## 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.

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

<table>
<thead>
<tr>
<th>Summary</th>
<th>Theta</th>
<th>T score</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>-2.58</td>
<td>24.20</td>
</tr>
<tr>
<td>1</td>
<td>-2.18</td>
<td>28.20</td>
</tr>
<tr>
<td>2</td>
<td>-1.94</td>
<td>30.60</td>
</tr>
<tr>
<td>3</td>
<td>-1.76</td>
<td>32.40</td>
</tr>
<tr>
<td>4</td>
<td>-1.60</td>
<td>34.00</td>
</tr>
<tr>
<td>5</td>
<td>-1.46</td>
<td>35.40</td>
</tr>
<tr>
<td>6</td>
<td>-1.34</td>
<td>36.60</td>
</tr>
<tr>
<td>7</td>
<td>-1.22</td>
<td>37.80</td>
</tr>
<tr>
<td>8</td>
<td>-1.10</td>
<td>39.00</td>
</tr>
<tr>
<td>9</td>
<td>-0.99</td>
<td>40.10</td>
</tr>
<tr>
<td>10</td>
<td>-0.89</td>
<td>41.10</td>
</tr>
<tr>
<td>11</td>
<td>-0.78</td>
<td>42.20</td>
</tr>
<tr>
<td>12</td>
<td>-0.67</td>
<td>43.30</td>
</tr>
<tr>
<td>13</td>
<td>-0.56</td>
<td>44.40</td>
</tr>
<tr>
<td>14</td>
<td>-0.45</td>
<td>45.50</td>
</tr>
<tr>
<td>15</td>
<td>-0.33</td>
<td>46.70</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Summary</th>
<th>Theta</th>
<th>T score</th>
</tr>
</thead>
<tbody>
<tr>
<td>16</td>
<td>-0.22</td>
<td>47.80</td>
</tr>
<tr>
<td>17</td>
<td>-0.10</td>
<td>49.00</td>
</tr>
<tr>
<td>18</td>
<td>0.03</td>
<td>50.30</td>
</tr>
<tr>
<td>19</td>
<td>0.15</td>
<td>51.50</td>
</tr>
<tr>
<td>20</td>
<td>0.27</td>
<td>52.70</td>
</tr>
<tr>
<td>21</td>
<td>0.40</td>
<td>54.00</td>
</tr>
<tr>
<td>22</td>
<td>0.53</td>
<td>55.30</td>
</tr>
<tr>
<td>23</td>
<td>0.65</td>
<td>56.50</td>
</tr>
<tr>
<td>24</td>
<td>0.78</td>
<td>57.80</td>
</tr>
<tr>
<td>25</td>
<td>0.92</td>
<td>59.20</td>
</tr>
<tr>
<td>26</td>
<td>1.06</td>
<td>60.60</td>
</tr>
<tr>
<td>27</td>
<td>1.22</td>
<td>62.20</td>
</tr>
<tr>
<td>28</td>
<td>1.42</td>
<td>64.20</td>
</tr>
<tr>
<td>29</td>
<td>1.67</td>
<td>66.70</td>
</tr>
<tr>
<td>30</td>
<td>2.10</td>
<td>71.00</td>
</tr>
</tbody>
</table>

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

Thanks...

U. of WA Core Team
Kathy Yorkston
Deanna Britton
Dagmar Amtmann
Tanya Eadie

Aphasia Project
UW Aphasia Lab
Diane Kendall
Megan Oelke
Sarah Wallace
Eileen Hunsaker
Catherine Off

Student Projects
Janaki Torrence
Helen Mach
Christina Runne
Jolene Mogharreban
Caroline Umeda
Cornetta Mosley

NZ Parkinson’s Project
Megan McAuliffe

Hearing Loss Projects
Kelly Tremblay (and team)
Christi Miller (and team)

...and more thanks

- NIH- NIDCD
  — 1R03DC010044-Baylor (PI)
  — R01 DC012510-Baylor (PI)
- American Speech-Language-Hearing Foundation
  — Clinical Research Grant-Baylor (PI)
- National Cancer Institute
  — 1R03CA132525-Eadie (PI)
  — 1R01CA177635-Eadie (PI)
- NIH PROMIS – Amtmann (PI)
- National Center for Medical Rehabilitation Research, Yorkston (PI)
- University of Washington Dept. of Rehabilitation Medicine
- ANCDS Meeting Registration

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

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)

Finding the balance for treatment targets and outcomes measurement

- Broad enough to capture meaningful information about experiences
- Specific enough to capture what we can change

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

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
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

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

Is communicative participation the same as...?

