not. Find people willing to help.

Purchase your copy now! All proceeds are donated to UConn's Aphasia Language-Support Program



Five contributors to the book, "Caring For a Loved One with Aphasia After Stroke." In back left is Jennifer Mozeiko and in front right is Deborah Yost, essayist. Mozeiko and Yost co-edited the book. Mozeiko also runs UConris Aphasia Rehab Lab. (Contributed photo)



### by Manal Sheikh

In the last two decades, mental health awareness has influenced unprecedented social, academic, and political discussion. Among U.S. adults, the percentage who had received any mental health services within the past year increased from 27.2 million people in 2002 to 40.2 million people in 2019<sup>.1</sup> We are living in an era where the stigma and barriers around seeking therapy are disappearing, and many people benefit from this cultural shift. However, what happens when you are physically unable to talk about those feelings?

Unfortunately, when diagnosed with aphasia, a person's quality of life changes dramatically and they require a lot of support. People with aphasia can experience cognitive challenges, making it difficult to continue to perform well in their jobs. In an exploration of life with aphasia in workingaged adults, some individuals discussed that there was a lack of support from their employers.

This harmful lack of compassion can cause them to lose their jobs or prevent them from advancing in their career, which can contribute to feelings of isolation and possible depression. While there are plenty of speech, physical, and occupational therapy services for physical impairments, there is a lack of awareness regarding the mental health of people diagnosed with aphasia.

You might be wondering, "Does my loved one with aphasia really need a therapist?" The National Institutes of Health revealed that 53% of people with aphasia experience depression within the first three months post-stroke, and 42% persist with depression after one year<sup>2</sup> This indicates a correlation between post-stroke depression and cognitive struggles. Why is there this link? During a stroke, parts of the brain sustain damage or die as a result of blocked or ruptured arteries. After a stroke, the brain's ability to recover the function of the damaged areas involves many complex processes including rewiring brain circuits and changing neurotransmitter levels, affecting the moodregulating areas of the brain.<sup>3</sup> In addition, inflammatory responses and hormonal shifts can cause stress, frustration, and anxiety–all of which play a significant role in developing depression.

### **Speech-Language Pathologists**

A speech-language pathologist is trained to assess, diagnose, and treat people with aphasia. They are skilled in facilitating communication and are a vital part of helping people with aphasia regain their communication skills. However, a majority of speech pathologists lack the specialized training to deal with mental health issues and report emotional discomfort when addressing issues such as depression and anxiety.<sup>4</sup> Many avoid asking their clients about their emotional state during sessions. A speechlanguage pathologist may be uncomfortable tackling mental health issues as it is out of their knowledge and specific training.

### **Mental Health Providers**

A research study from Central Michigan University, conducted by Katie Strong and Jenna Randolph, interviewed six mental health providers who have provided services to people with aphasia.<sup>4</sup> They revealed significant barriers that prevent mental health providers from giving proper treatment such as insufficient training and education about aphasia.

An interview conducted with mental health providers who have had little to no experience with people with aphasia found that 46.2% of providers do not feel very confident or are somewhat doubtful about providing services ethically to people with aphasia.<sup>5</sup> This is an alarming discovery. Even when conversations about mental health are at an all-time high, people with aphasia are often left behind. In general, researchers urge for the implementation of updated training protocols tailored to working with individuals with aphasia.

### Caregivers

How do you advocate for your loved one if you see signs of their personality or behavior changing? You know them better than any provider, so keep detailed records of changes that concern you. Reach out to their speech pathologist and ask for some resources or ways to help. A great way to supplement their individual therapy is with group therapy. Group therapy has many advantages as it can boost self-esteem, connect people with aphasia with others who share their condition, and allow them to tell their stories<sup>..6</sup>

In fact, at UConn, we have such groups that provide support as well. This includes the aphasia language-support group program, run by Jennifer Mozeiko, in both Storrs and Farmington, Connecticut. The program features different sessions including book clubs for people with aphasia, an aphasia group choir, and even support groups for caregivers and families.

