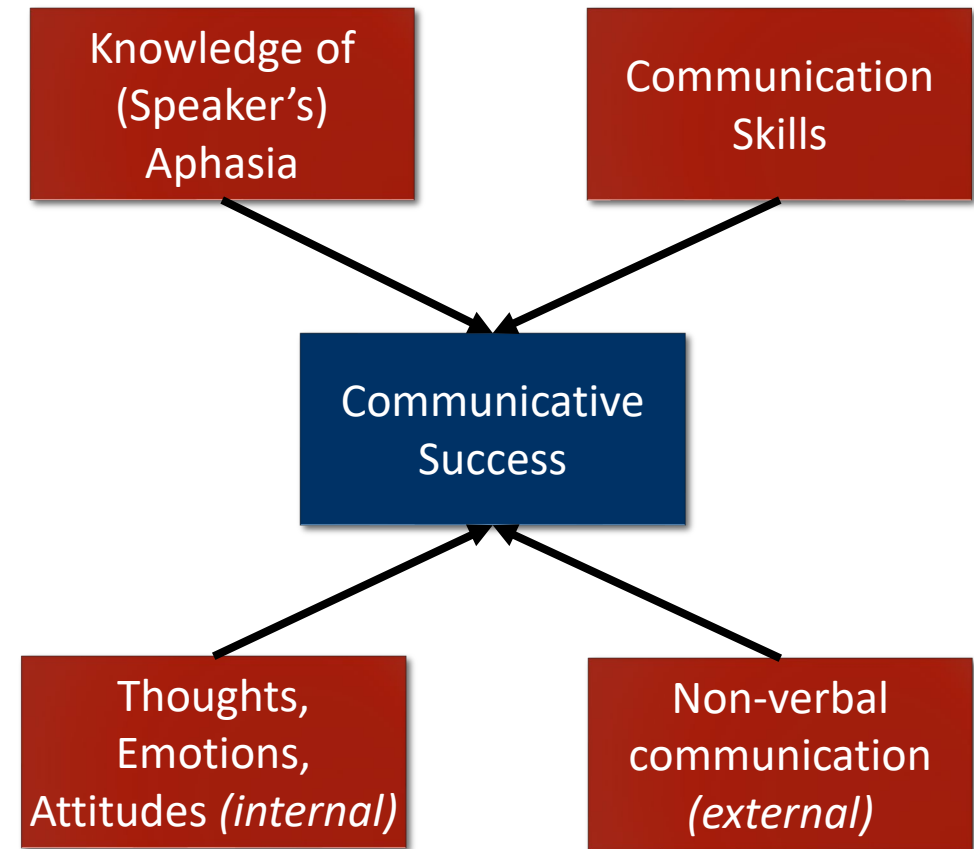# The effects of spoken aphasia self-advocacy scripts on the thoughts, emotions, and attitudes of unfamiliar non-aphasic listeners

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How do unfamiliar communication partners (CPs) contribute to communicative success for PWA?

Knowledge of (Speaker's) Aphasia

Communication Skills

Communicative Success

Thoughts, Emotions, Attitudes (internal)

Non-verbal communication (external)

Brown et al., 2006; Dalemans et al., 2010; Duffy et al., 1980; Harmon, 2020; Harmon et al., 2016, 2020; Howe et al., 2008a, 2008b; Kagan, 2001; Khvalabov, 2019; Le Dorze et al., 2014; Simmons-Mackie et al., 2020; Tessier et al., 2020; Wallace et al., 2017; many others

Self-Advocacy Statements

- Self-disclosure of aphasia

- Definition of aphasia
  - 60% of US adults do not know aphasia is a language disorder (National Aphasia Association, 2022)

- Intelligence

- Communication Strategies

Advocacy Script (Spoken)

I have aphasia. This means I have difficulty with language. Aphasia affects my language, not my intelligence. It is hard for me to understand what people are saying and to find the words to speak my thoughts. Please speak directly to me and give me time to communicate.

Fridriksson et al., 2012

Aphasia ID Card (Written)

Please Read This

I have aphasia from a **stroke**. **Aphasia** means I have trouble understanding you, reading, writing, and speaking. It is a medical condition.

I am intelligent but need some help with language. This can be frustrating for me.

To help me:
Give me a minute to respond

TheAphasiaCenter.com/pocket-card

Facilitate communication between PWA and unfamiliar CPs (Brown et al., 2006; Harmon, 2020; Howe, 2008a; Le Dorze et al., 2014)

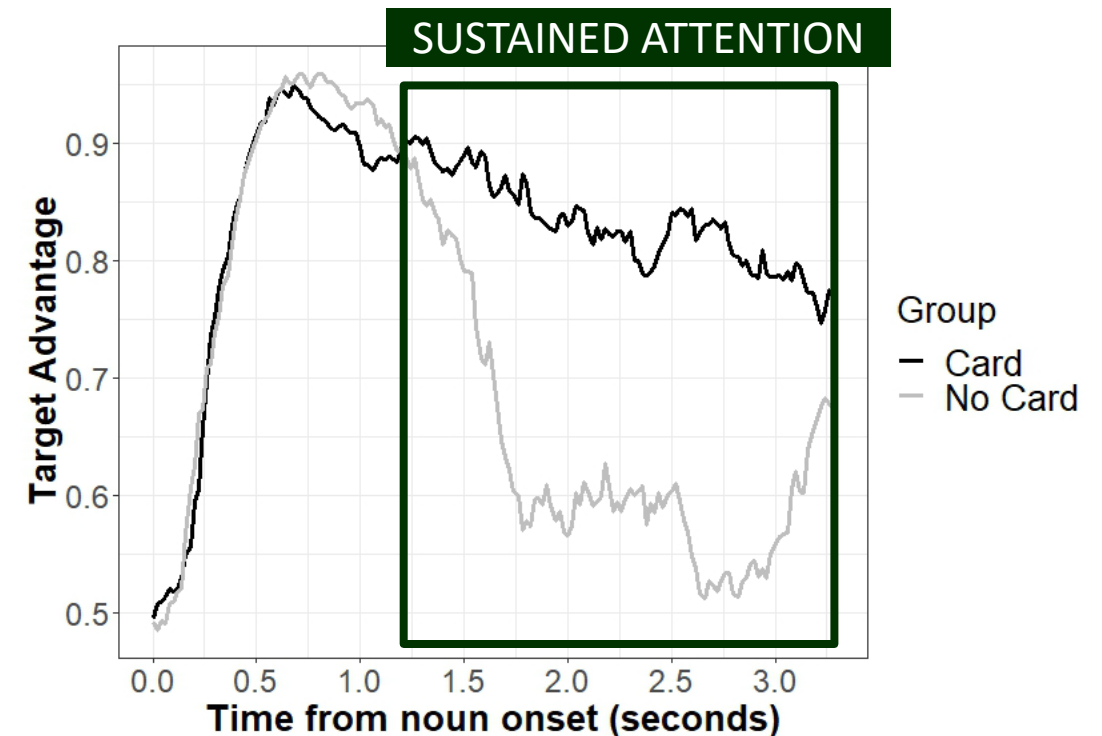# Self-advocacy statements increase CPs' patience and sustained attention