<table>
<thead>
<tr>
<th>Diagnosis</th>
<th>Measure</th>
<th>Correlation with CPIB</th>
</tr>
</thead>
<tbody>
<tr>
<td>Parkinson’s disease</td>
<td>Self-reported speech severity</td>
<td>.471</td>
</tr>
<tr>
<td>Multiple sclerosis</td>
<td>Self-reported speech severity</td>
<td>.349</td>
</tr>
<tr>
<td>ALS</td>
<td>Self-reported speech severity</td>
<td>.629</td>
</tr>
<tr>
<td>Head and neck cancer</td>
<td>Self-reported speech severity</td>
<td>.600</td>
</tr>
<tr>
<td>Aphasia</td>
<td>Western Aphasia Battery</td>
<td>.290</td>
</tr>
</tbody>
</table>

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

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) (Chapley et al., 2000)
Is it part of this picture?

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

Does it encompass anything that improves...

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

...to communicate in life roles

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

- Successful
- Comfortable
- Achieve what is personally meaningful

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, 55)

Female with spasmodic dysphonia questioning career in teaching

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 know 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

"The therapy program really did cause a psychological shift in my mind and how I feel 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"
Speaking is a process... 
...in which speech is only one step (n=24, PD)

Planning to talk 
Prepared to speak 
How do people react when they do they mean? 
How do I understand? 
How did am I? 
Following up after speaking

“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-LS]
• “Participation-focused intervention makes a lot of sense.” [SLP-L8]

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)

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 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]

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

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

"…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

"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

PD; male

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.

Stigma

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)

Some examples of conversation support

For Aphasia

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

For Dysarthria
**Some barriers to mobile phone use**

**For Aphasia**
- Understanding symbols
- Too many steps to complete a task
- Poor sound quality
- Often do not know person on other end
- Loss of visual information to help with communication

**For Dysarthria**
- No
- No
- Yes!
- Yes!
- Yes!

---

**Does it encompass anything that improves...**

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

Disorder specific?

Not disorder specific?

---

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

---

**A peek at early data...**

**Response to standard-of-care treatment**

Unilateral Vocal Fold Immobility (n=14)

- CAPE-V Overall Voice Severity (low scores better)
- CPIB (high scores better)

Before treatment and six months later

**Spasmodic Dysphonia**

- CAPE-V Overall Voice Severity (low scores better)
- CPIB (high scores better)

Before first botox injection and 6 months later

Satisfied with outcome at T=52.7
A peek at early data…
Response to standard-of-care treatment

Predicting Communicative Participation:
Multiple Sclerosis (n=216)

<table>
<thead>
<tr>
<th>Non-significant Variables</th>
<th>Significant Variables (Adjusted $R^2 = .507$)</th>
<th>Standardized Coefficient</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>Cognitive symptoms (Neuro-QOL)</td>
<td>.559</td>
</tr>
<tr>
<td>Gender</td>
<td>Self-reported speech severity (ALS-FRS)</td>
<td>.194</td>
</tr>
<tr>
<td>Living situation (alone; family)</td>
<td>Speech Usage</td>
<td>.254</td>
</tr>
<tr>
<td>Employed (yes / no)</td>
<td>Physical activity (PROMIS)</td>
<td>.127</td>
</tr>
<tr>
<td>Time since diagnosis</td>
<td>Education</td>
<td>-.108</td>
</tr>
<tr>
<td>Emotional problems (PROMIS)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Fatigue (PROMIS)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pain (PROMIS)</td>
<td>(Yorkston et al., 2014)</td>
<td></td>
</tr>
</tbody>
</table>

