The Communicative Participation Item Bank – General Short Form

Instructions:
The following questions describe a variety of situations in which you might need to speak to others. For each question, please mark how much your condition interferes with your participation in that situation. By "condition" we mean ALL issues that may affect how you communicate in these situations including speech conditions, any other health conditions, or features of the environment. If your speech varies, think about an AVERAGE day for your speech – not your best or your worst days.

	Not at all (3)	**A little (2)**	**Quite a bit (1)**	**Very much (0)**
1. Does your condition interfere with... **…talking with people you know?**	◯	◯	◯	◯
2. Does your condition interfere with... **…communicating when you need to say something quickly?**	◯	◯	◯	◯
3. Does your condition interfere with... **…talking with people you do NOT know?**	◯	◯	◯	◯
4. Does your condition interfere with... **…communicating when you are out in your community (e.g. errands; appointments)?**	◯	◯	◯	◯
5. Does your condition interfere with... **…asking questions in a conversation?**	◯	◯	◯	◯
6. Does your condition interfere with... **…communicating in a small group of people?**	◯	◯	◯	◯
7. Does your condition interfere with... **…having a long conversation with someone you know about a book, movie, show or sports event?**	◯	◯	◯	◯
8. Does your condition interfere with... **… giving someone DETAILED information?**	◯	◯	◯	◯
9. Does your condition interfere with... **…getting your turn in a fast-moving conversation?**	◯	◯	◯	◯
10. Does your condition interfere with... **…trying to persuade a friend or family member to see a different point of view?**	◯	◯	◯	◯

Scoring guide for the CPIB General Short Form

To score the short form, add the scores for the ten items to obtain a summary score (Not at all = 3; A little = 2; Quite a bit = 1; Very much = 0). The summary score will range from 0 – 30. High scores are more favorable, meaning that high scores indicate less interference in participation. Using the table below, the summary scores can be converted to IRT theta values (logit scale). On the logit scale, scores generally range from -3.0 to +3.0 with 0 logits representing the mean for the calibration sample. Again, high scores are preferable. The table also includes a conversion to standard T scores (mean = 50; standard deviation = 10). **VERY IMPORTANT: This score translation table is ONLY valid for the 10 item short form presented in this manuscript.** Remember that in IRT, the person score is based on the parameters of the individual items and on how the person answers the items. This scoring table has been generated using the item parameters for the ten items in this short form, and these parameters would differ for different items. A new score translation table must be created for any other combination of items.

CPIB 10-Item General Short Form Scoring Table

Summary	Theta	T score	Summary	Theta	T score
0	-2.58	24.20	16	-0.22	47.80
1	-2.18	28.20	17	-0.10	49.00
2	-1.94	30.60	18	0.03	50.30
3	-1.76	32.40	19	0.15	51.50
4	-1.60	34.00	20	0.27	52.70
5	-1.46	35.40	21	0.40	54.00
6	-1.34	36.60	22	0.53	55.30
7	-1.22	37.80	23	0.65	56.50
8	-1.10	39.00	24	0.78	57.80
9	-0.99	40.10	25	0.92	59.20
10	-0.89	41.10	26	1.06	60.60
11	-0.78	42.20	27	1.22	62.20
12	-0.67	43.30	28	1.42	64.20
13	-0.56	44.40	29	1.67	66.70
14	-0.45	45.50	30	2.10	71.00
15	-0.33	46.70			

Baylor, C., Yorkston, K., Eadie, T., Kim, J., Chung, H., & Amtmann, D. (2013). The Communicative Participation Item Bank (CPIB): Item bank calibration and development of a disorder-generic short form. *Journal of Speech Language and Hearing Research, 56*, 1190-1208.

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Improving communicative participation for people with motor speech (and other) disorders: Is this something different?

Carolyn Baylor, PhD, CCC-SLP
University of Washington

ANCDS
November 11, 2015

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Thanks…

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- ANCDS Meeting Registration

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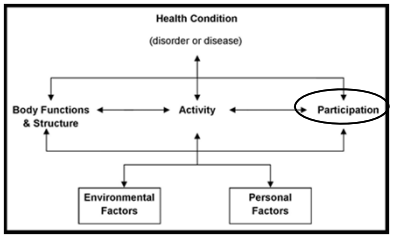
Today's Questions

- Is 'participation' something different…and if so, does it matter?
- What do we mean by 'participation-focused' intervention and should we do it?
- Is there a case for a 'cross-disorder' approach?
- What is the missing link to maximize communicative participation?

