

A “PROM-posal:” Inviting accessible patient-reported outcomes measures into patient care

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Conference
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Three Studies: Open Anywhere in the US!

1. Survey for people with any of the following:
 - Parkinson’s disease
 - Mild Cognitive Impairment / early Dementia
 - Head and Neck Cancer:
2. Study for people with Stroke and communication difficulties (aphasia and/or motor speech)
3. SLPs working with people with stroke and use the CPIB



<https://redcap.link/speaclabresearch>

DISCLOSURES

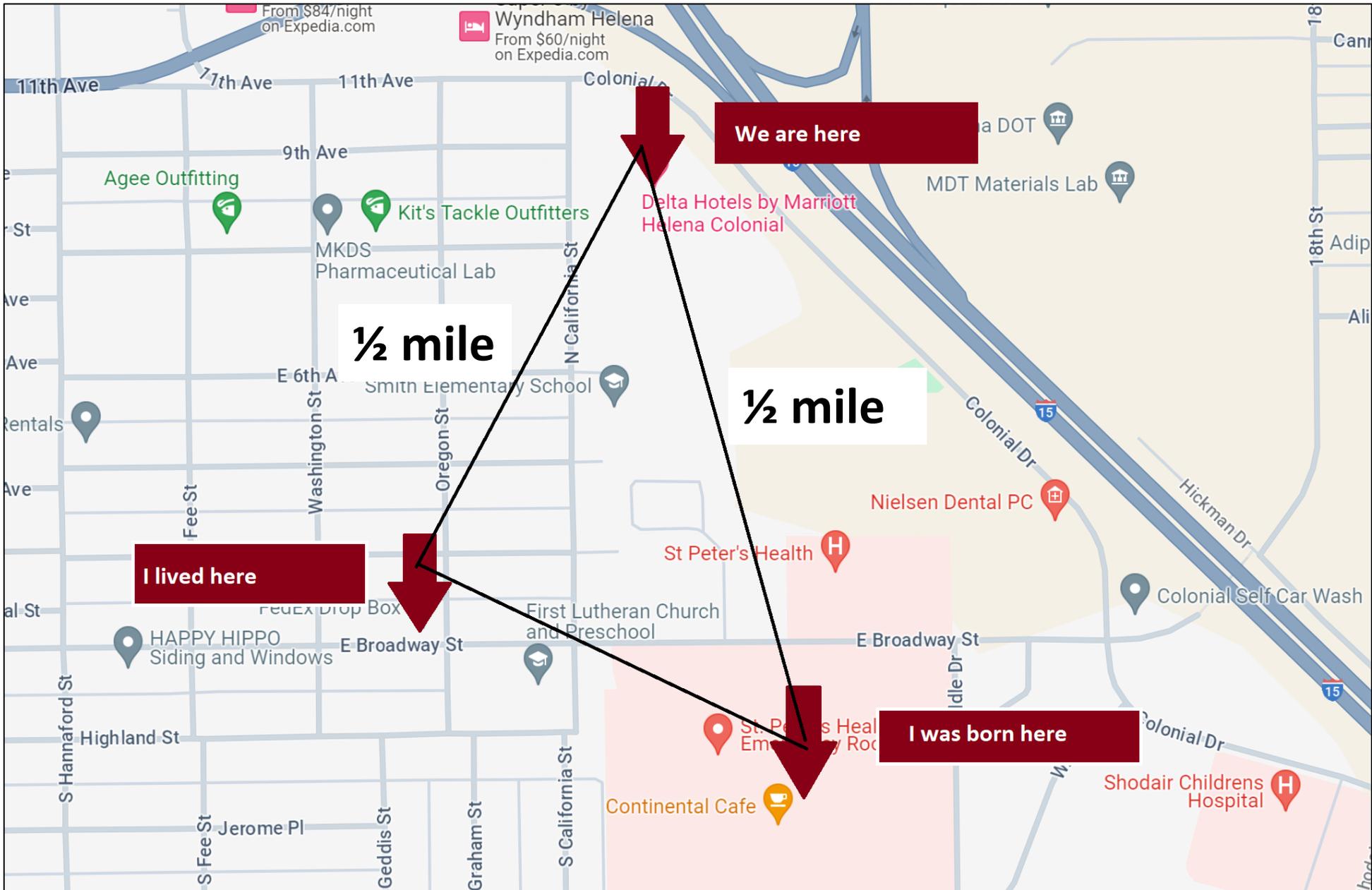
- Employee at University of Washington
- Current / past grant funding contributing to this work
 - National Institute on Deafness and other Communication Disorders
 - American Speech-Language Hearing Foundation
 - University of Washington Royalty Research Fund
- Conference travel support honorarium



The University of Washington acknowledges the Coast Salish peoples, the tribes and bands on whose native land and waters the university resides.

I acknowledge our intersecting identities. Mine include being a cis-gendered white female with the privilege of educational opportunities and representing a discipline dominated by white females.







A “PROM-posal:”
Inviting accessible
patient-reported outcomes
measures into patient care

**Patient – Reported
Outcomes Measures**

Data reported directly by the
patient / client without filtering or
interpretation by another person.



<https://www.dreamstime.com/illustration/prom-night.html>

I know you already use PROMs but...