> "I … say it, "I've had a stroke." And … it's amazing how it changes people to … me … then they have more … patience."
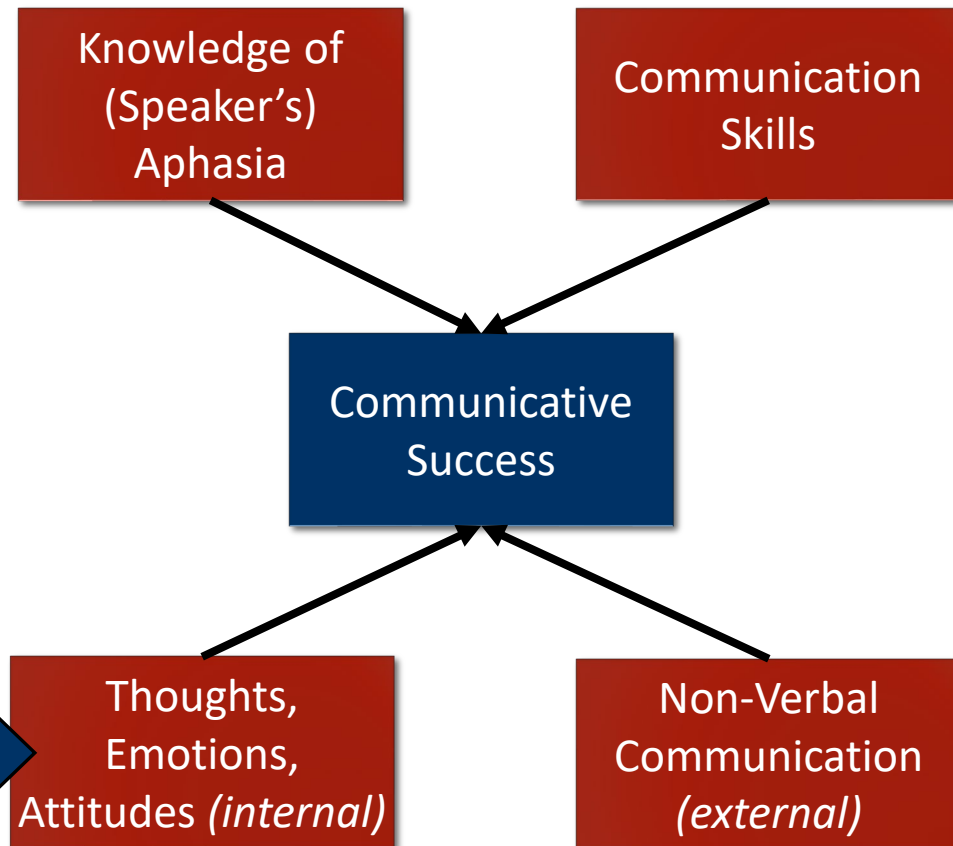> **-In Howe et al., 2008a**

> "When waitresses in busy restaurants come over, they're obviously rushed. Trish will say, 'I have a speech problem.' You can feel them calm down, recognizing they're just not going to be able to rush this customer."
> **-In Meyerson & Zuckerman, 2019**

Effects of self-advocacy statements on CPs' processing of language produced by PWA
(Ward & Mack, 2022)

SUSTAINED ATTENTION

Group
— Card
— No Card

Present Study

```
┌─────────────────┐        ┌─────────────────┐
│  Knowledge of   │        │  Communication  │
│   (Speaker's)   │        │     Skills      │
│     Aphasia     │        │                 │
└─────────────────┘        └─────────────────┘
              ↘            ↙
          ┌─────────────────────┐
          │   Communicative     │
          │     Success         │
          └─────────────────────┘
              ↗            ↘
┌─────────────────┐        ┌─────────────────┐
│   Thoughts,     │        │   Non-Verbal    │
│   Emotions,     │        │  Communication  │
│ Attitudes       │        │   (external)    │
│   (internal)    │        │                 │
└─────────────────┘        └─────────────────┘
```

PRESENT STUDY →

RESEARCH QUESTIONS
1. How do spoken self-advocacy scripts impact unfamiliar CPs' perceptions of speakers with aphasia?
2. How do these scripts affect unfamiliar CPs' experience of listening to speakers with aphasia?

Methods

Study Design

Online Study (December 2021)
Recruitment: Prolific
Experiment: Qualtrics

PARTICIPANTS (N=238)
- Age 40-59
- Residing in US
- High school diploma or GED
- Fluent in English
- Typical language and hearing (self-report)

Random Assignment

GROUPS (N = 4)
Speaker 1, Advocacy Script
Speaker 1, Control Script
Speaker 2, Advocacy Script
Speaker 2, Control Script

Scripts and Speakers

- Audio-only scripts from the Fridriksson Script Corpus in AphasiaBank

- Each script produced with high accuracy by two speakers with chronic aphasia using Visually Assisted Speech Technology (VAST)