World Health Organization's
International Classification of Functioning, Disability, and Health (ICF)



Participation: Taking part in life situations (WHO, 2001)

Communicative Participation: Taking part in life situations in which information or ideas are exchanged between people (Eadie et al., 2006)

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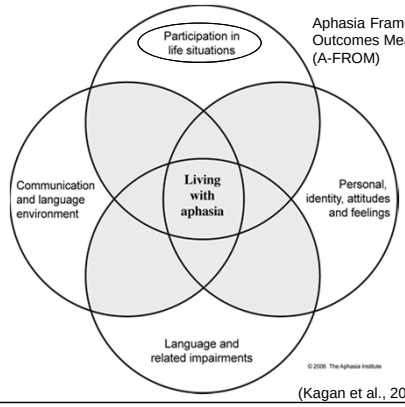
Aphasia Framework for Outcomes Measurement (A-FROM)



(Kagan et al., 2007)

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Question 1: Is 'participation' something different…and if so, does it matter?

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Survey of SLP's views on 'Participation-focused intervention' (n = 66 U.S. SLPs)

- We asked about participation. SLPs answered:
  - *"I think it is very important to incorporate functional, participation-focused tasks in treatment."* [A33]
  - *"QOL is a critical outcome following any intervention…the initial evaluation focuses on the patient's lifestyle and activities of importance to them …."* [L12]
  - *"Support from family also allows for increased carryover outside of the brief 45-60 minute sessions..."* [A21]

(Torrence et al., submitted)

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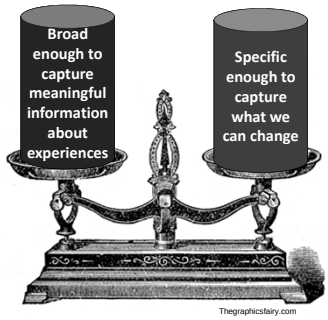
Finding the balance for treatment targets and outcomes measurement



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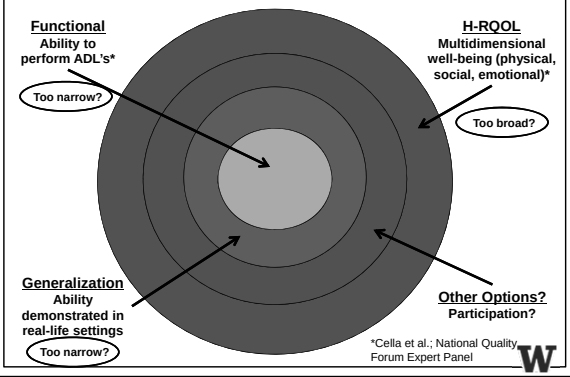

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Exploring Communicative Participation with the Communicative Participation Item Bank (CPIB)

- Targets community-dwelling adults
- Addresses verbal communication - variety of situations
- Developed with Item Response Theory (IRT) with goal of computerized adaptive testing
- Developed to be valid across communication disorders
  - Spasmodic dysphonia
  - Multiple sclerosis
  - Parkinson's disease
  - ALS
  - Head and neck cancer
  - Aphasia

(Baylor et al., JSLHR, 2013)

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Example CPIB Item

Does your condition interfere with…

… having a conversation while riding in a car?

___ Not at all
___ A little
___ Quite a bit
___ Very much

Full item bank: 46 items; Short form: 10 items

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Example CPIB Item

Does your condition interfere with…

… getting your turn in a fast-moving conversation?

___ Not at all
___ A little
___ Quite a bit
___ Very much

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Example CPIB Item

Does your condition interfere with…

…trying to persuade a friend or family member to see a different point of view?

___ Not at all
___ A little
___ Quite a bit
___ Very much

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Is communicative participation the same as….?

Diagnosis	Measure	Correlation with CPIB
Parkinson's disease	Self-reported speech severity	.471
Multiple sclerosis	Self-reported speech severity	.349
ALS	Self-reported speech severity	.629
Head and neck cancer	Self-reported speech severity	.600
Aphasia	Western Aphasia Battery	.290

Is communicative participation the same as…?