## **Connecting Speech-Language Pathology** with Mental Health

It is important to remember that speechlanguage pathologists (SLPs) play a critical role in advocating for their clients. While providing mental health services is out of their scope of practice, working with clients and their caregivers to identify talk therapy as a communication goal may focus speech therapy efforts on promoting self-agency. SLPs should also try to provide additional resources outside of speech therapy that can open up more avenues of support for their client.

More collaborations should exist between SLPs and mental health providers. SLPs should openly share tips for communicating with people with aphasia, and mental health providers should discuss possible warning signs of depression and anxiety. This will empower all professionals to make appropriate referrals and break down barriers to accessing services. By supporting one another as professionals, clients with aphasia will be more supported in their treatment journey. These small steps in collaboration can address and mend the gap between mental health services and people diagnosed with aphasia.

### **Future Steps**

Strong discussed the future of mental health services for people with aphasia. She questions, "How do we train who's out there (professionals) and is there a way to influence the pipeline?" At the foundational level, she suggested that training programs in psychology, social work, mental health, etc. should integrate the topics into the graduate curriculum. These courses can equip students to address the mental health needs of people with aphasia or other communication barriers. Similarly, such training could also be done in speech-language pathology graduate to familiarize students programs with understanding emotional wellness. By educating future students on the areas in which current clinicians lack proficiency, we can solve the issue at the root.

Overall, the hope for the future is to raise awareness and incite change. Over the next few decades with the help of more research and discussions, there should hopefully be statistics that highlight a surge in mental health treatment for individuals living with aphasia, mirroring the current rise in mental health awareness.

<sup>1</sup>SAMHSA, Center for Behavioral Health Statistics and Quality. "Key Substance Use and Mental Health Indicators in the United States:Results from the 2019 National Survey on Drug Use and Health."

<sup>2</sup>Kauhanen, M.-L., Korpelainen, J. T., Hiltunen, P., Brusin, E., Mononen, H., Määttä, R., Nieminen, P., Sotaniemi, K. A., & Myllylä, V. V. (1999). Poststroke Depression Correlates With Cognitive Impairment and Neurological Deficits. *Stroke*, *30*(9), 1875–1880https://doi.org/10.1161/01.STR.30.9.1875

<sup>3</sup>Naghavi, F. S., Koffman, E. E., Lin, B., & Du, J. (2019). Post-stroke neuronal circuits and mental illnesses. *International Journal of Physiology, Pathophysiology and Pharmacology, 11*(1), 1–11.

<sup>4</sup>Strong, K. A., & Randolph, J. (2021). How Do You Do Talk Therapy With Someone Who Can't Talk? Perspectives From Mental Health Providers on Delivering Services to Individuals With Aphasia. *American Journal of Speech-Language Pathology*, *30*(6), 2681–2692. https://doi.org/10.1044/2021 AJSLP-21-00040

<sup>5</sup>Morrow-Odom, K. L., & Barnes, C. K. (2019). Mental Health Professionals' Experiences with Aphasia. *Journal of rehabilitation*, *85*(1).

<sup>6</sup>Brumfitt, S. M., & Sheeran, P. (1997). An evaluation of short-term group therapy for people with aphasia. *Disability and Rehabilitation*, *19*(6), 221-230.



If you participate in a research study they might start with having you answer a few questions about yourself. You might wonder, why would a researcher need to ask me questions about my race, ethnicity, age, or other personal questions? Why do these demographic questions matter when participating in research studies?

Demographics are the specific characteristics or qualities that describe people within a given population. This can include age, sex, education, income, race, nationality, ethnicity, or religion. In an ideal world, these factors should not influence the quality of medical care one receives. This is an unfortunate reality though, as there has been a historical pattern of racial and ethnic minorities receiving lower-quality care than that of White people, leading to greater incidence for ethnic and racial minorities to experience illness throughout their lifetime.

