

**SERIES:** Caucus: New Jersey with Steve Adubato  
**TITLE:** Families in Focus: Aphasia, Part 1  
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STEVE ADUBATO, host:

Aphasia is a condition that affects our ability to speak and communicate.  
Aphasia is up next on CAUCUS: NEW JERSEY.

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by the Adler Aphasia Center...

(Graphic on screen)

Adler Aphasia Center  
Where people touched by Aphasia  
can comfortably communicate

Announcer: ...The Russell Berrie Foundation...

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Mr. PAUL BENSON: (Unintelligible) (On telephone) Hello.

PAULA M. LEVINE reporting:

Imagine if you couldn't answer the telephone...

Mr. BENSON: How are you doing?

LEVINE: ...or you couldn't write your own name...

Unidentified Man: Physically--I am physically...

LEVINE: ...or if you tried to speak and the words came out garbled. If you  
can imagine all of this, you've just imagined what it's like to have aphasia.

Ms. KAREN TUCKER (Executive Director, Adler Aphasia Center): Aphasia's a  
communication disorder. It happens usually as a result of a stroke and can  
impair a person's ability to speak, as well as their reading, their writing,  
as well as comprehension. But most importantly, it does not affect their  
intellect.

LEVINE: Paul Benson knows the feeling all too well. Two years ago, a series

of strokes left him partially paralyzed on his right side and with slowed and slurred speech.

Mr. BENSON: I couldn't see what--I wanted to do stuff, I thought I was doing stuff, but I just couldn't do anything. And that was--that was driving me slightly crazy.

Ms. EILEEN ERICKSON (Paul's Wife): It turns your world--I don't even say upside down; I say inside out. It just turns your world inside out. Paul was not retired then. He was still actively working as a flight instructor, loved flying, loved teaching people to fly and was very, very successful at it. And I was enjoying retirement. I was enjoying doing my sewing, working with my chorus, visiting with friends.

(To Paul) We're going into the bedroom, OK?

LEVINE: But all of that soon changed.

Ms. ERICKSON: When Paul first came home, he still had some physical weaknesses. The therapist there said to me, 'The first week, you need to guard his safety.'

LEVINE: So Eileen pulled up all the rugs in the house so Paul wouldn't trip on them, and she moved chairs around, so he'd always have a place to rest.

For many families, living with aphasia can become a totally isolating experience. But Paul and Eileen were lucky. They live near the Adler Aphasia Center, one of only a handful of dedicated Aphasia centers in the country.

Ms. TUCKER: The mission of the center is to empower, enrich and enhance the lives of people with aphasia and their families. At the center we offer programs and activities that stimulate communication skills, such as exercise, art, music.

LEVINE: There's also a handwriting and spelling class...

Offscreen Voice #1: T.

LEVINE: ...cooking classes...

Ms. GINETTE ABBANAT, MA (Communication Coach, Adler Aphasia Center): Outside of the curtain, at the beginning of the scene.

LEVINE: ...and even a drama club.

Ms. ABBANAT: The overall purpose of all of the classes is to socialize and to have a place where they can feel very comfortable talking about a variety of different things and, for some of them, to just, you know, be able to get back to having a conversation again. For some folks that have very little verbal ability, it's huge.

LEVINE: And for family members and caregivers, the center's support groups can be a godsend.

Ms. ERICKSON: I even wrote 911 on the paper for me because I thought, if something ever happened...

Unidentified Woman: That's a good idea because...

Ms. ERICKSON: ...I'd be a nervous wreck.

Woman: Yeah.

Ms. ERICKSON: I wouldn't know what to do.

Actually, you can complain a little bit to other people who will understand what you're going through. It's also a place to share information, to say, 'You know, I noticed early on when Paul says yes he might mean no. What's that all about?' And then you have five other people say, 'Oh, yeah, that happens all the time.'

Ms. ABBANAT: It's sort of a sense of community here. It's--they've--most people have been very isolated after the onset of aphasia, and when they come here they feel that they're a part of a social circle again.