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

<table>
<thead>
<tr>
<th>Non-significant Variables</th>
<th>Significant Variables (Adjusted $R^2 = .427$)</th>
<th>Standardized Coefficient</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age*</td>
<td>Cognitive symptoms (Neuro-QOL)</td>
<td>.092</td>
</tr>
<tr>
<td>Gender*</td>
<td>Self-reported speech severity (ALS-FRS)</td>
<td>.321</td>
</tr>
<tr>
<td>Living situation (alone; family)</td>
<td>Emotional problems (PROMIS)</td>
<td>.149</td>
</tr>
<tr>
<td>Employed (yes / no)</td>
<td>Fatigue (PROMIS)</td>
<td>.110</td>
</tr>
<tr>
<td>Time since diagnosis</td>
<td>Swallowing</td>
<td>-.174</td>
</tr>
<tr>
<td>Education</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pain (PROMIS)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Speech Usage*</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Physical activity (PROMIS)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hearing problems</td>
<td>(McAuliffe et al., submitted)</td>
<td></td>
</tr>
</tbody>
</table>

Predicting Communicative Participation:
ALS (n=70)

<table>
<thead>
<tr>
<th>Non-significant Variables</th>
<th>Significant Variables (Adjusted $R^2 = .562$)</th>
<th>Standardized Coefficient</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cognitive symptoms (Neuro-QOL)</td>
<td>Self-reported speech severity (ALS-FRS)</td>
<td>.450</td>
</tr>
<tr>
<td>Emotional problems (PROMIS)</td>
<td>Swallowing (ALS-FRS)</td>
<td>.317</td>
</tr>
<tr>
<td>Physical activity (PROMIS)</td>
<td>Speech Usage</td>
<td>.303</td>
</tr>
</tbody>
</table>

(Mach et al., in preparation)

Predicting Communicative Participation:
Aphasia (n=110)

<table>
<thead>
<tr>
<th>Non-significant Variables</th>
<th>Significant Variables (Adjusted $R^2 = .215$)</th>
<th>Standardized Coefficient</th>
</tr>
</thead>
<tbody>
<tr>
<td>ASHA Quality Communication Life</td>
<td>Western Aphasia Battery - AQ</td>
<td>.394</td>
</tr>
<tr>
<td>Education</td>
<td>PROMIS – General Participation</td>
<td>.371</td>
</tr>
<tr>
<td>Time since diagnosis</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Employment</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Living status (alone; family)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Marital status</td>
<td>(Baylor et al., in preparation)</td>
<td></td>
</tr>
</tbody>
</table>
Predicting Communicative Participation: Head and Neck Cancer (n=197)

<table>
<thead>
<tr>
<th>Non-significant Variables</th>
<th>Significant Variables</th>
<th>Standardized Coefficient</th>
</tr>
</thead>
<tbody>
<tr>
<td>Speech usage</td>
<td>Speech severity (ALS-FRS)</td>
<td>.498</td>
</tr>
<tr>
<td>Fatigue (PROMIS)</td>
<td>Cognitive symptoms (Neuro-QOL)</td>
<td>.358</td>
</tr>
<tr>
<td>Pain (PROMIS)</td>
<td>No Laryngectomy</td>
<td>.146</td>
</tr>
<tr>
<td>Education</td>
<td>Longer time post-onset</td>
<td>.137</td>
</tr>
<tr>
<td>Physical activities (PROMIS)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Emotional Problems (PROMIS)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Swallowing (ALS-FRS)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

(Eadie et al., in preparation)

What’s Missing?

Demographics: SES
Well-being
Self efficacy
Social Support
Resilience

?????

"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."

How?
• Include the client’s voice in treatment decisions
• People with different disorders may speak with a similar voice. Get out of our silos!

Thank you

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

Contact information:
Carolyn Baylor
cbaylor@uw.edu