After generations caught within this negative feedback loop, researchers and policymakers have become aware of the problem. There is a new movement towards developing an inclusive medical community, in which everyone can be equally cared for. As medical practices rely heavily on discoveries from basic research, it is essential for researchers to adjust how they present their findings.

The National Institute of Health (NIH) is a government agency in the United States that continuously works to improve wellness through public health research. Their mission statement reiterates their powerful movement: "[The NIH's] mission is to seek fundamental knowledge about the nature and behavior of living systems and the application of that knowledge to enhance health, lengthen life, and reduce illness and disability." Studies funded by the NIH require you to fill out the questionnaires mentioned earlier when collecting data, so they can generalize findings to all demographics.

Generalizing research data to diverse populations is a big task, with challenges stemming from getting participants to come to the lab, the inability to control for every confounding variable, and limited resources to surmount these barriers. This is even harder to achieve when the broader research community is unsure who exactly participated in the study, as studies typically only publish the experimental data.

So, even though researchers may collect demographic data about their participants, it's not mandatory for them to share that information with their data. This means that unless the study is directly assessing how demographics (age, sex, race, ethnicity) relate to the questions they ask, it's unlikely that you'll find detailed information about the participants in the published paper.

In 2017, the NIH required that all studies that they fund must outline plans for how they will include women and other minority populations in their research. This is a huge step in the right direction when it comes to representation, as before there were no baseline expectations for purposefully including people with diverse backgrounds in research studies.

There is linguistic and cultural variation across different racial and ethnic groups that can be easily overlooked when not factored into research studies. The fields of cognitive science, psychology, and speech, language, and hearing science are still trying to understand how demographic variation relates to questions they're asking.

Yina Quique, a current postdoctoral scholar at Northwestern University, is dedicated to researching culturally-sensitive interventions tailored for individuals from diverse backgrounds.

Quique shares her thoughts on representation through her research experience by noting, "I've seen some increased representation for the sake of increasing representation...it's almost like you get a checkmark. And that is not enough. Instead, we need to really focus on specific populations and adapt treatment assessments for those specific populations, rather than just come with the same project

### for everyone."

This emphasis on representation and inclusivity isn't just about meeting regulatory requirements. It is about recognizing that diverse perspectives and experiences, including those affected by conditions like aphasia, influence how we interact with the world. Black Americans are remarkably underrepresented in aphasia research, despite being twice as likely to experience a stroke and its associated consequences.<sup>1</sup> This massive oversight of this population has raised concern within aphasia research and other advocacy groups.

Part of the challenge in correcting this egregious neglect is that only 30% of aphasia treatment research reports include information on race and ethnicity.<sup>2</sup> Further, the demographic composition of participants in aphasia research rarely provides a fair and comprehensive reflection of the diversity within minority communities, amplifying the existing gap in knowledge, calling into question if previous findings are still relevant. Successfully tailoring language treatments for those with aphasia depends on including people from different racial and ethnic backgrounds to understand the disorder and its management more fully. If we involve a wider range of people in research, we can develop treatments that work better for everyone.

At UConn, we have a lot of opportunities for research, and many of us are actively addressing underrepresentation. Many language researchers on campus are doing studies funded by the NIH (including the head of the Language and Brain Lab, Emily Myers), including graduate students that receive NIH funding to learn how to increase representation in research. It's crucial for research environments to prioritize the inclusion of women and minorities, and is especially important to ensure that aphasia research reflects the diverse experiences and needs of all individuals affected by the disorder, leading to the most effective and inclusive treatment strategies.

So, you may ask yourself, what can you do? The next time you're in a doctor's office, reflect on the importance of representation and consider participating in research initiatives. Participants are the first step in advancing our understanding of various health conditions and how to best manage them. Your involvement in research can pave the way for groundbreaking discoveries and improved healthcare outcomes for everyone.