1. Making the case for PROMs
2. Selecting high-quality PROMs
3. Creating your own client-specific PROMs
4. Making PROMs communicatively accessible
5. Elevate the role of PROMs in clinical care – using patient-reported outcomes for goals



Overview of my work in PROMs

- Adults with acquired communication disorders, particularly speech / voice
- Communicative Participation:
 - Engagement in communication in daily activities
- Impact on
 - People with the diagnosis
 - Family members / friends (communication partners)

	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?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
2. Does your condition interfere with... ... communicating when you need to say something quickly?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
3. Does your condition interfere with... ... talking with people you do NOT know?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
4. Does your condition interfere with... ... communicating when you are out in your community (e.g. errands; appointments)?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
5. Does your condition interfere with... ... asking questions in a conversation?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
6. Does your condition interfere with... ... communicating in a small group of people?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
7. Does your condition interfere with... ... having a long conversation with someone you know about a book, movie, show or sports event?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
8. Does your condition interfere with... ... giving someone DETAILED information?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
9. Does your condition interfere with... ... getting your turn in a fast-moving conversation?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
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Communicative Participation Item Bank (CPIB): General Short Form

(Baylor et al., JSLHR, 2013)

New Project: Social Support for Communication

Sample Items: Person experiencing communication disability

How often do you experience the following?	With people who know you well					With people who do NOT know you well				
	Never	Rarely	Sometimes	Often	Always	Never	Rarely	Sometimes	Often	Always
1. People interrupt you when you are trying to communicate	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
2. People try to finish your sentences when you do not want them to	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
3. People hang up the phone on you	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
4. People seem to avoid you because of how you communicate	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

New Project: Social Support for Communication

Sample Items: Communication partner (family / friends)

When interacting with this person, I find myself...

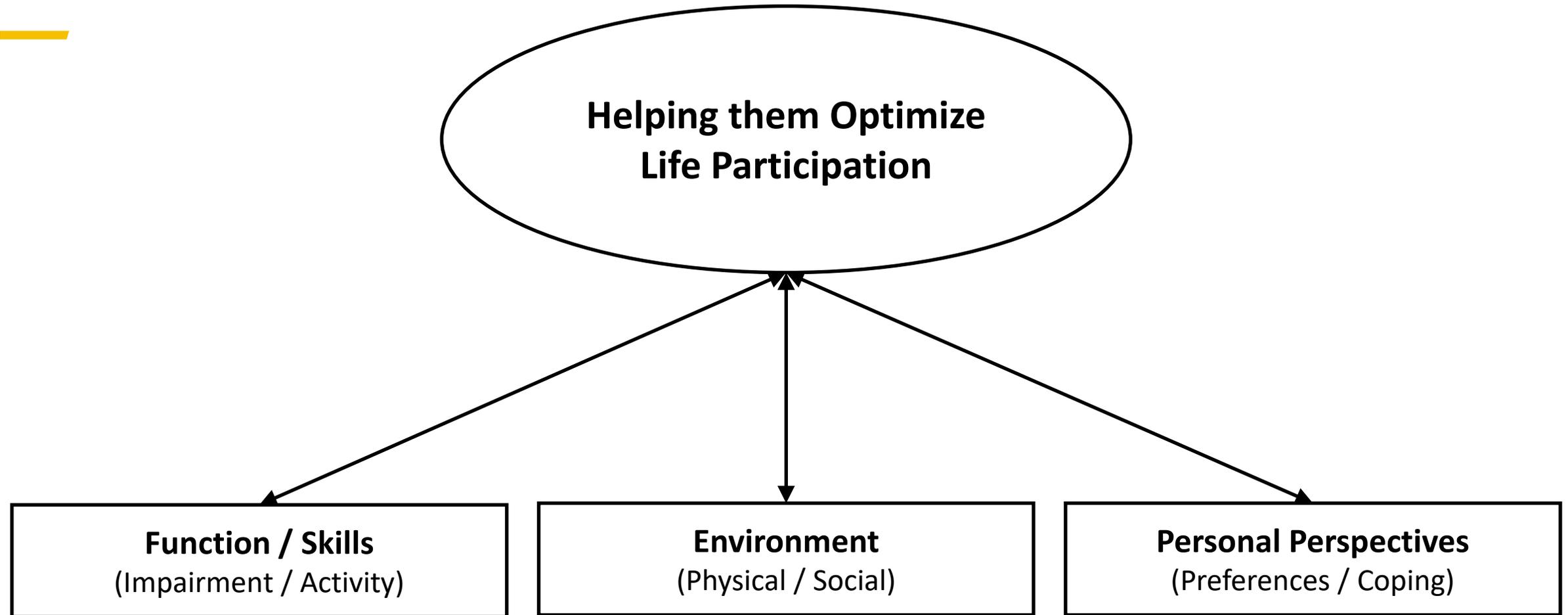
	Never	Rarely	Sometimes	Often	Always
1) ...interrupting them when they are trying to communicate.	<input type="radio"/>				
2) ...finishing their sentences for them.	<input type="radio"/>				
3) ...cutting my phone calls short with them.	<input type="radio"/>				
4) ...avoiding conversations with them.	<input type="radio"/>				
5) ...pretending to understand them when I do not.	<input type="radio"/>				