Diagnosis (n)	Comparison Measure	Correlation with CPIB
PD (378)	PROMIS – Physical	.337
	PROMIS - Mental	.414
	PROMIS – Social Roles – ability item	.413
	PDQ-8	-.573
MS (216)	PROMIS – Social Roles – ability item	.480
	PROMIS – Social Roles and relationships – satisfaction item	.380
Aphasia (110)	ASHA Quality of Communication Life - Average	.647
	ASHA Quality of Communication Life – Overall QOL item	.286
Spasmodic Dysphonia (208)	Voice Handicap Index (VHI)	-.678
Head and Neck Cancer (195)	Voice Handicap Index (VHI)	-.790

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Question 1: Is 'participation' something different…and if so, does it matter?

- Perhaps be thoughtful and cautious about using terms interchangeably
- Work towards better understanding of the similarities and differences in 'lived experience constructs' and the role of each in assessment and intervention
- Include elements in treatment and assessment that go beyond skills / ability to look at fulfillment / satisfaction with communication in real life
- Keep elements focused enough that we can influence change in treatment programs

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Question 2: What do we mean by 'participation-focused' intervention?

- "A broadening and refocusing of clinical practice and research on the consequences of aphasia"
- "It focuses on re-engagement in life"
- "Residual skill is thus seen as only one of many requisites"

(Life Participation Approach to Aphasia)
(Chapey et al., 2000)

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Is it part of this picture?

- Patient-Centered Care
- Value-driven Care
- Shared decision-making
- Participation-focused intervention

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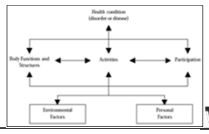
Does it encompass anything that improves…

- Ability
- Accessibility
- Ease
- Comfort
- Confidence
- Success
- Satisfaction
- Acceptance

… to communicate in life roles



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We can help clients be satisfied with communicative participation when we help them be…

- **Successful**
  - Achieve Function
  - Make connections
- **Comfortable**
  - Easy
  - Confident
- **Achieve what is personally meaningful**
  - Preferences; priorities
  - Comparison with past
  - Think about communication

Qualitative Interviews
8 adults with MS
Yorkston, 2007

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Clients want therapy to help them with real life…

"I'm sitting in a job thinking should I really be doing this? …I would have liked some sort of guidance. And I don't know if just going in and reading five sentences—I'm thinking you don't know what I'm going through. You're not close to what I'm going through. I can read, 'a puppy bit the tape' or whatever but that's not it." (Female; SD)

Female with spasmodic dysphonia questioning career in teaching

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When I first was meeting with therapists…I wanted to make sure they understood me, before they told me what to do…I wanted to make sure they understood what my situation was. Maybe they knew more about my condition than I did. I didn't care about that. I wanted them to understand my world, what I was being asked to do.

Female with dysarthria due to CVA

And I think it's always good to give the person a chance to express what is on their mind as far as the therapy itself. Ask them, "What do you expect? What do you want? What are you afraid that you can't have?"

Female with aphasia due to CVA

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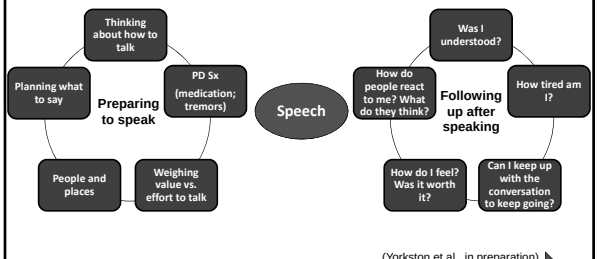
It (therapy program) really did cause a psychological shift in my mind and how I felt about my stuttering…I think it was the change in my attitude toward my stuttering that was really pivotal…..to realize that my stuttering didn't have to hold me back from doing anything that I wanted to do

Female; stuttering

"The two [therapists] I had didn't …take …into account my previous job or my previous lifestyle. (and they didn't take it and then) into the their therapy, they didn't take into [consideration] what direction I wanted to go in, or what I thought I had the most problem with. It was mostly their agenda and what they wanted to accomplish rather than have me involved."