Your actions today can shape the future of healthcare for generations to come.

<sup>&</sup>lt;sup>1</sup>The National Institutes of Health (https://www.nih.gov/)

<sup>&</sup>lt;sup>2</sup>The Centers for Disease Control (https://www.cdc.gov/index.html)

<sup>&</sup>lt;sup>3</sup>Nguy, B., Quique, Y. M., Cavanaugh, R., & Evans, W. S. (2022). Representation in Aphasia Research: An Examination of U.S. Treatment Studies Published Between 2009 and 2019. *American Journal of Speech-Language Pathology*, *31*(3), 1424–1430. https://doi.org/10.1044/2022\_AJSLP-21-00269

# beyond words...

# A CONVERSATION WITH LINDSAY BUTLER, PhD, CCC-SLP

Interview and Story by **Ava Buckmir** 



Lindsay Butler. Provided by Butler

r. Lindsay Butler is among the newest faculty members in the Speech. Language, and Hearing Sciences (SLHS) department the Universitv at of Connecticut. She has a PhD in linguistics from the University of Arizona, received her MS in speech-language pathology from Penn State, is a certified speech-language pathologist, and completed a postdoctoral fellowship at Boston University. Her work revolves around learning about how nonverbal and minimally verbal children on the autism spectrum understand language.



(ABOVE) Flowers and trees bloom across the Storrs campus on April 15, 2024 Sydney Herdle/ UConn Photo

As a double major in SLHS and psychology, I have learned quite a bit about autism and its impacts on speech and language, but I was eager to learn more about Butler's work with nonverbal and minimally verbal youth. I began our conversation by asking her what sparked her interest in working with this specific population, especially as it is one that can be hard to work with:

"One of the reasons I do the research that I do with kids on the autism spectrum who are nonverbal or have minimal spoken language is because working with them as a clinician was really, really hard, just because there's not much research on them, so there's no evidence-base for 'how do we help them develop more complex language' and 'how do we help them communicate better.'"



(ABOVE) The front of the Phillips Building on UConn Storrs' South Campus. This building hosts the Speech and Hearing Clinic, research labs, and the Brain Imaging Research Center. Hannah Mechtenberg



Butler mentioned that 1 in 4 children diagnosed with autism are nonverbal or minimally verbal. Despite this dramatic statistic, minimal research exists on how these people experience language. Butler's lab, the Brain & Language on the Autism Spectrum Lab, aims to measure what language these nonverbal and minimally verbal individuals understand to better recognize autism spectrum disorder itself. I asked her what her lab does and why autism is important for people to understand:

"There's been a little bit of research on receptive language [listening and reading] suggesting that of those individuals who are nonverbal, at least 25% of them have good receptive language. But we don't have good ways to test that. You can't really do a paper and pencil assessment with them because of behavioral challenges, attention issues, and having a severe communication impairment it's hard to communicate.

We're starting to look at receptive language and we have designed a study to really meet the needs of nonverbal kids. We're doing it remotely so they can do it at home with a parent so they're comfortable. There's research that shows they [minimally verbal and nonverbal children] perform better in those circumstances than if we try to bring them into the lab or the clinic where it's an unfamiliar environment with a new person. They can give a touch screen response; it's a pictureword matching task so they hear a word, see four pictures, and they can give a touch screen response, so it has very low communication demands.

I think people just assume that they're severely cognitively-impaired because we don't have a way to test what they know. So making something that meets their unique needs, we have a way to test that and they understand way more than everyone assumes they can. And I hope that message gets out there too because I think, this might happen with people who have aphasia also, especially if it's more severe, people will talk about them, in their presence, kind of thinking that they don't understand and it's hurtful to those people. They probably understand more than what people think they understand, which is absolutely the case with nonverbal people on the autism spectrum."