TOPIC 1

Making the case for PROM measurement in clinical care

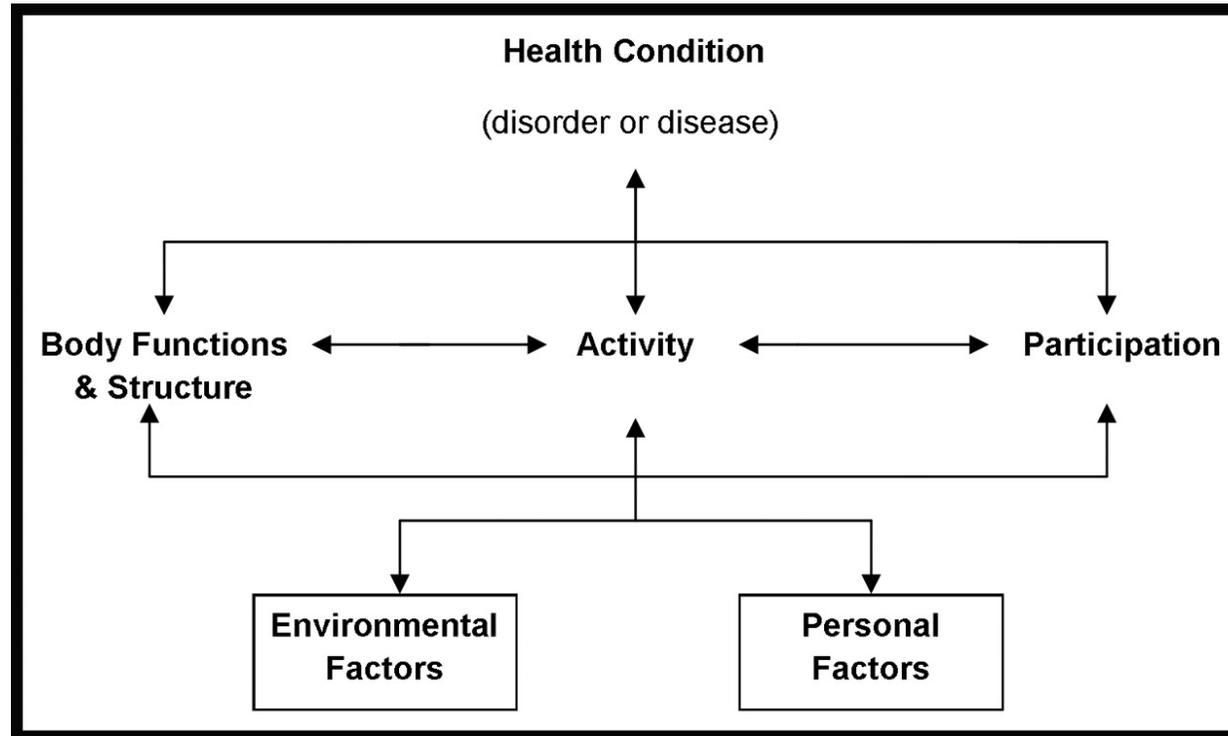


What is our role with our clients?



Biopsychosocial Models of Health and Disability

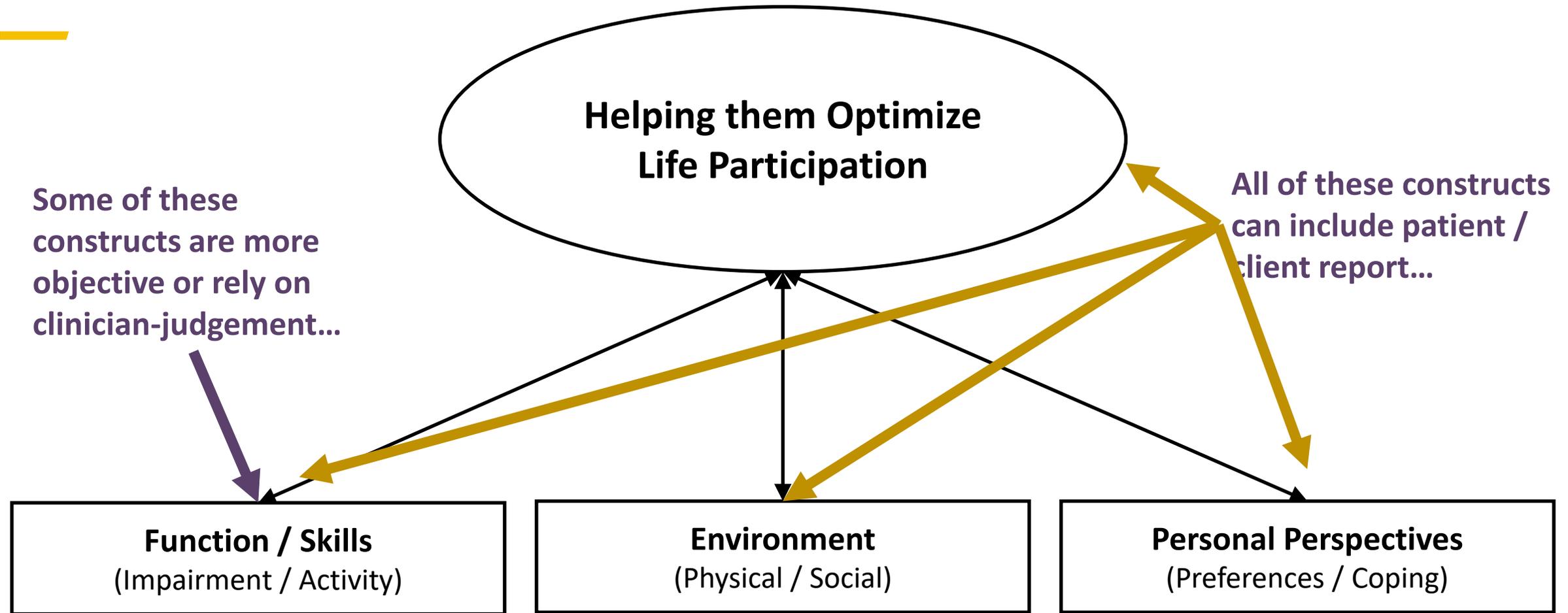
World Health Organization's International Classification of Functioning, Disability, and Health (ICF)



“Disability results from the interaction between individuals with a health condition and the environment.”

(WHO, 2001)

What is our role with our clients?



Why we use patient-reported outcomes measures (PROMs)

- PROM data often do NOT correlate strongly with physical function
- Promotes patient-centered care by including the ‘voice’ of the patient in our assessment and treatment data
- Helps us consider the client’s viewpoint in setting goals and measuring outcomes
- Important to determining the value of our services – did we help create meaningful change for the patient
- Convert patient anecdotal data to the numbers stakeholders want
 - Referral sources
 - Insurance payers
 - Quality metrics
 - Administrators

(Cohen & Hula, 2020; Francis et al., 2017)

TOPIC 2

Selecting high-quality PROMs for clinical use



Selecting High-Quality PROMs: Healthmeasures.net



HealthMeasures
TRANSFORMING HOW HEALTH IS MEASURED



SEARCH &
VIEW MEASURES

EXPLORE
MEASUREMENT SYSTEMS

IMPLEMENT
HEALTHMEASURES

SCORE &
INTERPRET

RESOURCE
CENTER

NIH PROMIS

- Constructs Measured
 - Physical Health
 - Social Health
 - Mental Health
- Adults and Pediatrics
- General Population
- Chronic Conditions
- Translations Available