Female, aphasia after CVA

Speaking is a process… …in which speech is only one step (n=24; PD)



(Yorkston et al., in preparation)

"I have to make the unconscious conscious" (PD participant)

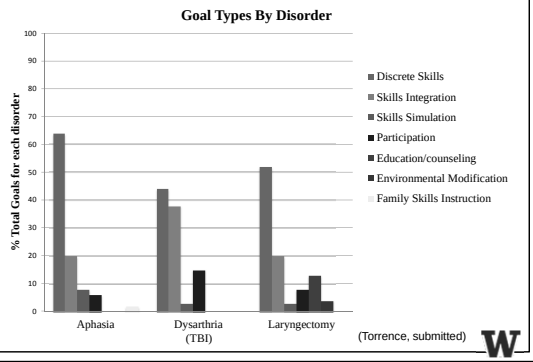
How many of these steps do we target in treatment?

Many SLP's think participation-focused intervention is a good idea…

- *"We should always be focusing on participation."* [SLP-A43]
- *"Participation-focused intervention is a great thing to incorporate into therapy."* [SLP-L5]
- *"Participation-focused intervention makes a lot of sense."* [SLP-L8]

(Torrence, submitted)

…but are we really doing it?



(Torrence, submitted)

Where is the evidence of a participation focus in our work?

SLPs asked to write goals for 3 outpatient vignettes

- 242 goals written
- 121 (50%) goals had a participation-focused rationale
- 21% of goal SETS had a participation-specific goal
- 20 (8%) of all goals were participation-specific
- 1 (.004%) goal had a published, psychometrically-tested 'lived experience' outcome measure (Voice Handicap Index)

(Torrence, submitted)

If we value participation-focused intervention, why isn't it more evident in what we do?

- The clinic setting does not look like real life
  - *"We should always be focusing on participation. However, it is often hard when we work in 1:1 quiet controlled settings."* [D9]
- Harder and more time consuming to plan
  - *"I have to spend a little more time thinking of fun, creative or functional activities for each client."* [A40]
- Productivity constraints
  - *"Productivity requirements make it difficult to take our patients out into the real world and really see how they are participating in their day to day activities."* [A10]

…and more reasons…

- Documentation constraints
  - *"It is difficult to be highly specific in goal writing because some insurance providers (e.g. Medicare) only pay for home/community focused goals. So the goal for the woman to go back to work in her bakery required careful wording not to say 'work' in any of them."* [A5]
- Insurance constraints
  - *"I have gone to senior day care centers to work with patients but this is very difficult to account for most insurances."* [D8]

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…and a few more reasons

- Lack of tools, training, and resources
  - *"Measuring was less specific which I find may be hard and out of the comfort zone for an SLP to not have very specific data to report."* [A41]
  - *"I have tried normed scales but often find these are too long and unwieldy and are measuring so many other factors beyond the impact of our intervention."* [L15]
  - *"I would love resources on specific protocols for doing this (that is, home programming and the process of taking their feedback and tweaking treatment approach."* [D2]

(Torrencen et al., submitted; Collis & Bloch, 2012; Verna, Davidson, & Rose, 2009; Sherratt et al., 2011; Rose et al., 2014; Johansson et al., 2011; Miller et al., 2011)

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Question 3: Is there a case for a 'cross-disorder' approach to participation-focused intervention?

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Stigma

"…Cause if they think you're dumb, they'll treat you dumb… they tended to baby me."

Male, dysarthria due to CVA

"People become condescending like you're not capable anymore because you don't speak well."

Female, Spasmodic Dysphonia

"I hated being treated like I was mentally deficient because I stuttered. "

Female, stuttering

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"I put off getting my hearing aid when I could have. I wasn't ready. I knew there was a problem but I was still working and I thought, 'Ooh, I'll put that thing on my ear, am I even thought of as capable?'"

Hearing loss; unknown gender

They're trying to figure out what the hell's the matter with me, what the hell I'm doing, even who I am, and they're not paying as much attention to what I'm saying as they should be.

PD; male

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How do we help communication partners understand the competence and capabilities of people with speech / language disorders?

Supported Conversation

"Competence of people with aphasia can be revealed through the skill of a conversation partner who provides a 'communication ramp' for increasing communicative access."

(Kagan, 1998)

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Some examples of conversation support

For Aphasia (extracted from Kagan, 1998)	For Dysarthria
Age-appropriate tone of voice	**Yes!**
Give person time to respond	**Yes!**
Verify responses	**Yes!** (Verify you understood)
Humor and other natural conversational features	**Yes!**
Use gestures, writing, drawing, pictures	**Yes!** (Offer to person to use)

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Phone

"Hate the phone"

Female, laryngectomy

The phone causes "anticipation and anxiety"

Male, stuttering

The phone "trumps" all other situations for difficulty

Male, Spasmodic dysphonia

"I don't like telephones. I'd walk ten miles to talk to you before I make a phone call."