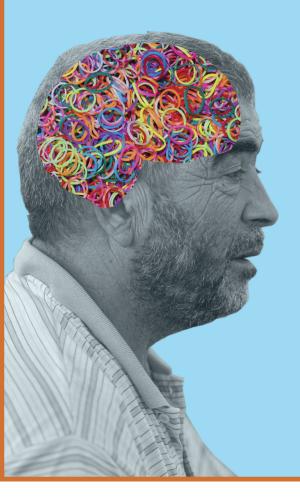
Butler's lab also uses brain imaging techniques, primarily focusing on functional near-infrared spectroscopy (fNIRS), which allows researchers to pass light into the top surface of the brain to see which parts are working or not. As someone who has used other brain imaging techniques (primarily measuring the electrical output of the brain using electroencephalography, or EEG) I wanted to know more about fNIRS and how she implements it in her work with the autism population:

"In my lab, we're using a new brain imaging technique called near-infrared spectroscopy that is much more 'autism friendly.' It's wearable and portable, so it's a bit more sensory friendly. So it's a cap and then the instrument is actually quite small so you can wear it on your back like a backpack. It's the kind of thing that we can even take to someone's home and do brain imaging there where they're going to be more comfortable."



(ABOVE) An SLP student at UConn works with a child. UConn Photo

I was fascinated to learn about Dr. Butler's work with nonverbal and minimally verbal youth on the autism spectrum. Her lab provides accessible testing that includes adaptations that fit the needs of these youth, such as the use of fNIRS and comfortable environmental options. Understanding the true nature of language acquisition in the autism population is critical in fully grasping the inner workings of this understudied disorder and I hope that future research can expand upon this work to provide more interventions and treatments for this population that can be hard to work with. I thanked Butler for her time, thought-provoking answers, and commitment to being a part of this interview.



Source: Heffner, C. C., Myers, E. B., & Gracco, V. L. (2022). Impaired perceptual phonetic plasticity in Parkinson's disease. The Journal of the Acoustical Society of America, 152(1), 511–523. https://doi.org/10.1121/10.0012884

Stock photos from Pexels.com

# Ilasticity in Iarkinson's

### by Elizabeth Teskey

It's pretty common to call your best friend after a long day, so much so that most people don't think twice about it. However, for people struggling with Parkinson's Disease, a progressive disease that makes movements difficult and stochastic, such a simple conversation can be pretty challenging. For these people, it can be difficult to talk during everyday interactions, such as checking out at a grocery store, speaking to a coworker, or even ordering a coffee.

Although tremors, shaking, and loss of coordination are the primary symptoms of Parkinson's, this disease impacts more than large movements. Unfortunately, fine motor skills are also affected. These delicate skills help us plan the movements of our lips and tongue, which are necessary for our ability to produce speech. Over time, the loss of fine control can result in slurred or slowed speech, caused by weakness in the muscles used to produce speech, which is called dysarthria.

Beyond movement, Parkinson's disease also impacts the way they understand spoken language. Concerning language, most studies focus on the motor impact of Parkinson's Disease. This may be because deficits in the ability to talk are more noticeable in conversation than comprehension is. However, we know that these people also have trouble understanding speech during conversations. It is extremely important that we understand how people understand speech so that we can better assist the Parkinson's community to improve their quality of life. Luckily, groundbreaking research is racing to uncover more about how the disease affects the brain.

In 2022, Chris Heffner and Emily Myers at the University of Connecticut, along with Vincent Gracco of Haskins Laboratories, conducted a research study that looked closer at how people with Parkinson's Disease perceive speech.

The team was most concerned with a phenomenon called "phonetic plasticity." It refers to the ability of listeners to adjust to changing situations in speech perception. In their study, they measured behavior from three groups of people: young adults without Parkinson's, older adults without Parkinson's, and people with Parkinson's. These people participated in four tasks designed to tap into different aspects of phonetic plasticity. Two tasks looked at the ability to learn new speech sounds (from another language) using two different strategies, the third task tested people's ability to listen to extremely sped up speech (rate adaptation), and the fourth measured how well people can cope with accented speech.