LEVINE: Paul has been coming to the center for over two years now. He's made literally dozens of friends and his self-confidence as returned, as well. But every day is still a struggle.

Mr. BENSON: (Looking at flash cards) Q. Y.

Ms. ERICKSON: Great.

LEVINE: Eileen still works with him daily. And even though Paul can no longer drive or ride his motorcycle, he can and does ride a tricycle.

Mr. BENSON: Here we go, here we go.

Ms. TUCKER: We're trying to help people find a new life, find a good life with aphasia and live successfully. That's our goal.

Ms. ERICKSON: The biggest thing for us now is we're moving. We're leaving all these wonderful supports that we have here and we are going to find new ones.

ADUBATO: What a powerful piece.

Welcome to FAMILIES IN FOCUS, a very special series looking at the many challenges and pressures facing the modern American family. I'm Steve Adubato. Now joining us here in the studio to talk about patients and the families coping with aphasia are Dr. Ronald Lazar, who's a professor of clinical neuropsychology for the neurological institute at the very prestigious Columbia University. Barbara Martin is the executive board president of the National Aphasia Association. Barbara has been living with aphasia for 23 years. Our great friends Elaine and Mike Adler. Mike is also living with aphasia. He and his wife, Elaine, founded--co-founded the Adler Aphasia Center in 2003. You saw the tape piece all about the center. And finally, Shirley Morganstein is a speech language pathologist in private practice based in Montclair, New Jersey, who works with clients living with aphasia.

I want to thank all of you for joining us to talk about the whole range of issues facing people with aphasia, families of people with aphasia. By the way, throughout this program you're going to see a Web site, our Web site,

linked directly to the Adler Aphasia Center. There is so much that we do not know about aphasia.

(Graphic on screen)

Caucus [www.caucusnj.org](http://www.caucusnj.org)  
Online Resource Center

ADUBATO: Correct me if I am mistaken here. One million Americans affected by aphasia, correct?

Ms. ELAINE ADLER (Co-Founder & Vice-President, Adler Aphasia Center): Yes. That's what we've been told.

ADUBATO: Is that more, Elaine, than Americans who have Parkinson's?

Ms. ADLER: We believe so.

ADUBATO: Eighty-thousand Americans diagnosed with aphasia every year?

Ms. ADLER: Yes. And there will be more because the GIs coming back who have had brain injuries may fall into that category, as well.

ADUBATO: What do the GIs coming back have to do with increasing--or the increased number of people dealing with aphasia? What's the connection?

Ms. ADLER: The fact is that they are an isolated group, whereas normal people--normal...

Mr. MIKE ADLER (Co-Founder & President, Adler Aphasia Center): They have a brain injury. This...(unintelligible)...a stroke when the IED goes off and attacks their brain. They have the same symptoms that you do when you get a stroke, and stroke was a cause of aphasia.

ADUBATO: So let me get this straight. We're going to have more and more Americans dealing with, struggling with, facing aphasia because of the war, because of the head injuries, the brain injuries that we talked about.

Mr. ADLER: Yes.

ADUBATO: How could it be, Doctor, that there is no national discussion about this and the only reason we are doing this program on public television is because I met Elaine and Mike several years ago through our mutual friend Angelica Berrie. I visited the center and I said--and it's not about us. But we said, 'Wait a minute? How could it be that we're not doing something on a disease--we're a series that deals with health care. A million Americans with it. Eight hundred'--excuse me--'Eighty thousand a year diagnosed. How could the mainstream media be missing such a huge issue?'

Mr. RONALD M. LAZAR, PhD (Clinical Neuropsychologist): I think one of the tragic ironies of the process is that the people can't articulate their own cause. It's the very nature of their problem. So if you have a difficulty communicating, how are you going to tell other people about it and what they have to do, how to understand what their needs are? So you need outside advocacy in order to make that possible, and it takes a center like the Adler Center to make that aware to the larger population.