Male; PD

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Some barriers to mobile phone use

For Aphasia (extracted from Grieg et al., 2008))	For Dysarthria
Understanding symbols	No
Too many steps to complete a task	No
Poor sound quality	Yes!
Often do not know person on other end	Yes!
Loss of visual information to help with communication	Yes!

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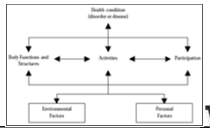
Does it encompass anything that improves…

- Ability
- Accessibility
- Ease
- Comfort
- Confidence
- Success
- Satisfaction
- Acceptance

Disorder specific?

Not disorder specific?



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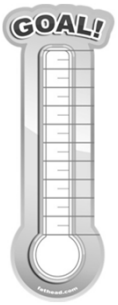
Question 4: What is the missing link to maximize communicative participation?



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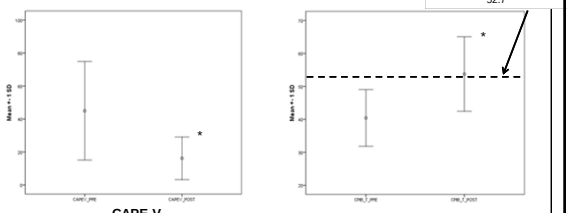
A peek at early data… Response to standard-of-care treatment

Unilateral Vocal Fold Immobility (n=14)

Satisfied with outcome at T= 52.7



CAPE-V
Overall Voice Severity
(low scores better)

CPIB
(high scores better)

Before treatment and six months later

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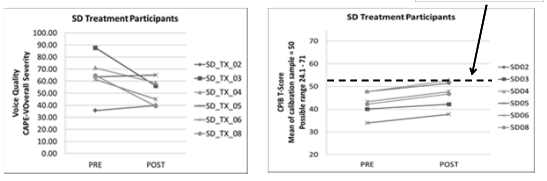
A peek at early data… Response to standard-of-care treatment

Spasmodic Dysphonia

Before first botox injection and 6 months later

Satisfied with outcome at T= 52.7



CAPE-V
Overall Voice Severity
(low scores better)

CPIB
(high scores better)

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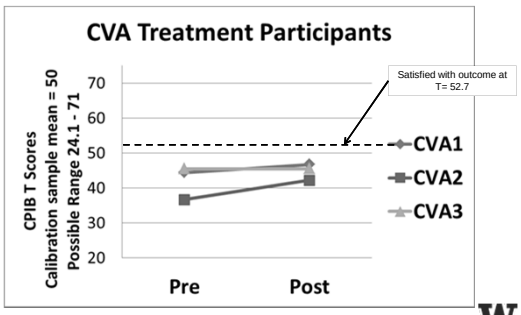
A peek at early data… Response to standard-of-care treatment



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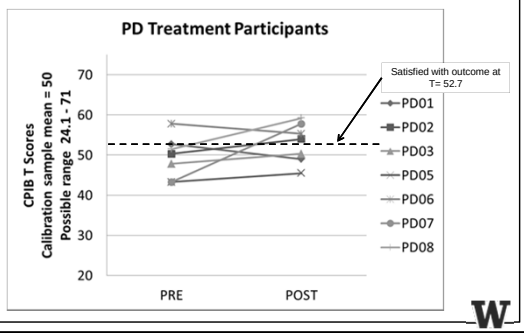
A peek at early data… Response to standard-of-care treatment



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Predicting Communicative Participation: Multiple Sclerosis (n=216)

Non-significant Variables	Significant Variables (Adjusted R^2 = .507)	Standardized Coefficient
Age	Cognitive symptoms (Neuro-QOL)	.559
Gender	Self-reported speech Severity (ALS-FRS)	.194
Living situation (alone; family)	Speech Usage	.154
Employed (yes / no)	Physical activity (PROMIS)	.127
Time since diagnosis	Education	-.108
Emotional problems (PROMIS)		
Fatigue (PROMIS)		
Pain (PROMIS)		

(Yorkston et al., 2014)

Predicting Communicative Participation: Parkinson's Disease(n=200 in US / 178 in NZ))

Non-significant Variables	Significant Variables (Adjusted R^2 = .427)	Standardized Coefficient
Age*	Cognitive symptoms (Neuro-QOL)	.032
Gender*	Self-reported speech severity (ALS-FRS)	.321
Living situation (alone; family)	Emotional problems (PROMIS)	.149
Employed (yes / no)	Fatigue (PROMIS)	.110
Time since diagnosis	Swallowing	-.174
Education		
Pain (PROMIS)		
Speech Usage*		
Physical activity (PROMIS)		
Hearing problems		

* When younger, better to be female and in NZ; When older, better to have higher speech usage.