The results showed that those with Parkinson's performed worse on being able to perceive spedup speech than older adults without Parkinson's. In addition, people with Parkinson's on medication performed worse on some of the phonetic plasticity tasks than those off medication.

The ability to adapt to different types of speech and taking into account medication status is especially important in clinical work, as it has such a significant impact on learning.

Heffner describes the real-world implications of these findings, stating, "If learning is better off medication, [then] try to learn [new] things when you are just about to take your next dose. We can time things so that [when] you are low on your medication, then we can teach you something at a time when you are prime to learn."

Understanding common deficits in this population will allow for a more effective treatment, and therefore higher quality of life. The ability to communicate is an extremely important, and complex, aspect that everyone deserves to have.

So, what does this mean? This study demonstrates that speech perception is impacted in people with Parkinson's Disease, and that the disease is not limited to motor deficits. Encouraging other researchers to focus on speech perception when researching Parkinson's will help change lives.

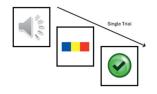
Everyone deserves the ability to communicate effectively, and researching any differences in how the brain perceives speech is essential in order for this goal to be reached. So next time you come across someone with Parkinson's, keep this in mind and remember to be patient.

### A PEEK BEHIND THE RESEARCH CURTAIN...

Heffner and colleagues designed four different tasks to probe the degree of "phonetic plasticity" of the people that participated in their study

### **Explicit Learning**

**Task**: learn to group sounds into three categories using explicit feedback



### **Context Adaptation**

Task: parse a single sentence with word segmentation ambiguity that could be heard as ending either with "SC" or "SE"



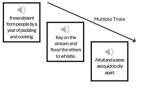
### **Accent Adaptation**

Task: adapt to foreign-accented speech by staircase procedure changing amount of noise in background



### **Rate Adaptation**

Task: adapt to highly rate-compressed speech using staircase procedure



Each of these tasks are thought to measure different types of adaptation and learning people do in everyday life, from learning new speech sounds (the leftmost task) to adjusting to someone speaking quickly (second from right) to working to understand someone with an unfamiliar accent (rightmost task).

# Unlocking Communication: Empowerment in

## Aphasia

### More on Augmented Alternative Communication

Augmentative and Alternative Communication (AAC) are one of the tools in a speech-language pathologists tool kit. AAC is an exciting innovation because they can be personalized to fit the communication goals of each client. For the purposes of this article, "devices" will refer to all types of AAC such as tablets, drawings, communication, or picture books. In speech-language therapy, AAC devices help patients develop strategies to produce and interpret non-verbal communication. Companies producing technological AAC devices serve multiple populations, including people with developmental disabilities, Autism Spectrum Disorder, traumatic brain injury, and aphasia!

### **Author Aside**

Attending the 2023 American Speech-Language-Hearing Association (ASHA) convention, I was able to speak with representatives from the company Lingraphica to get an inside look at their tablets. They provided me with a walkthrough of a device designed for an older person. The AAC tablet displayed a personal profile catered to the client's interests alongside talk, type, drawing, and media apps at his disposal. Users are also free to customize any personal information, photos, icons, and symbols that are unique to their identity or condition.

### by Ava Sheard

**F** or most of her life, Deb was known as a wife, mother, grandmother, and friend. Her roles as an active community member and involved family woman made up large parts of her identity. After surviving an unexpected stroke, Deb had to add "person with aphasia" to her list of roles. At 52 years old, relearning how to communicate had a big effect on shaping Deb's sense of self.