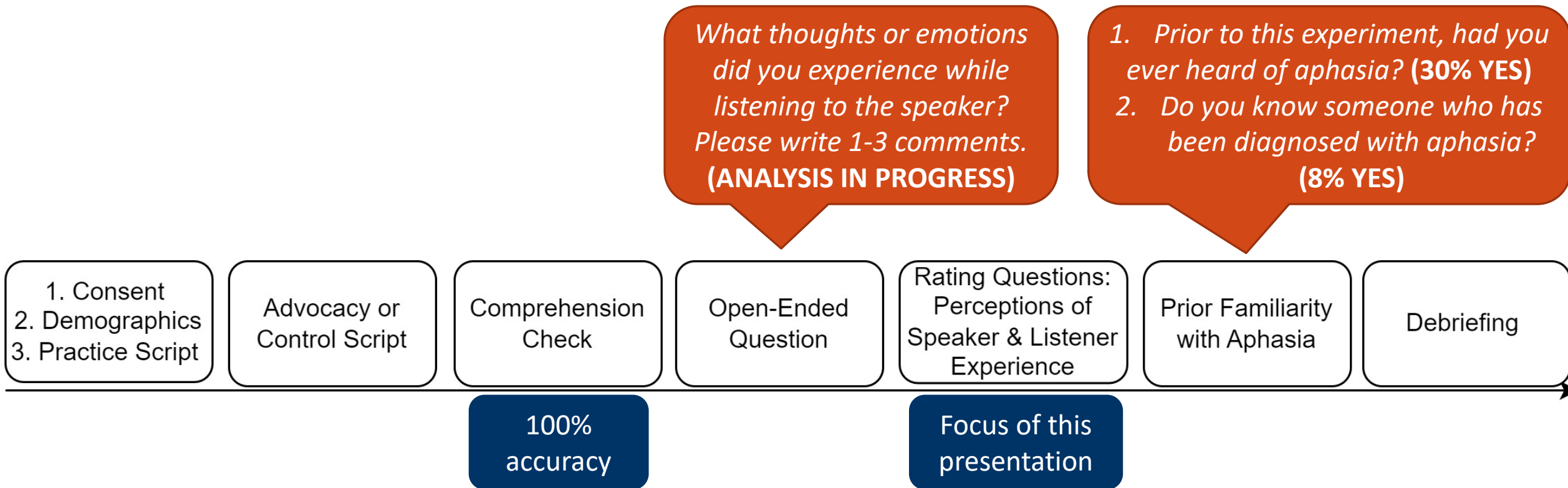|	Speaker 1	Speaker 2
Age	50	60
Gender	M	F
Aphasia Type	Broca's	Broca's
Fluency (WAB-R)	4	4
Speech Repetition (WAB-R)	6.2	5.8
AOS (Subtest 6 of ABA-2)	9	13
Aphasia Quotient (WAB-R)	47.6	73.5

ADVOCACY
I have aphasia. This means I have difficulty with language. Aphasia affects my language, not my intelligence. It is hard for me to understand what people are saying and to find the words to speak my thoughts. Please speak directly to me and give me time to communicate.

WEATHER (CONTROL)
The weather in the Southern United States is usually very pleasant. During the spring it is warm and sunny. During the summer it is very hot with frequent thunderstorms. During the fall it is cold and the leaves change colors. The winter is usually cold and dry and it rarely snows.

Procedure

What thoughts or emotions did you experience while listening to the speaker? Please write 1-3 comments. **(ANALYSIS IN PROGRESS)**

1. *Prior to this experiment, had you ever heard of aphasia?* **(30% YES)**
2. *Do you know someone who has been diagnosed with aphasia?* **(8% YES)**

| 1. Consent 2. Demographics 3. Practice Script | Advocacy or Control Script | Comprehension Check | Open-Ended Question | Rating Questions: Perceptions of Speaker & Listener Experience | Prior Familiarity with Aphasia | Debriefing |

100% accuracy

Focus of this presentation

Rating Questions

Please move the slider to complete the sentence below (even to indicate "neutral").

I felt that understanding the speaker was _____

Hard	Neutral	Easy

●

- Scoring
  - 0 = left (negative)
  - 0.5 = neutral
  - 1.0 = right (positive)

PERCEPTIONS OF SPEAKER

Sentence Fragment	Negative	Positive
I think that the speaker is _____	Unintelligent	Intelligent
	Unsure	Confident
	Unfriendly	Friendly
	Unkind	Kind

LISTENER EXPERIENCE

Sentence Fragment	Negative	Positive
I felt that understanding the speaker was _____	Hard	Easy
When listening to the speaker, I felt _____	Uncomfortable	Comfortable
	Impatient	Patient
	Distracted	Engaged

Byrd et al., 2017; Eadie et al., 2017; Harmon et al., 2016

Statistical Analysis

- Data from each speaker and rating question analyzed separately

- Bayesian generalized linear regression models with zero-one-inflated beta family

- Parameters
  - Proportion of 0/1 ratings out of all ratings *(zoi)*
  - Proportion of 1 ratings out of 0/1 ratings *(coi)*
  - Mean of non-0/1 ratings *(mu)*
  - Dispersion of non-0/1 ratings *(phi)*

Bürkner, 2017 (*brms*); Ospina & Ferrari, 2012 (zero-one-inflated beta regression); R Core Team, 2022

Results

Listener Experience: Ease of Understanding

	Speaker 1					Speaker 2				
	β	SE	2.5%	97.5%	PP β>0	β	SE	2.5%	97.5%	PP β>0
Proportion 0/1 responses (*zoi*)	0.06	0.05	-0.02	0.15	0.88	-0.01	0.07	-0.12	0.10	0.44
Proportion 1 responses (*coi*)	0.16	0.17	-0.08	0.49	0.85	0.02	0.18	-0.27	0.32	0.54
Mean (*mu*)	0.18	0.05	0.10	0.26	1.00	0.00	0.03	-0.05	0.06	0.53

- Speaker 1 was more easily understood in the Advocacy vs. Control scripts (higher mean ratings)