NEURO-QOL

- Constructs Measured
 - Physical Health
 - Social Health
 - Mental Health
- Adults and Pediatrics
- Neurological Conditions
- Translations Available

NIH ToolBox

- Patient-Report Measures
 - Emotion
 - Sensation
- Performance Measures
 - Cognition
 - Motor

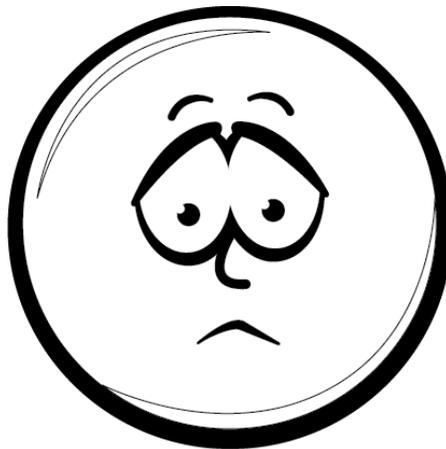
Free to download and use!!

Selecting High-Quality PROMs

- Step 1: The PROM is measuring a construct that is:
 - What you need to know for your intervention purposes
 - Relevant to your client



<https://pictarts.com/03/01-lifestyle/e-0023-simple-art.html>



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https://www.flaticon.com/free-icon/chef-cooking_10554

Selecting High-Quality PROMs

- Step 2: Evidence of systematic and rigorous stakeholder input

“Many questionnaire items...can be perceived by the client as irrelevant, meaningless, or built on the researcher’s point of view rather than on the client’s needs, and the resulting data can be patient-reported without being personally significant.”

(Bothe and Richardson, 2011)



Selecting High-Quality PROMs

- Step 2: Evidence of systematic and rigorous stakeholder input
 - Look for evidence of cognitive interviews completed with people with lived experience

(Willis, 2005; Collins, 2003; Drennan, 2003)



Examples of Feedback from our Cognitive Interviews on our Communication PROM (CPIB)

Original Version of Item

Asked about “feeling satisfied” with communication in daily activities

Problem Identified

Being asked about ‘satisfaction’ did not sufficiently capture lived experience of problems

Solution Developed with Stakeholders

Rephrase items to ask about ‘interference’ and ‘difficulty’

Examples of Feedback from our Cognitive Interviews on our Communication PROM (CPIB)

Original Version of Item

Asked about “using humor in conversations”

Problem Identified

Double-barreled item: Different types of humor have different communication demands

Solution Developed with Stakeholders

Split original item into two:

1. Telling a funny story or joke
2. Making a witty or funny comments

Examples of Feedback from our Cognitive Interviews on our Communication PROM (CPIB)

Original Version of Item

Version designed for people with communication disorders grouped “family and friends” together as “safe” communication partners

Problem Identified

People who are transgender stated that friends are safe, but “family” may not be safe depending on biological versus chosen family and range of family support

Solution Developed with Stakeholders

Rephrase items to refer to “people who know you well” as people who have been allowed into your circle and known to be safe.

Selecting High-Quality PROMs

- Step 3: Rigorous psychometric (statistical) analyses and development
 - Sufficient sample sizes for statistics (hundreds of research participants)
 - Sufficient representation of the following to avoid bias:
 - Key diagnosis characteristics
 - Race, ethnicity, sex, gender, geographic region
 - Cultural and language background
 - Instruments developed with Item Response Theory (IRT) have advantages of measurement precision and efficiency

(Hays et al., 2000; Cella et al., 2000)



Is your specific client represented in the research behind the PROM?

Selecting High-Quality PROMs

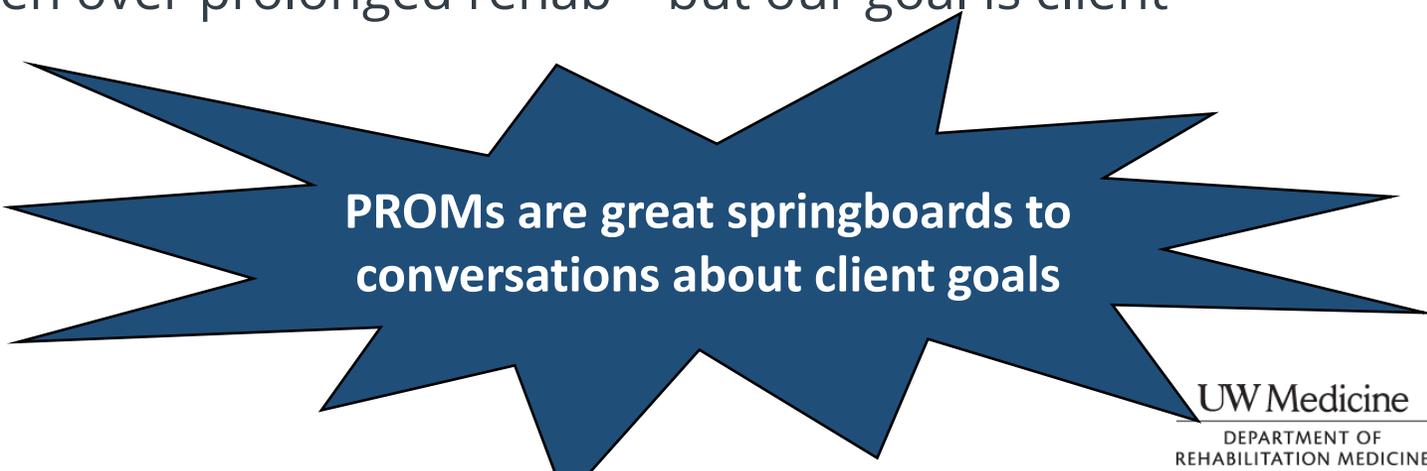
- Step 4: Know how to interpret scores, and changes in scores appropriately
 - “Minimally important difference” or “clinically significant difference”
 - May be based on group-level research
 - Helpful for interpreting change relative to external normative or clinical standards

“...we do not need to know only that clients’ scores have changed enough to justify their classification as “closer to normal” or as “performing much better” on some measure; we need to know that the clients themselves find the improvements to be helpful.”