Early days after a stroke can feel overwhelming to patients and families because a conversation can quickly become difficult to understand, and draining for both communicators. In Deb's case, having severe Broca's aphasia resulted in her family struggling to understand her non-fluent speech. Before her stroke Deb's social life felt natural and effortless, but eventually she started missing church meetings and stopped seeing friends. Even at home, she no longer felt confident communicating with the people she cared for the most. In a conversational world she felt silenced, and it took her a long time to adjust to her new normal. In the stressful time after receiving a diagnosis, speechlanguage pathologists (SLPs) alleviate the load by introducing new ways for patients and families to communicate, listen, and understand each other. SLPs can use new tools to remedy an old problem: how do we make communication accessible to all people?

The case study on Deb<sup>1</sup> illustrates a recovery journey from both a clinical and client perspective. Originally, Deb wasn't educated on AAC devices as an option. It wasn't until her family took an honest survey on Deb's progress that she realized she needed a change in her speech-language therapy services. It was recorded that, on average, "Prior to hospital discharge, only about 2% [of patients] receive AAC treatment."<sup>2</sup> Similarly, Deb was not introduced to AAC devices from an SLP, or open to this lifestyle change, until 3 years after her stroke incident.

Once it was clear that fluent speech was no longer a reality for Deb, rather than keep her life on pause any longer, she was introduced to an iPad and a new SLP that provided AAC support. She was reluctant at first, but her new speech therapy on the iPad offered writing, picture drawing, text, and a text-to-speech option. While she got more comfortable with the tablet, she also had the freedom to use communication books and other low-tech AAC options in her individual therapy sessions.

After only 6 weeks with her iPad, Deb felt comfortable enough going to a family party– something she hadn't done in over 4 years. With the assistance of her AAC iPad, she began feeling confident about being social again. Her AAC devices allowed her to reclaim meaningful conversation, produce complex sentences, and go beyond requests and basic needs.

"The idea around AAC is making sure that our patients have communication that empowers them," says Aimee Dietz, a current researcher and professor in communication sciences and disorders at Georgia State University who specializes in AAC and aphasia research. I had the honor of interviewing Dietz about her contribution to Deb's case study. Dietz emphasizes how AAC speech-language therapy is a "twopronged approach" that requires "train[ing] healthcare workers to know how to interact with people with aphasia, but also need[ing] AAC to help people with aphasia learn how to advocate for themselves."

Living with aphasia means that SLPs and clients have to be open to finding creative solutions for communication challenges, even years later. In Deb's case, AAC devices allowed her to take back a sense of identity and participation that felt out of her reach. With her iPad by her side, she returned to her church meetings, met with friends, and was excited to be with family again.

**"AAC is just one additional tool that can help in the recovery process,"** says Dietz. It's important to remember that AAC is not compensating for language; it's guiding assistance for it. She adds, "Even people [with aphasia] who can produce speech have better output when they use AAC."

Wife, mother, grandmother, friend, person with aphasia, and now, AAC user. Like Deb, people with aphasia may lose some physical qualities of communication, but they deserve to narrate their own stories. With the support of AAC devices, we should strive to build pathways towards manageable and accessible communication for all people with aphasia. Empowering voices for today, tomorrow, and beyond.



### (left) Drawing falls under the AAC umbrella, as sometimes it can help people communicate what they are thinking

#### Sources:

<sup>1</sup>Dietz, A., McKelvey, M., Schmerbauch, M., Weissling, K. S., & Hux, K. (2023). Deb: Increasing Participation for a Person With Severe, Chronic Aphasia Using Augmentative and Alternative Communication. *The Communication Disorders Casebook: Learning by Example*, 364.

<sup>2</sup>Chabon, S. S., Cohn, E. R., & Lee-Wilkerson, D. (2023). *The communication disorders casebook: Learning by example*. Plural Publishing.

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# Meet the Language and Brain Lab



Dave Saltzman graduated from Providence College in 2013 with a BS in Psychology, but his first experience with research was in the Word Recognition and Auditory Perception lab at Villanova University where he finished his MS in Psychology in 2016. There, Dave looked at how listeners adapt to changes in speaking rate, and which cues are most important for that process. Now, he studies how listeners generalize accent information across talkers, and how this process changes with age, while tackling these questions: Why, as we age, is it more difficult to quickly adapt to accented speech? How much accent information do we use from previously encountered talkers?