- Speaker 2 was relatively difficult to understand in both scripts
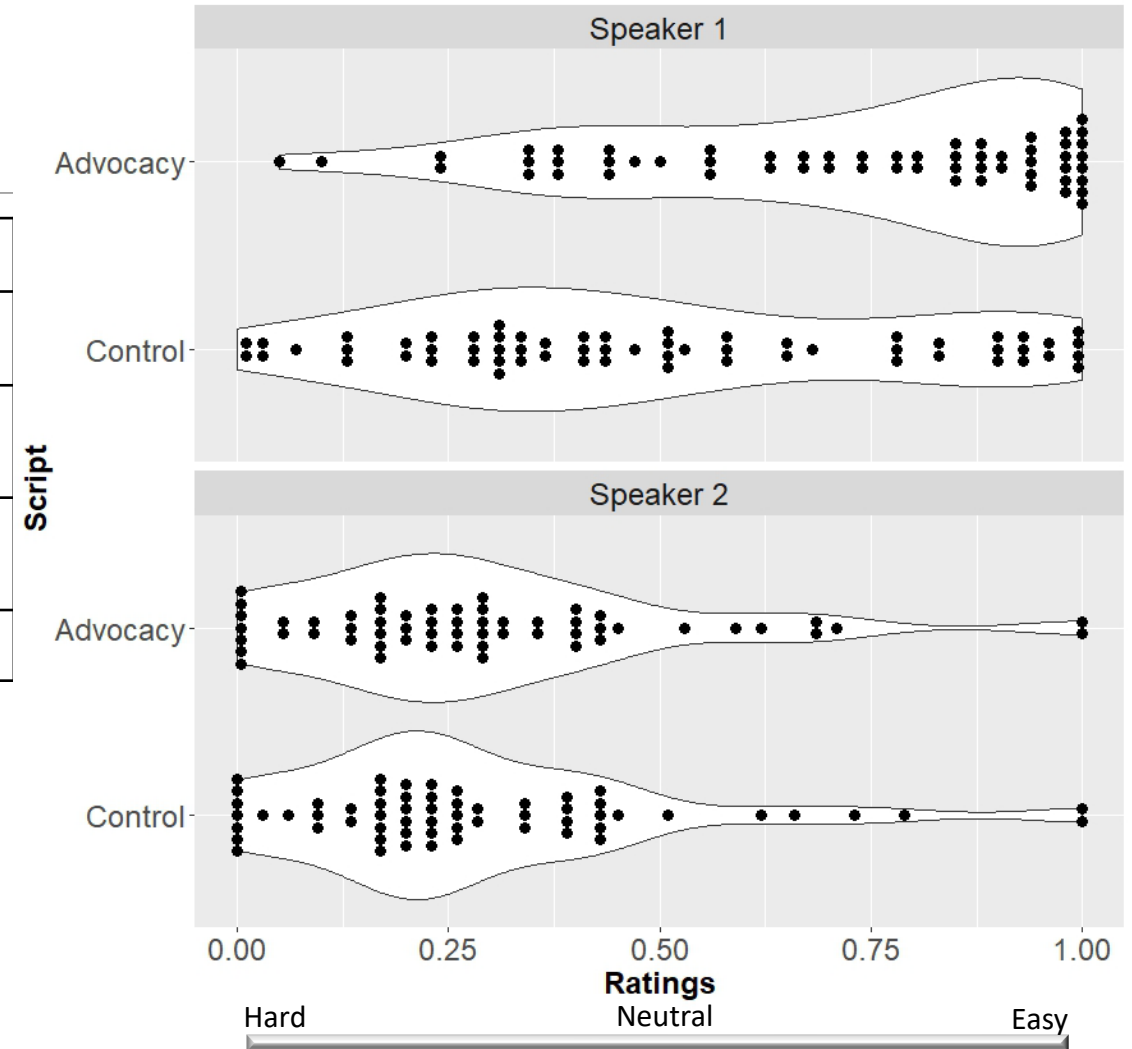
Listener Experience: Comfort

	Speaker 1					Speaker 2				
	β	SE	2.5%	97.5%	PP β>0	β	SE	2.5%	97.5%	PP β>0
Proportion 0/1 responses (*zoi*)	0.14	0.06	0.05	0.24	0.99	0.00	0.05	-0.07	0.08	0.53
Proportion 1 responses (*coi*)	0.64	0.19	0.28	0.89	1.00	0.13	0.19	-0.18	0.46	0.77
Mean (*mu*)	0.14	0.05	0.06	0.22	1.00	-0.02	0.04	-0.09	0.05	0.33

- For **Speaker 1 only**, the Advocacy script elicited more 1 ("Comfortable") responses and higher mean ratings
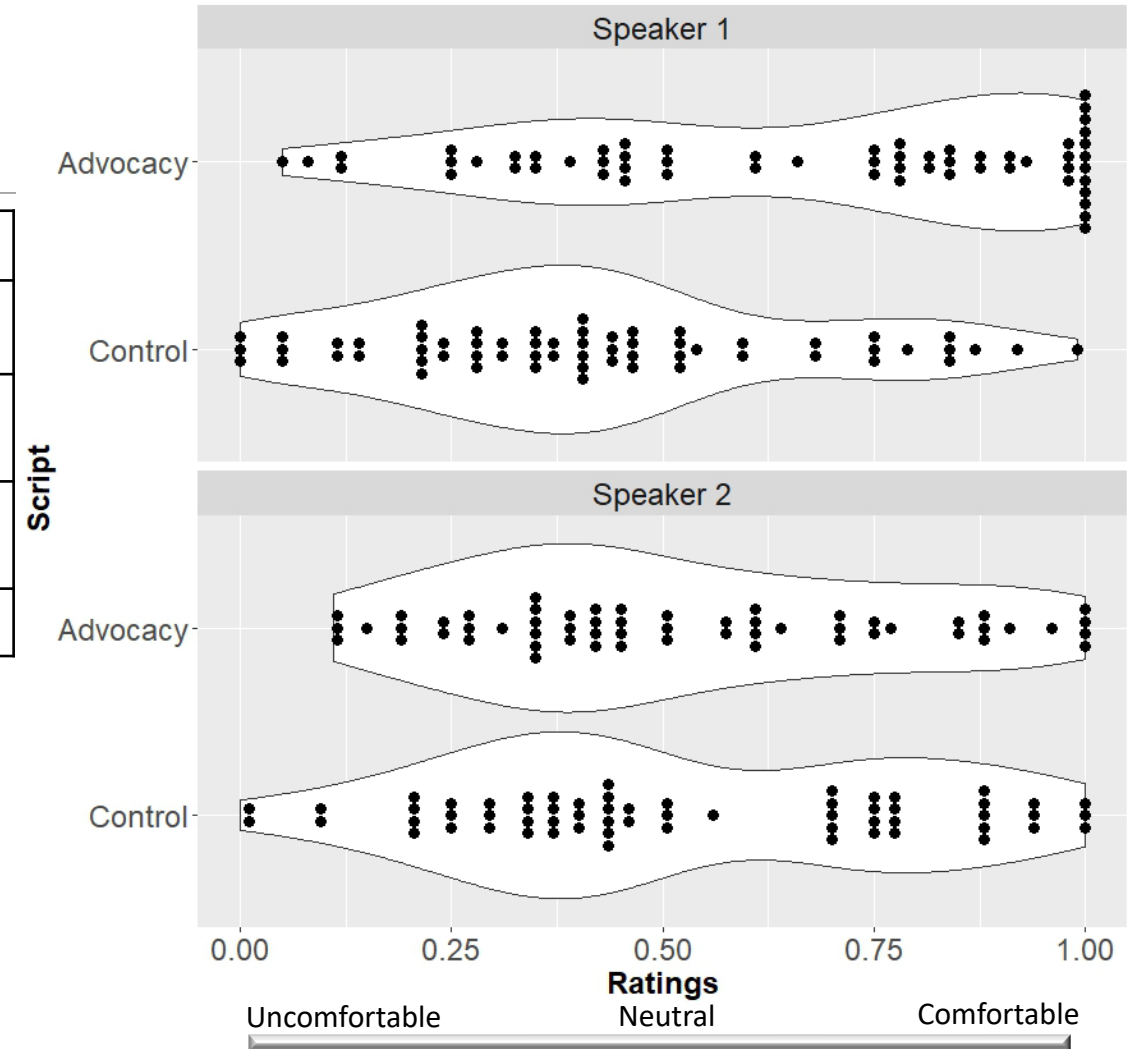
Rating Questions Closely Related to Advocacy Script Content