(Bothe and Richardson, 2011)

Client-specific PROM Targets and Interpretation

- Identifying the client's Personal Satisfactory Target (Zeppieri et al., 2012)
 - Complete PROM once to reflect "How are things now?"
 - Then go back and discuss / answer again with this prompt:
 - *"How would you answer if you had an ideal outcome of tx?"*
 - Then go back and discuss / answer again with this prompt:
 - *"How would you answer if you had what you considered satisfactory, if not ideal?"*
 - Use the "Satisfactory" score as the target (more later on using PROMs in goals)
 - Be aware response shift may happen over prolonged rehab – but our goal is client satisfaction...regardless of score.



**PROMs are great springboards to
conversations about client goals**

Communicative Participation Item Bank (CPIB): General Short Form

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People with chronic communication disabilities:

1. Most common target for satisfactory communication outcomes.
2. Second most common target for satisfactory outcomes:

“Every item would be one category better on the response options”

Proxy Report? OK with LOTS of Caveats

- When to use proxy report?
 - Children younger than elementary school age (many kids can complete relevant PROMs)
 - Adults too cognitively or linguistically impaired to participate (we will revisit this soon...)
- Who is serving as the proxy?
 - Close loved one is better than healthcare provider.
 - Even a close loved one may not really know client's wishes and views.
- How accurate are proxy reporters?
 - Family proxy tend to rate quality of life LOWER than person with the diagnosis
 - Correlation between family proxy and person with diagnosis usually weak-moderate

(Baylor et al., 2017; Doyle et al., 2013; Hilari et al., 2007; Matza et al., 2013; Williams et al., 2006)

Proxy Report? Consider these options...



Objective Constructs: “How often do they play baseball?”

VS

Subjective Constructs: “How important is playing baseball to them?”

“In your opinion what is your loved one’s quality of life”

VS

“How do you think your loved one would rate their quality of life?”

Language Translations / Cultural Translations

- Look for translations for client's preferred language
- Look for evidence that recommended translation procedures were followed
 - Forward and backwards translations
 - Cognitive interviews in translated language
 - Psychometric (statistical) evidence of validity / reliability in translated language
- Cultural relevance can be different than language translation
 - Just because someone can read and respond in the language of the PROM does not guarantee the PROM captures topics of most importance in the client's cultural experiences

(Wild et al., 2005)