Dave graduate with his PhD in July 2024 and is now working in insurance.



Hannah Mechtenberg started her journey at Colorado State University for her undergraduate degree and majored in Neuroscience with a concentration in Cognitive and Behavioral Science and minored in Biomedical Sciences. From there, she joined the LAB Lab as the lab manager and stayed here for graduate school. Hannah investigates whether reward matters for learning the individual ways people produce their speech sounds, using a variety of methods. She hopes that the results can inch us closer to understanding the mechanism behind our incredible ability to adapt to every person's unique way of speaking. In the future, Hannah wants to look into the question of whether accurate speech perception is inherently rewarding. In her spare time, Hannah loves to be outside.



**Anne Marie Crinnion** completed her bachelors degree at Harvard University, with a degree in Psychology, and since then has come to the LAB Lab and works with James Magnuson and Emily Myers. Anne Marie studies age-related hearing loss (ARHL). Natural listening environments contain a variety of cues that listeners can rely on to aid in speech comprehension. Her goal is to test the hypothesis that these individual patterns of cue use will explain differences in speech comprehension and to examine at what point in processing these individual differences arise using neural data collected from electroencephalography (EEG) and behavioral tasks. In her free time, Anne Marie enjoys crossword puzzles, running, and teaching fitness classes!



**Dr. Emily Myers** is the Director of the Language and Brain Lab and a Professor in the Department of Speech, Language, and Hearing Sciences. Her research attempts to unlock the mysteries of how the human brain understands language, and to use that knowledge to help people with language disorders.



Naomi Sellers majored in Linguistics and English at Regis University. Naomi researches how people might exert different amounts of effort when listening to sentences in noisy environments. She uses pupillometry to record the changes in pupil size while participants listen to sentences. Changes in pupil size correspond to differences in a number of cognitive processes like effort, directed attention, and surprise. In the future, she wants to dive deeper into how different people might vary in how sensitive they are to the predictability of a sentence context, and how use of prediction and predictive information might impact clinical strategies. In her free time, Naomi enjoys distance running and dancing.



Portia Washington is currently investigating the extent to which phonetic category structure is related to perceiving speech in an unfamiliar accent. She examines the relationship between the data derived from the Visual Analog Scale (VAS) task and an accented speech perception task, using fMRI and behavioral tasks. In the future, Portia is interested in the effects of using gamification in treatments with older adults, and the following questions: How does linguistic diversity affect speech perception, and does linguistic diversity affect treatment outcomes in aphasia?

In her free time, Portia loves serving her community and anything involving visual arts. She's an occasional art teacher for CT DOJ working specifically with students in juvenile facilities.



Matt Phillips completed his undergraduate thesis about speech and non-speech processing in people who stutter using behavioral methods, and his master's thesis with Tammie Spaulding used a mixedmethods survey to investigate what people who stutter found most and least helpful about speech therapy. Up next, Matt is applying to positions to complete a clinical fellowship in speechlanguage pathology, with plans to pursue a PhD specializing in stuttering in the future! In his spare time, Matt likes going to the gym, taking walks around campus, and baking!

Matt has now left the LAB Lab to work full time as an SLP. This issue is brought to you by the:



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## Interested in participating in language research?

At the UConn Language and Brain Lab, we're always looking for participants (age 18 and over). We're making a list of adults who may be interested in participating in our studies in the future. **We are also looking for adults with aphasia** who are interested in participating in our studies!

You can sign up to be contacted about future studies by completing a brief survey on our website or contacting us directly.

There is no payment for completing the survey, but you may qualify for future studies that compensate between \$15 and \$30 an hour.

TO FIND OUT MORE: Visit our website: myerslab.uconn.edu Contact us at: 860-486-0931 or uconnmyerslab@gmail.com



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