- Perceptions of Speaker: Intelligence
  - *"Aphasia affects my language, not my intelligence."*

- Listener Experience: Patience
  - *"Give me time to communicate."*

- Large effects of Advocacy for both speakers (larger for Speaker 1)

Perceptions of Speaker: Intelligence

	Speaker 1					Speaker 2				
	β	SE	2.5%	97.5%	PP β>0	β	SE	2.5%	97.5%	PP β>0
Proportion 0/1 responses (*zoi*)	0.20	0.06	0.11	0.31	1.00	0.15	0.06	0.05	0.25	1.00
Proportion 1 responses (*coi*)	0.57	0.22	0.18	0.88	1.00	0.23	0.19	-0.02	0.58	0.92
Mean (*mu*)	0.35	0.04	0.30	0.41	1.00	0.15	0.04	0.08	0.22	1.00

- For both speakers, the Advocacy script elicited:
  - More 1 ("Intelligent") ratings
  - Higher mean ratings
  - Fewer ratings below neutral
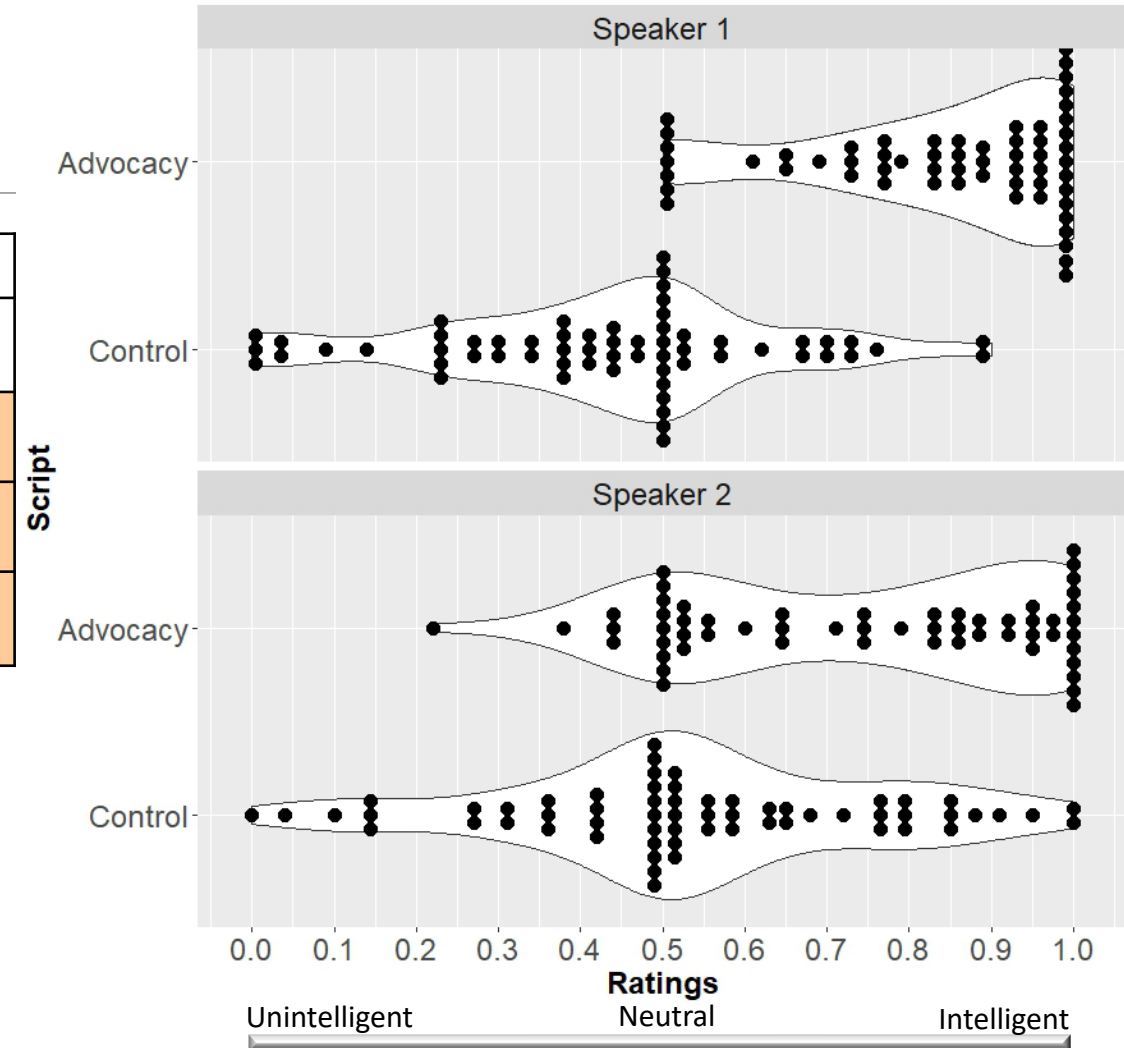
Listener Experience: Patience