**Guten
Tag**



Hola

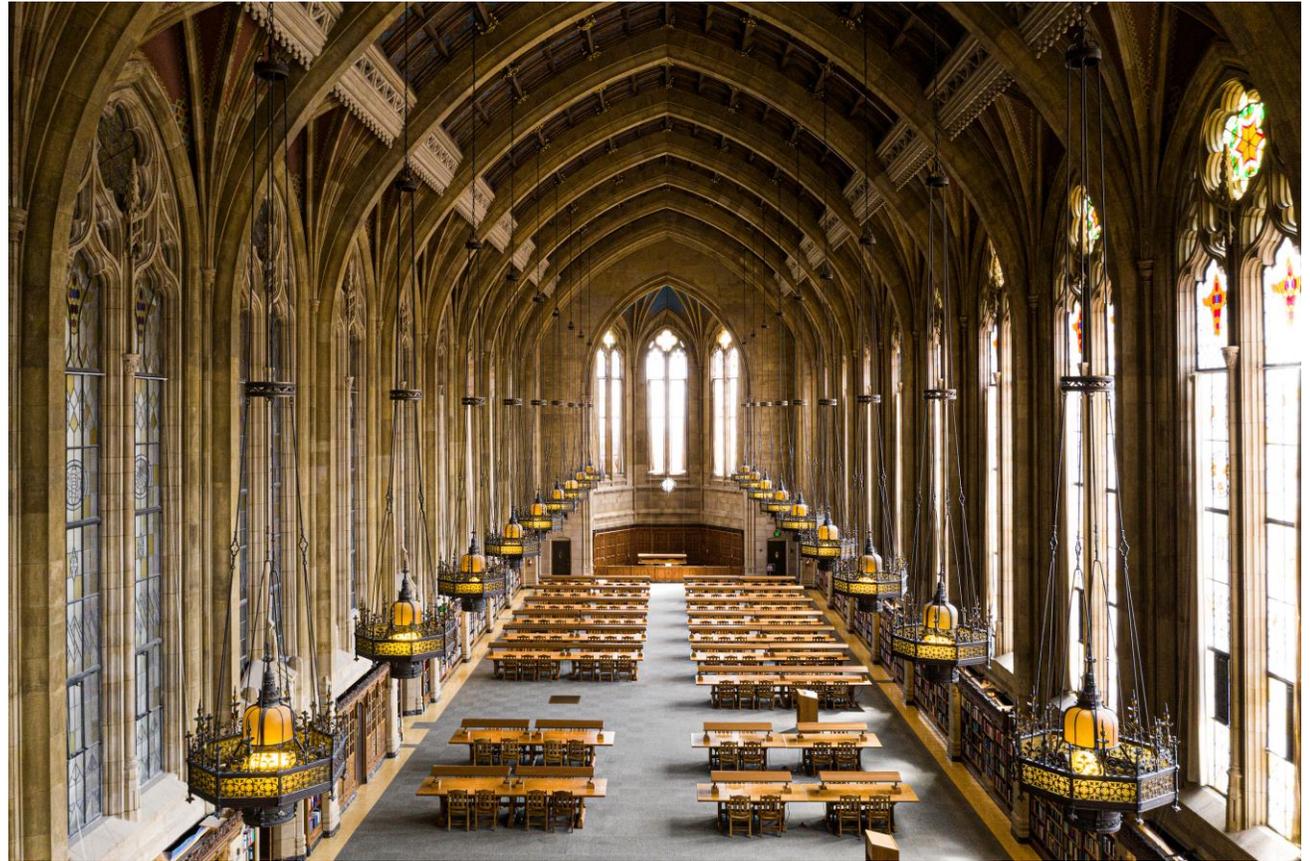


Xin chào

TOPIC 3

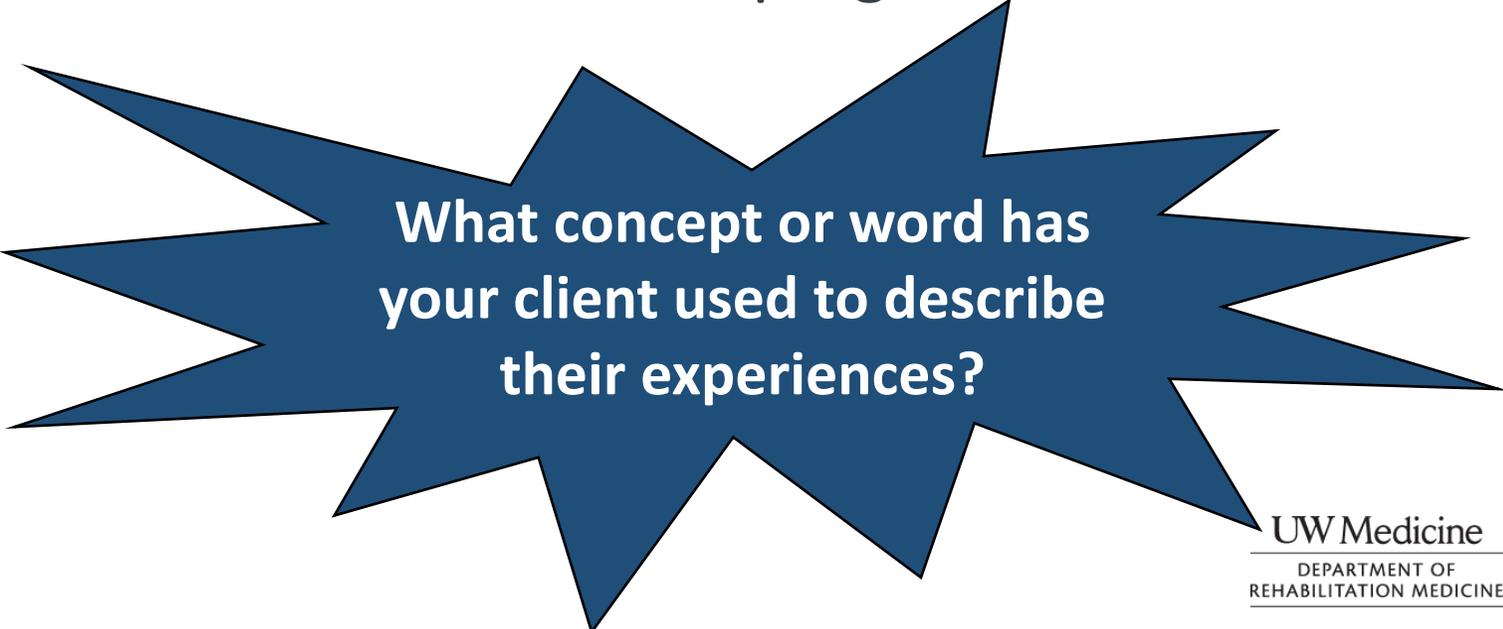
When you cannot find a PROM to fit your needs....

Creating your own valid and reliable PROMs



Creating client-specific scales

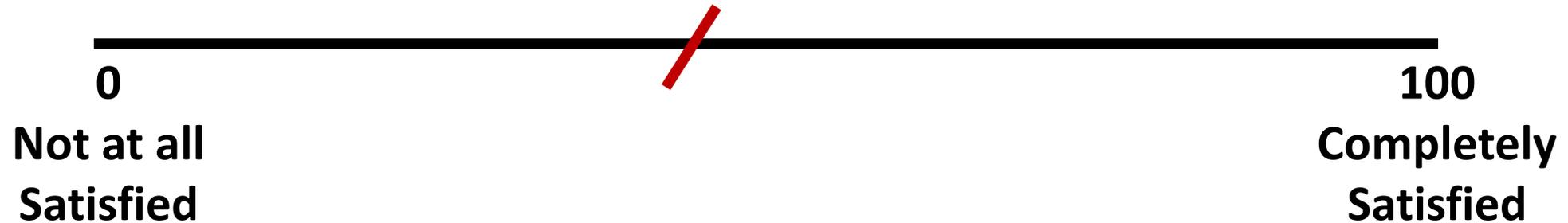
- Tailors PROMs to specific needs and interests of clients
- Converts anecdotal data into quantifiable data
- Can be valid and reliable non-standardized assessment
- Useful for patient-centered goals and measurement of progress



**What concept or word has
your client used to describe
their experiences?**

Same concept with a Visual Analog Scale (VAS)

Sample Item: “How satisfied are you with your mobility around your home?”



Document the Assessment

On a 100 mm visual-analog scale (0 = not at all satisfied; 100 = very satisfied), the client rated their satisfaction with their mobility around their home as a 43.