ADUBATO: Let's talk about that. The issue--we can say it's a family issue. Obviously, we're putting--this program is part of our FAMILIES IN FOCUS series, but the--and you've also talked about the isolation. You've talked about the friends who all of a sudden aren't there in the beginning. I know that you've talked about that privately and you also told our producer that recently, Elaine.

But I want to ask you, Barbara, what about the impact on the person who has aphasia? You had three children when you were diagnosed.

Ms. BARBARA C. MARTIN (President, National Aphasia Association): Yes.

ADUBATO: You were 45?

Ms. MARTIN: Yes.

ADUBATO: Three children. How old at the time?

Ms. MARTIN: All in high school.

ADUBATO: Could--first of all, how did you get aphasia?

Ms. MARTIN: I had a wonderful vacation with the whole family, going to Greece. My father is Greek and we went to see his house. And the last day we went to the airport and said we have to go and get dinner because the airport is late. So we went to dinner, and after dinner I have a massive stroke. And the kids took the flight and my husband and I went to the hospital.

ADUBATO: And you were diagnosed with aphasia?

Ms. MARTIN: Yeah. I had a massive stroke then.

ADUBATO: But they realized later on that you now have aphasia.

Ms. MARTIN: That...(unintelligible).

ADUBATO: As a result of the stroke.

Ms. MARTIN: Yes.

ADUBATO: One of your children...

Ms. MARTIN: Yes.

ADUBATO: ...had a very difficult time. Describe it.

Ms. MARTIN: The youngest, four...

ADUBATO: Was he 14 at the time?

Ms. MARTIN: Yeah, 14. And he didn't want to go to the hospital, and finally my husband dragged him to the hospital and he didn't want to see me. And now he is a doctor because he knows the way to do it.

ADUBATO: Your son's a doctor.

Ms. MARTIN: Yes.

ADUBATO: What kind of doctor?

Ms. MARTIN: He--the guts down here.

ADUBATO: Yes.

Ms. MARTIN: And he is very sensitive to people that have--handicapped people.

ADUBATO: Interesting family issue.

How much in your work--I mean as a speech pathologist specializing with--dealing with people with aphasia--how much of your work is also focusing on family members and helping family members communicate more effectively with someone who has aphasia and someone with aphasia communicating back? How much of it is family communication as opposed to just the individual work that a patient has to do?

Ms. SHIRLEY MORGANSTEIN, CCC-SLP (Speech Language Pathologist): I would say all of it. I think...

ADUBATO: Give us a for instance.

Ms. MORGANSTEIN: I don't think people live in isolation. And, for example, our intake process involves the family and anybody else significant in the lives of people with aphasia coming in to tell us their stories. I think--I think people with aphasia and their families have to begin that story telling at day one. How has it impacted you? How do you feel about it? What can we help to do to help you communicate?

ADUBATO: The patient?

Ms. MORGANSTEIN: Yes.

ADUBATO: But how--but the problem goes back to what you were saying, Doctor.

How is the patient, Elaine and Mike--because, Mike, because we've known each other a few years--by the way, I'll make it clear. You were a CEO at the time.

Mr. ADLER: Yeah.

ADUBATO: I believe that the company you were running--I don't know if you had 700 direct reports...

Mr. ADLER: ...but ultimately they all reported to you. Very successful business man. That happened in what year?

Mr. ADLER: Thirteen years ago.

ADUBATO: Your ability to communicate then, your willingness to communicate then, combined with your ability, compared to today, describe it.

Mr. ADLER: As you say, I had 700 people working for me. I have a stroke and my life turned upside down. I was the boss and I was ashamed to talk to my employees, and I took so long to get a word out that I was ashamed and I

stopped talking for a while. And...

ADUBATO: How long, Mike?

Mr. ADLER: Years. I didn't know that I had aphasia until seven years ago and--I--every communication is a problem for me. What am I going to say? How am I going to say it? And that's the problem all aphasics: They don't know what they're going to say. The mind is perfectly clear.