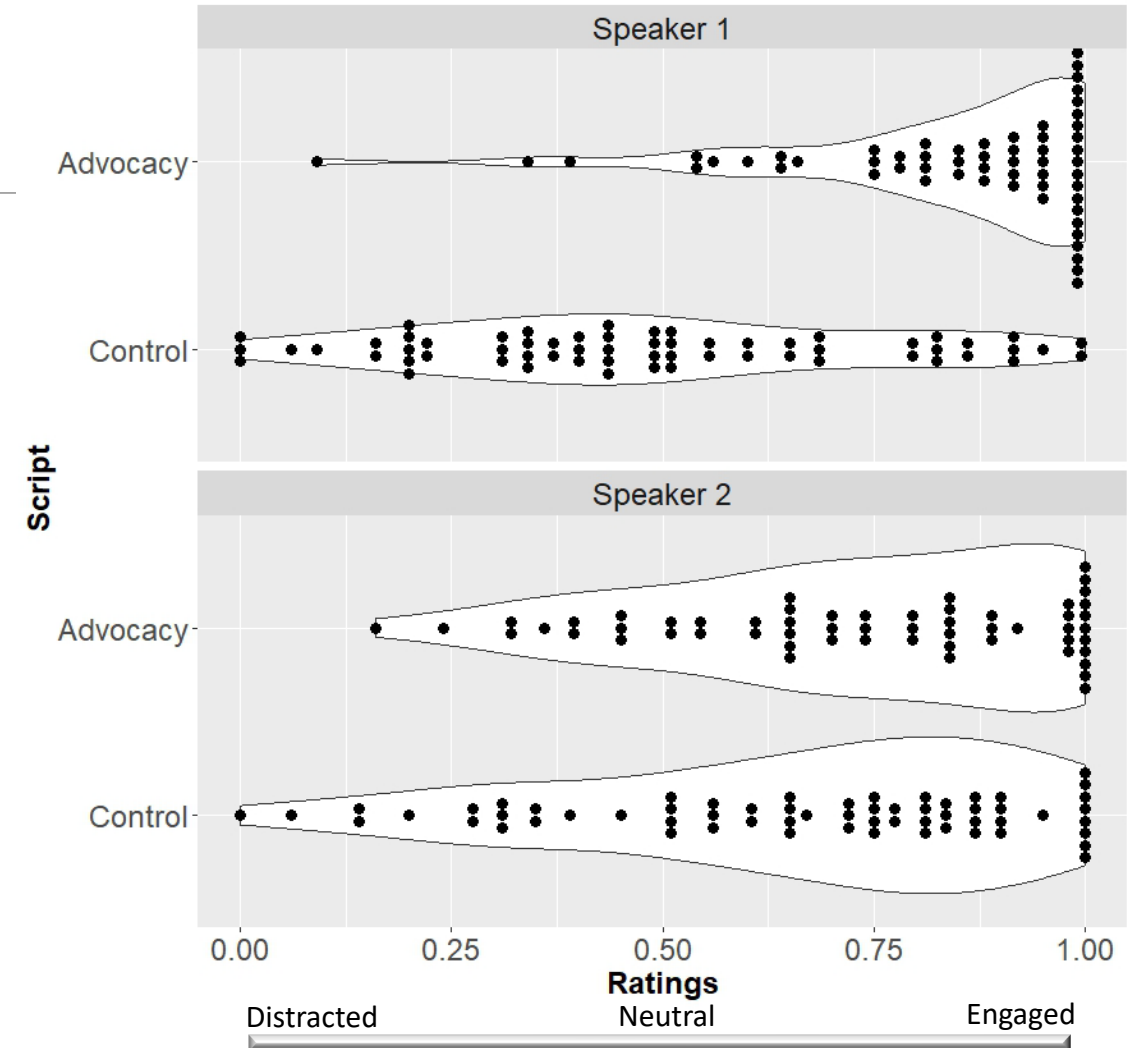|	Speaker 1					Speaker 2				
	β	SE	2.5%	97.5%	PP β>0	β	SE	2.5%	97.5%	PP β>0
Proportion 0/1 responses (*zoi*)	0.15	0.08	0.02	0.28	0.97	0.06	0.06	-0.05	0.16	0.82
Proportion 1 responses (*coi*)	0.80	0.09	0.63	0.92	1.00	0.31	0.17	0.05	0.59	0.98
Mean (*mu*)	0.29	0.05	0.20	0.38	1.00	0.16	0.05	0.08	0.25	1.00

- For both speakers, the Advocacy script elicited:
  - More 1 ("Patient") ratings
  - Fewer 0 ("Impatient") ratings
  - Higher mean ratings
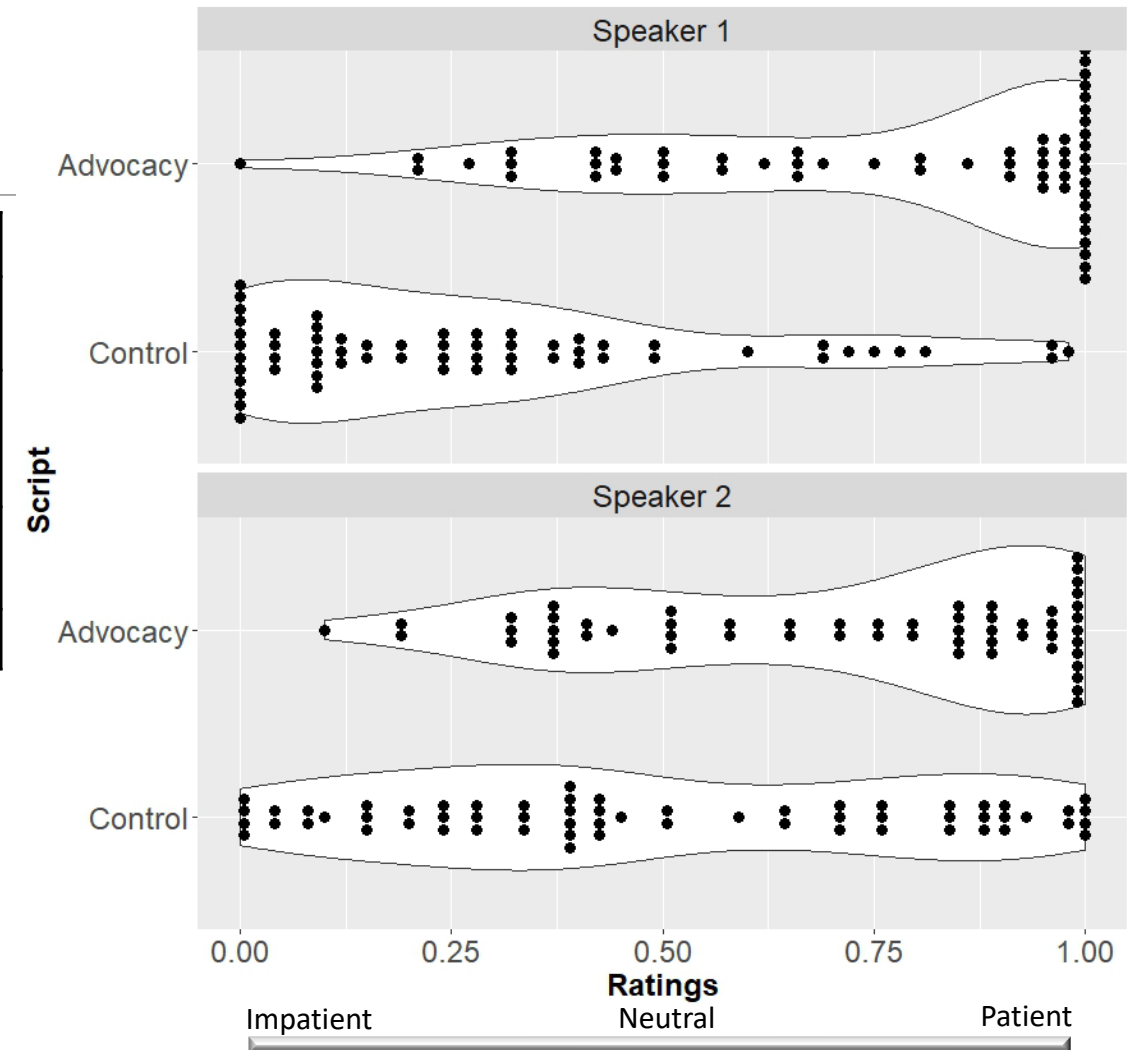
Listener Experience: Engagement