(McAuliffe et al., submitted)

Predicting Communicative Participation: ALS (n= 70)

Non-significant Variables	Significant Variables (Adjusted R^2 = .562)	Standardized Coefficient
Cognitive symptoms (Neuro-QOL)	Self-reported speech severity (ALS-FRS)	.450
Emotional problems (PROMIS)	Swallowing (ALS-FRS)	.317
Physical activity (PROMIS)	Speech Usage	.303

(Mach et al., in preparation)

Predicting Communicative Participation: Aphasia (n=110)

Non-significant Variables	Significant Variables (Adjusted R^2 = .215)	Standardized Coefficient
ASHA Quality Communication Life	Western Aphasia Battery - AQ	.394
Education	PROMIS – General Participation	.371
Time since diagnosis		
Employment		
Living status (alone; family)		
Marital status		

(Baylor et al., in preparation)

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Predicting Communicative Participation: Head and Neck Cancer (n=197)

Non-significant Variables	Significant Variables (Adjusted R^2 = .462)	Standardized Coefficient
Speech usage	Speech severity (ALS-FRS)	.498
Fatigue (PROMIS)	Cognitive symptoms (Neuro-QOL)	.318
Pain (PROMIS)	No Laryngectomy	.146
Education	Longer time post-onset	.137
Physical activities (PROMIS)		
Emotional Problems (PROMIS)		
Swallowing (ALS-FRS)		

(Eadie et al., in preparation)

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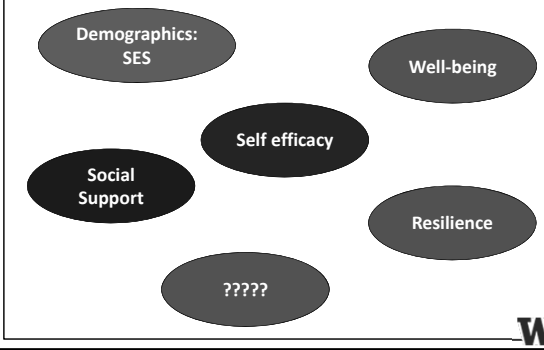
What's Missing?



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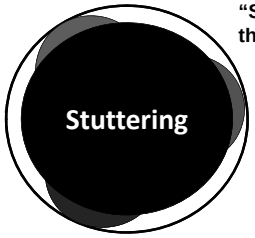
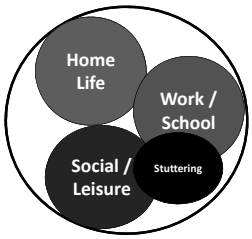


"Stuttering was the biggest thing" in my life (female, stuttering)

How?
Fluency techniques
Desensitization work
Support groups
Social support
Life Experience



"Stuttering has taken a smaller place in my life."

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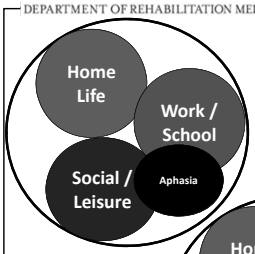

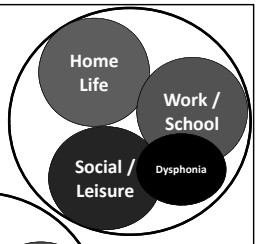

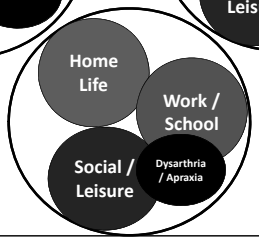

How?

- Include the client's voice in treatment decisions
- People with different disorders may speak with a similar voice. Get out of our silos!

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Thank you

Veterans on Veterans Day
Colleagues and Mentors
Research Participants and Families
Students
ANCDS

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