ADUBATO: Mind's perfectly clear.

Mr. ADLER: And you know what you're going to say, but you don't know if you're going to find the right words, and that's a problem.

ADUBATO: Elaine, you have known Mike for how many years?

Ms. ADLER: We'll be married 58 in June.

ADUBATO: Fifty-eight.

Ms. ADLER: So I know him 60 years.

ADUBATO: He grabbed your hand right now.

Ms. ADLER: It's because he's not sure he can count.

ADUBATO: It's close to 60, right?

Ms. ADLER: That's right.

ADUBATO: OK. Describe the television version, which doesn't even begin to do justice to the power, the poignancy of your story together. Describe your sense of Mike before and after he was diagnosed with aphasia, or we found--you found out he had aphasia, and also how your communication has changed.

Ms. ADLER: Well, he was a very, very high verbal person. He--very bright, very quick and very perceptive. And we had a good life, everything was fine. We had four children. Everything was on the up when he was playing tennis one morning, came home. Make a long story short, triple bypass. Had the triple bypass, and all of a sudden a blood clot went to the brain and he had the stroke. Well, from a wonderful lifestyle, everything turned upside down and here's a man who couldn't walk, couldn't talk and had no cognition. When we did come home from the hospital, I used to--I had to hold him to walk. Well, we found a wonderful nurse who took care of him during the day when I went to work. But I always say, 'We could afford it.' What about the poor souls who are breadwinners, all of a sudden have aphasia? They can't talk, they can't communicate. Many of them have lost the ability of their right sides. It's devastating.

ADUBATO: Excuse me, Elaine, are you saying that Mike's recovery in the past 13 years has much to do with the fact that you have means, you're able to use those means to get Mike--get Mike the best medical, clinical, rehab support and that's atypical for most people who are suffering with aphasia?

Mr. ADLER: Yeah. The paycheck stops.

ADUBATO: The what?

Mr. ADLER: Paycheck stops for...

Offscreen Voice #2: Stops.

ADUBATO: And how about insurance?

Ms. ADLER: I think the government gives \$1500 these days, Medicare.

Ms. MORGANSTEIN: Yes.

Ms. ADLER: That's--covers OT, occupational therapy, physical therapy and speech. When the \$1500 are gone, where do they go? Shirley knows.

Ms. MORGANSTEIN: Yeah.

Ms. ADLER: Shirley teaches one-on-one speech therapy.

Ms. MORGANSTEIN: Well, and just to clarify there, it's \$1500 for physical therapy and 15--for occupational therapy and 15 for PT and speech combined.

ADUBATO: OK, let's be clear. We can quibble about the numbers, but on average...

Ms. MORGANSTEIN: Very limited.

ADUBATO: ...what does it cost yearly? And I don't want to say a typical person dealing with aphasia because I don't know what that is. I know there are--because I visited the center, I saw a whole range of people with a whole range of challenges that they're dealing with, who have aphasia. It's got to be several, several thousand dollars in a year, and I've got to believe that the insurance doesn't even begin to cover the cost we're talking about.

Ms. MORGANSTEIN: Not at all. I mean, and rehabilitation payments have altered drastically. When I first started out as a speech language pathologist, it was very common for a patient in the inpatient rehabilitation phase to be there for three months.

Ms. ADLER: Yes.

Ms. MORGANSTEIN: Then they were discharged and it was very typical for me to be able to follow them for one year.

Ms. ADLER: Yes.

Ms. MORGANSTEIN: So after 15, 16 months, people would be well on the road to getting back to our life.

Ms. ADLER: Yeah.

ADUBATO: Right. `Oh, you're fine. This is about all we can do for you.'

Ms. MORGANSTEIN: Now, virtually nothing. The inpatient stay is 21 days...

Ms. ADLER: Yeah.