	Speaker 1					Speaker 2				
	β	SE	2.5%	97.5%	PP β>0	β	SE	2.5%	97.5%	PP β>0
Proportion 0/1 responses (*zoi*)	0.26	0.07	0.15	0.37	1.00	0.04	0.07	-0.07	0.15	0.74
Proportion 1 responses (*coi*)	0.54	0.19	0.20	0.83	1.00	0.07	0.10	-0.08	0.26	0.79
Mean (*mu*)	0.24	0.04	0.17	0.32	1.00	0.07	0.04	-0.01	0.14	0.93

- For both speakers, the Advocacy script elicited higher mean ratings

- For Speaker 1, the Advocacy script elicited more 1 ("Engaged") responses

Perceptions of Speaker:
Confidence, Kindness, Friendliness

- Effects of Advocacy for all speakers (larger for Speaker 1)

Key Findings, Limitations, Future Directions

- Robust effects of self-advocacy scripts on ratings of intelligence and patience for both speakers
  - The content of self-advocacy statements matters!
  - Future research should investigate the effects of <u>specific components of self-advocacy statements on unfamiliar CPs</u>

- Effects of spoken self-advocacy scripts are speaker-specific
  - Speakers with relatively mild AOS may receive greater benefits
    - Scripts may be more easily understood
    - Communication disability may be less "visible" so script may be more informative
  - Future research is needed to better understand <u>how speaker characteristics shape the effects of self-advocacy statements</u>

- Limitations of the present study: Scripted statements, no direct interaction between PWA and CPs
  - Future research should investigate the effects of <u>self-advocacy statements on unscripted interactions between PWA and unfamiliar CPs</u>

Thank you!

- Neuroscience of Language and Aphasia Lab

- Funding sources: UMass-Amherst (faculty start-up), American Speech-Language-Hearing Association (AARC award), Institute for Social Science Research at UMass

- Department of Communication Disorders, Institute for Social Science Research, Massachusetts Society of Professors

- Speakers, AphasiaBank, research participants

Thank you for listening! Please feel welcome to contact me: jemack@umass.edu

Perceptions of Speaker: Confidence

	Speaker 1					Speaker 2				
	β	SE	2.5%	97.5%	PP β>0	β	SE	2.5%	97.5%	PP β>0
Proportion 0/1 responses (*zoi*)	0.06	0.05	-0.02	0.15	0.90	0.00	0.05	-0.07	0.08	0.54
Proportion 1 responses (*coi*)	0.52	0.21	0.15	0.82	0.99	0.12	0.20	-0.19	0.46	0.76
Mean (*mu*)	0.29	0.04	0.23	0.36	1.00	0.05	0.04	-0.03	0.12	0.85

- For **Speaker 1 only**, the Advocacy script elicited higher mean ratings and more 1 ("Confident") responses
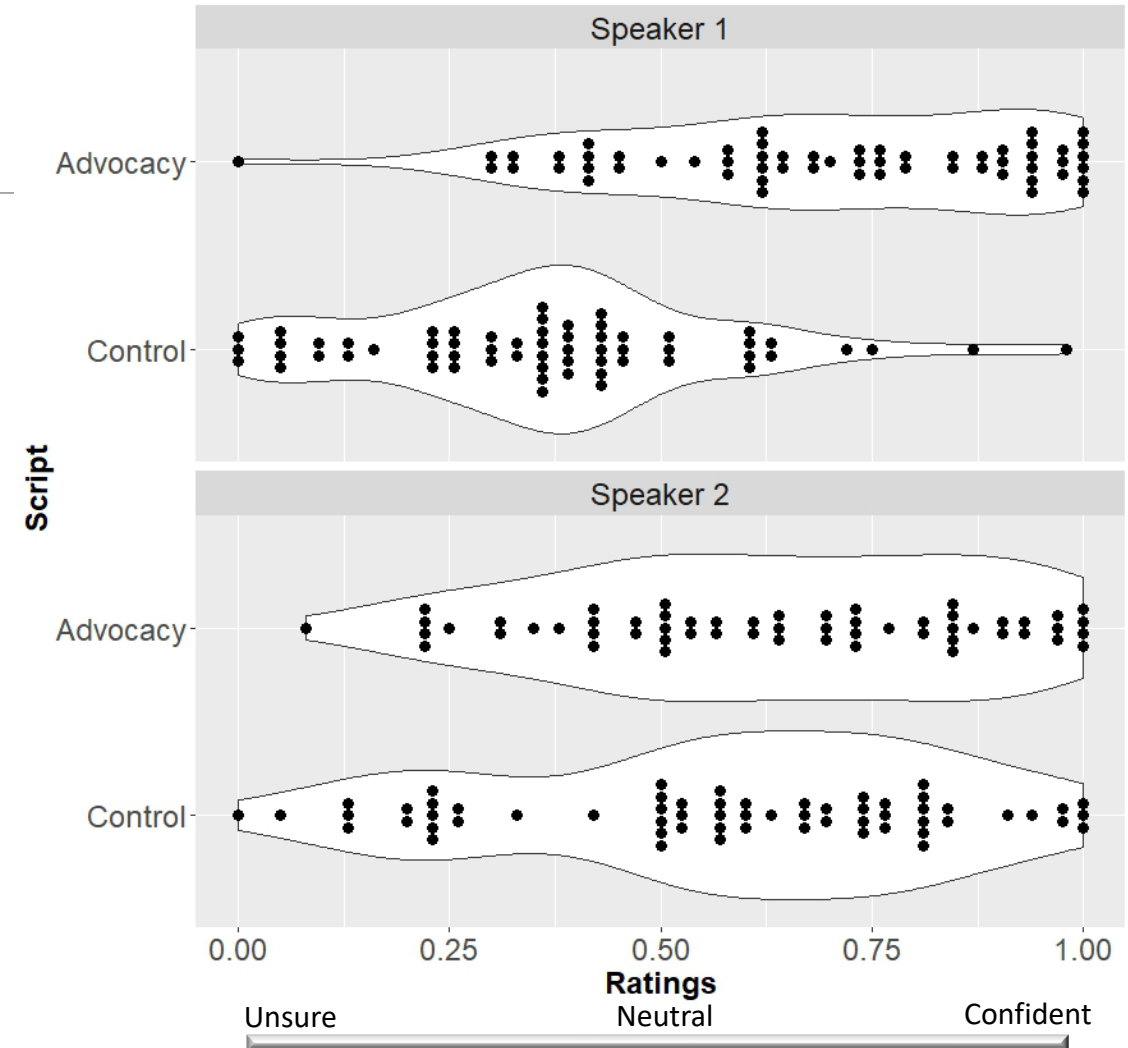
Perceptions of Speaker: Kindness

	Speaker 1					Speaker 2				
	β	SE	2.5%	97.5%	PP β>0	β	SE	2.5%	97.5%	PP β>0
Proportion 0/1 responses (*zoi*)	0.16	0.06	0.07	0.25	1.00	0.11	0.07	0.00	0.22	0.95
Proportion 1 responses (*coi*)	0.07	0.14	-0.07	0.37	0.68	0.02	0.07	-0.08	0.15	0.58
Mean (*mu*)	0.08	0.03	0.02	0.13	0.99	0.01	0.04	-0.04	0.07	0.66

- For both speakers, the Advocacy script elicited more 1 ("Kind") ratings

- For Speaker 1, the Advocacy script also elicited higher mean ratings

- "Friendliness" had a similar pattern of results
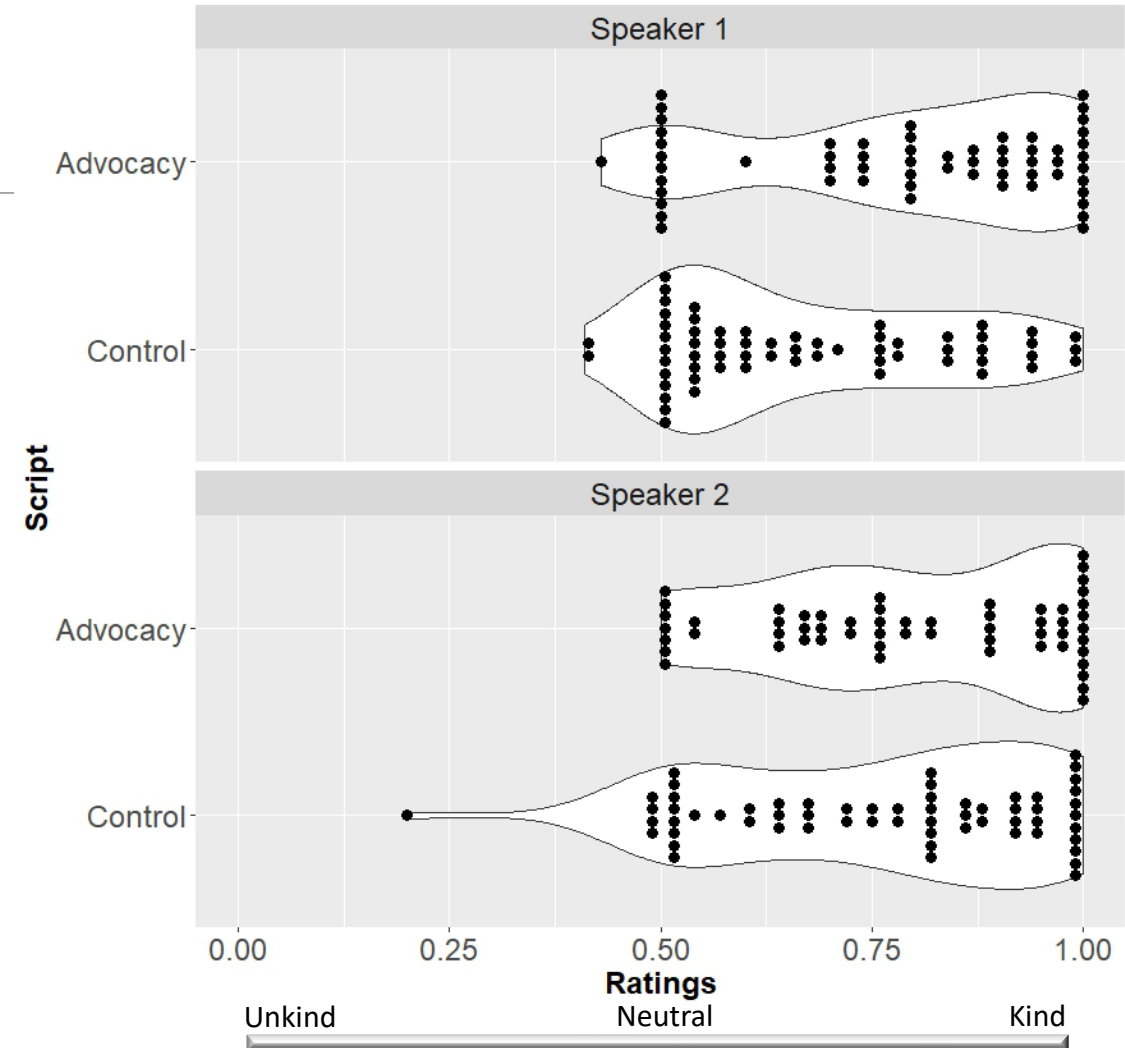
Perceptions of Speaker: Friendliness

	Speaker 1					Speaker 2				
	β	SE	2.5%	97.5%	PP β>0	β	SE	2.5%	97.5%	PP β>0
Proportion 0/1 responses (*zoi*)	0.11	0.06	0.02	0.21	0.97	0.08	0.07	-0.04	0.20	0.86
Proportion 1 responses (*coi*)	0.04	0.10	-0.09	0.24	0.62	0.01	0.05	-0.07	0.10	0.55
Mean (*mu*)	0.14	0.03	0.09	0.20	1.00	0.00	0.03	-0.05	0.06	0.55

- For Speaker 1, the Advocacy script elicited more 1 ("Friendly") ratings and higher mean ratings