Ms. MORGANSTEIN: ...under Medicare guidelines. Outpatient, if you're

lucky--if you're lucky--three months.

ADUBATO: So wait a minute--so wait a minute, Doctor. I'm up against a break here.

Offscreen Voice #3: But...(unintelligible).

ADUBATO: So what happens to the average person? The Adlers are not typical. First of all, not many people establish their own center to deal with aphasia, which is, in fact, the national model. If you logon to our Web site, we'll connect you directly to the Adler Aphasia Center. They had the means to take--to deal with Mike and he's still, obviously, working on it. But their dedication is not just to Mike but to millions of others. Again, we're talking about one million people in this country. Eighty-thousand a year diagnosed with aphasia.

What happens to most patients? I know we're up against a break, guys, I hear you over there. But what happens to most patients?

Mr. LAZAR: I think the extraordinary problem is that most patients who continue to need therapy don't get it.

ADUBATO: Don't get it. So, therefore, what's their prognosis?

Mr. LAZAR: We don't know, and could certainly be better than it is.

Offscreen Voice #4: How...

ADUBATO: Wait a minute. If we see Mike and we see Barbara and we see the progress that they've made--and we can't really see it because we weren't there then. But it's--can't be as good as this. Anecdotally, it can't be as good as this. So, therefore, the ability of those people to function, the quality of their lives, cannot be as good. And I just--I guess the point I'm making as we go up against the break is, folks, we're doing this program to raise awareness, not for the sake of raising awareness, but to hopefully change public policy, to hopefully get people to say, 'Wait a minute. It doesn't make sense.' And it's no disrespect to people with other diseases. Again, we're talking about aphasia. More people suffer with aphasia than do those with Parkinson's disease, and there's much more awareness there. This is our FAMILIES IN FOCUS series. We decided to look at aphasia. I assure you this will be--not be the last time we look at it. After this break I--we will continue the conversation. Stay with us. We'll be right back.

Announcer: If you would like more information on this program or if you'd like to express an opinion, e-mail us at [info@caucusnj.org](mailto:info@caucusnj.org) and visit us on the Web at [www.caucusnj.org](http://www.caucusnj.org).

ADUBATO: Welcome back. By the way, during that very short break I had 12 hands up in the studio, 'Hey, I want to talk about this and that.' What are we missing? And then I'll come back to you, I promise, Elaine, to talk about the need for a national spokesperson. By the way, we've been talking about this for two years now.

Go ahead.

Ms. MARTIN: Yes, I had it 23 years ago and the expense--I paid--the insurance paid for it. So when--I have five months in the hospital, then

every day the speech come to my house, and then after that, two hours on a mirror for two and a half years. That's why I am speaking.

ADUBATO: And insurance paid for virtually all of that?

Ms. MARTIN: Yes. Yes. Yeah.

ADUBATO: That's no the case today.

Ms. MARTIN: Exactly.

Ms. MORGANSTEIN: No, it's not.

Ms. MARTIN: Exactly. Exactly.

ADUBATO: OK.

You want to make a point...

Ms. MORGANSTEIN: OK.

ADUBATO: ...I'll come back and then we'll do the national spokesperson.

Yes.

Mr. LAZAR: Yeah, there are a couple points I wanted to make. First is, I think insurance companies are working on some very old notions that turn out not to be correct. First is that older people are not capable of relearning and recovering, that once the brain reaches a certain age they can't do any anymore, and the research certainly does not show that.

ADUBATO: Incorrect. So--by the way, when you logon to our Web site, we're going to have a section on myths and misconceptions about aphasia. First one, you get past a certain age, the brain's not going to recover in that way. It's not going to make much difference. Wrong, Doctor, correct?

Mr. LAZAR: That's correct.

ADUBATO: Next.

Mr. LAZAR: The other is that if you don't get a therapy within a certain period of time, then therapy after that point will be of no benefit. And that also is another myth that needs to be dispelled.

ADUBATO: Time-out. Why would those health care experts in the federal government who are shape--who are really shaping federal policy in this regard and insurance companies shaping insurance policies--why would this believe this old model when, in fact, the evidence contradicts it? I see you lean--listen, I read body language here, Elaine.

Ms. ADLER: I know. I was told.

ADUBATO: Jump in. Go ahead.

Ms. ADLER: If you lined up all of the neurologists who have been the neurologists for the people at our center, nine out of 10 caregivers would shoot them dead. They do not tell you a thing about aphasia. They don't even

mention the word for the most part.

ADUBATO: Why?

Ms. MORGANSTEIN: I think you also have to look at the...

ADUBATO: No, but why? Why would it be that--why would it be that there would be a secret being open about what it is, what the challenges are, what needs to be done, how long the rehab has to be, what the myths are, overcoming those myths? What would be the benefit of denying that?

Ms. MORGANSTEIN: Well, I think you first of all have to distinguish between those professionals who deal in an acute model and those who deal in chronic. Most physicians are used to dealing with a disease, treating a disease and curing a disease.

Ms. MARTIN: That's right.

ADUBATO: OK.

Ms. MORGANSTEIN: They do not have a history of looking at chronic illness. Also, in this country, we have a lot of stigmatization of people with disabilities. People with aphasia are right there. You know, there is a movement, healthwise, in the international classification of functioning and disability which is going to radically change the way our health care system operates. We're now looking at...

ADUBATO: Translate that.

Ms. MORGANSTEIN: OK. The World Health Organization...

ADUBATO: Yes.

Ms. MORGANSTEIN: ...is trying to get people to look at, not the impairment of people, which is what we look at, but how they are functioning in life, how they participate in life, and what kinds of activities they can be successful in.

ADUBATO: So, therefore, question--you go--and this is not a commercial for the Adler Aphasia Center, but you go there and what you see--here's what I saw. I saw people in cooking class, I saw people reading the newspaper, I saw people conversing, Mike talking about--also debating about the issues of the day, including the war in Iraq. I saw an exercise class. I also saw a discussion group with people--of people with aphasia talking about what they had done over the weekend, back and forth, what they were planning--I believe it was Thanksgiving. They were planning their Thanksgiving dinner. And also a support group for families. That is the exception. The Adlers went all around the country to figure out what existed and they created the model. How could it be that they are the model and they're the exception and others haven't said, 'Wait a minute, that's what you need to rehab over 10, 15, 20 years'? How could that be?

Ms. MORGANSTEIN: Well, I think it is--I think what we're trying to do, both, you know, at Adler and the international centers around the world, is change the focus of interventions that focus more on activities, participation, the development of our identity, who you are as a person. If the ICF coding comes through...

ADUBATO: ICF?

Ms. MORGANSTEIN: International Classification of Functioning and Disability...

ADUBATO: Go ahead.

Ms. MORGANSTEIN: ...which will radically alter what third-party payers will look at...

ADUBATO: Insurers. Go ahead.

Ms. MORGANSTEIN: ...so that there will be money, there will be funding for interventions that target the kinds of things that Mike and Elaine are doing or that individual practitioners in hospitals and private practices are doing, so that people will have an insurance base.

ADUBATO: So you're hopeful in that regard.

Ms. MORGANSTEIN: I am dedicated to that.

ADUBATO: Why don't we do this? Barbara, I know you want to get back in. Here's what we're going to do. We've decided to do this program in two separate half-hours, so here's what we're going to do: We're going to wrap up this discussion. When we pick up--join us next week as we continue our discussion of aphasia. One million Americans, it's an important topic. See you then.

Announcer: The preceding program has been a production of the Caucus Educational Corporation, celebrating 20 years of broadcast excellence, NJN Public Television, and 13 WNET New York.

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Don't miss Steve Adubato and co-host Raphael P. Ramon each week on "Inside Trenton," Saturdays at 8:30 AM on 13 WNET New York and Sundays at 7:30 AM on NJN Public Television.