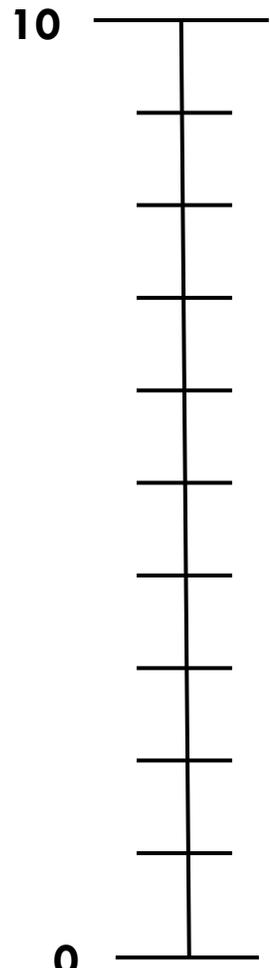
(The VAS line MUST be exactly 100 mm and measure with a ruler from the “0” end; or adjust to proportion)

Tips for using Likert and VAS scales

- Define the anchors (endpoints) as the opposite ends of the same construct (e.g. not at all satisfied – very satisfied)
- In all reporting and goals, include the scale definition (e.g. type of scale, anchor labels, number of response options) so the reader can interpret
- Use the SAME scale for initial evaluation, probes, and DC reporting to show change / progress
- More on Likert Scales
 - Most common to use 5, 7, or 10 levels (e.g. 1 – 7 or 1 – 10)
 - Fewer than 5 – may not be sensitive enough to capture change (5 might be too few)
 - More than 10 – hard to distinguish that different levels mean anything
- More on VAS
 - The line must be exactly 100 mm; Measure in mm from the '0' end

Self-Anchored Rating Scales

(Fox, 2012)



Client defines what outcome would be satisfactory (write in the terms)

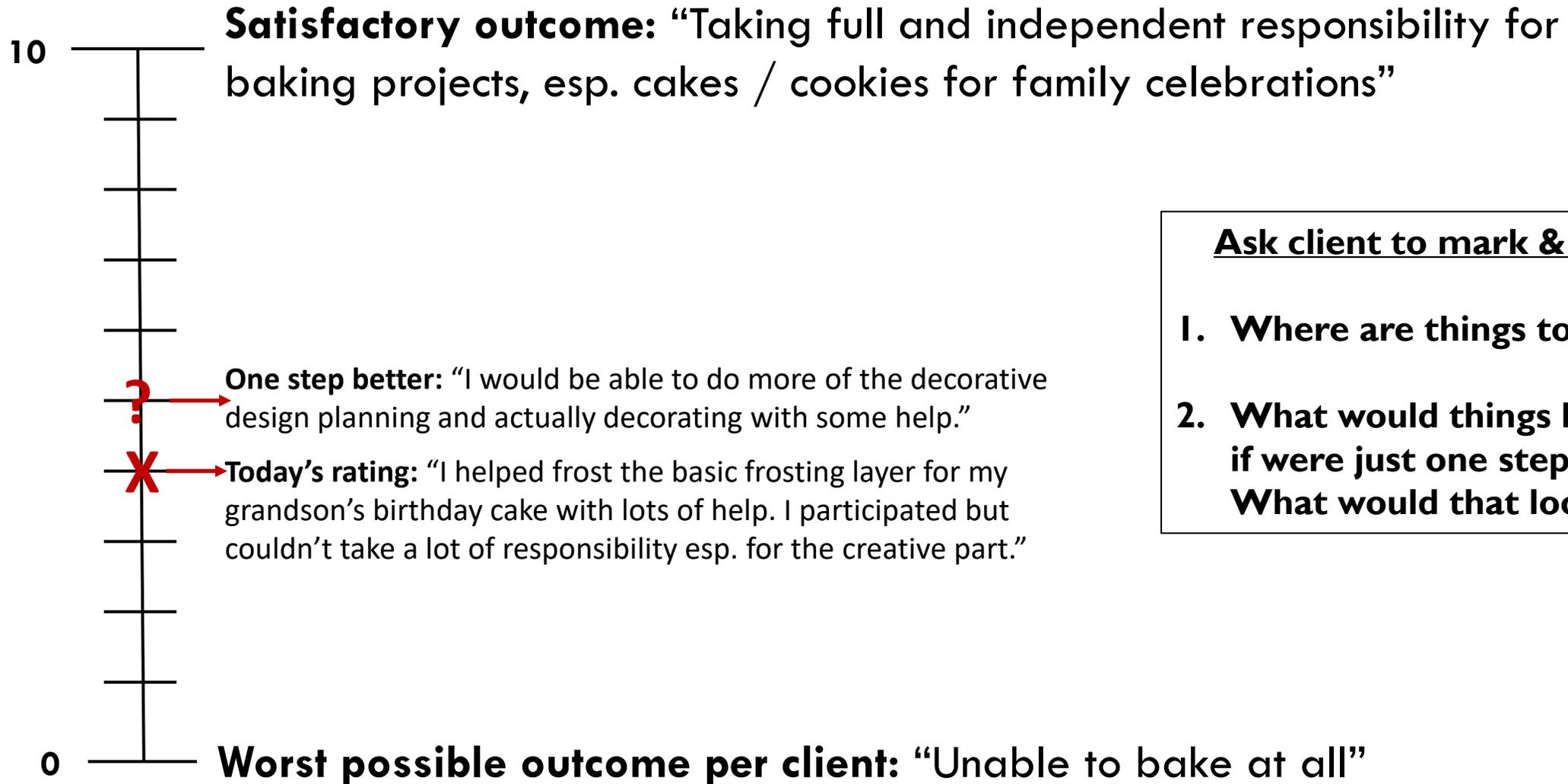
Ask client to mark and describe:

- 1. Where are things today?**
- 2. What would things look like if it were just one step better?
What would that look like?**

Client defines worst possible outcome (or when things were at their worst)

Example: Client working on kitchen function / safety

(Fox, 2012)



Ask client to mark & describe:

- 1. Where are things today?**
- 2. What would things look like it if were just one step better?
What would that look like?**

Goal Attainment Scaling

(A rehab example: Krasny-Pacini et al., 2016)

Score	Interpretation	Define what each level means with client
+2	Most favorable outcome	(Define this with client – what does unrestricted and satisfactory participation look like to the client – how do they describe it.)
+1		(Define this with client)
0	Most likely outcome	(Define this with client)
-1		(Define this with client)
-2	Least favorable outcome	(Define this with client)

A side note on client-defined scales

The client-defined scales such as self-anchored and goal-attainment scaling require longer and more in-depth conversations with clients. That is a good thing because:

- We get to know clients wishes / needs / strengths in more detail
- Helps establish working relationship
- Likely uncovers logical areas where we can help clients



TOPIC 4

Making PROMs communicatively accessible



People with communication disabilities

- 3x more likely to experience adverse events in healthcare (complications; errors) (Bartlett et al., 2008)
- Lower satisfaction with healthcare (Hoffman et al., 2005)
- Excluded from healthcare decision-making (Burns et al., 2015; Fox & Pring, 2005; Hemsley et al., 2008; Law et al., 2005; Morris et al. 2013, Murphy, 2006)
- Higher prevalence in complex patient situations (Stransky et al., 2018)
 - Higher prevalence of chronic conditions
 - Poorer health and unmet medical needs
 - More frequent healthcare visits including emergency room visits and hospital stays
 - More difficulty finding a healthcare provider



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Consider this:

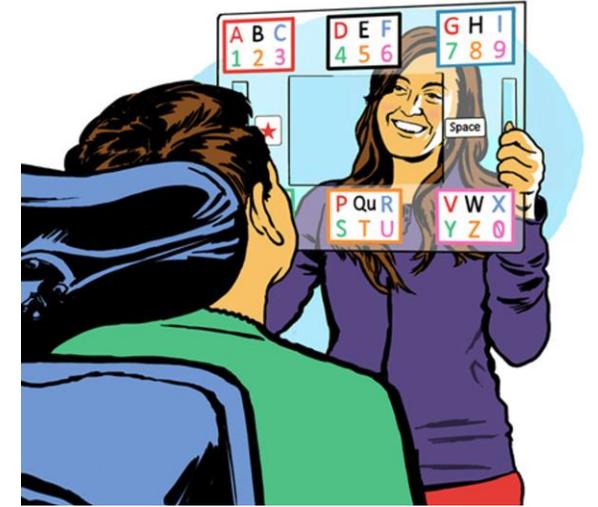
Many people with communication disabilities can participate in PROMs and other healthcare communication more than we might initially assume!

- PROMs are NOT a test of independent reading comprehension, motor function, or any other aspect of performance.
- Judicious help is ok if it facilitates the client's authentic viewpoint without biasing or distorting that viewpoint through the lens of the assistant.

Consideration #1:

Clients do not have to be the ones to mark their answers

- If your client cannot mark their own answers, can they...
 - Tell you the answer they want marked?
 - Indicate through any motor movement as you verbally / visually 'scan' (read) the options for them
 - Indicate through eye gaze
 - Use an e-tran system
 - Use an eye point (e.g. point up with your eyes) when you verbally / visually 'scan' (read) the option they want (eye blinks less reliable)



Consideration #2:

If the client has difficulty understanding the items, can you change them?

- Assistance that is ok if it does not change the meaning of the item:
 - Read items aloud to client to help with comprehension (read aloud as they read to themselves)
 - Repeat the questions and choices – sometimes repetition helps
 - Rephrase to simplify the question, explain, or provide an example
 - Can you convert the item to a yes/no format if the client can answer
 - Use a picture or illustration (some risk that pictures alter the meaning)
 - Verify response

(Tucker et al., 2012)

Consideration #3:

If the questionnaire page is difficult to process visually, can you simplify it without changing the meaning?

- Reformat the visual presentation of the PROM:
 - One item per page (save this for future use)
 - Use a blank paper to cover up items other than the one being answered
 - Get creative if other ideas needed

Communicative Participation Item Bank (CPIB): Short Form

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**There is NO requirement that
this questionnaire be laid out in
this grid format!**

Research underway on response options to provide visual support

Modified Perceived Stress Scale (mPSS) for Aphasia

(Hunting Pompon et al., 2018)

Original Response Format	Never	Almost Never	Sometimes	Fairly Often	Very Often
	<u>0</u>	<u>1</u>	<u>2</u>	<u>3</u>	<u>4</u>
	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Modified Response Format	Never	Rarely	Sometimes	Often	Very Often																																																																																																																																																																																																																	
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Research underway on response options to provide visual support

Modified UW Resilience Scale

(Pompon, 2024)

**Original
Response
Format**

Not at
all

A little
bit

Somewhat

Quite
a bit

Very
much

**Modified
Response
Format**

Not at
all

A little
bit

Somewhat

Quite
a bit

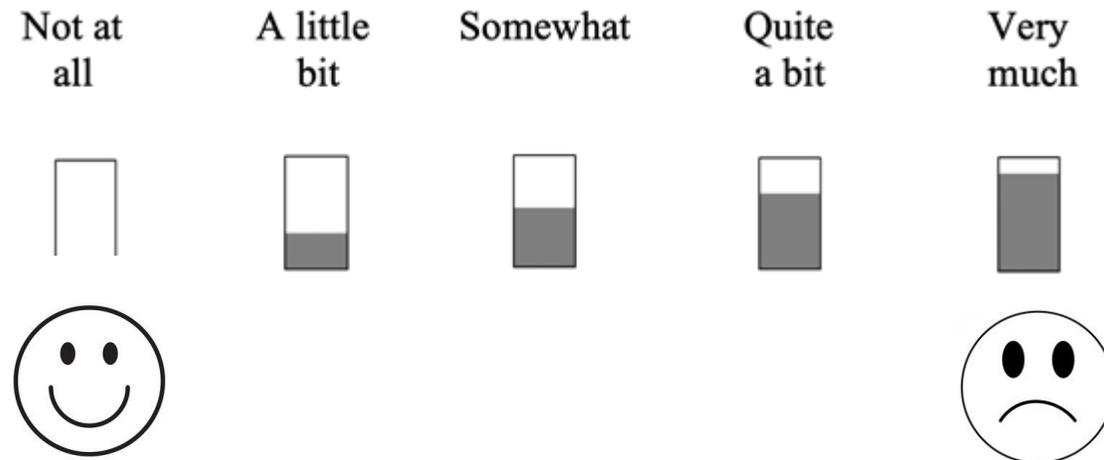
Very
much



Example of alternate layout for CPIB:

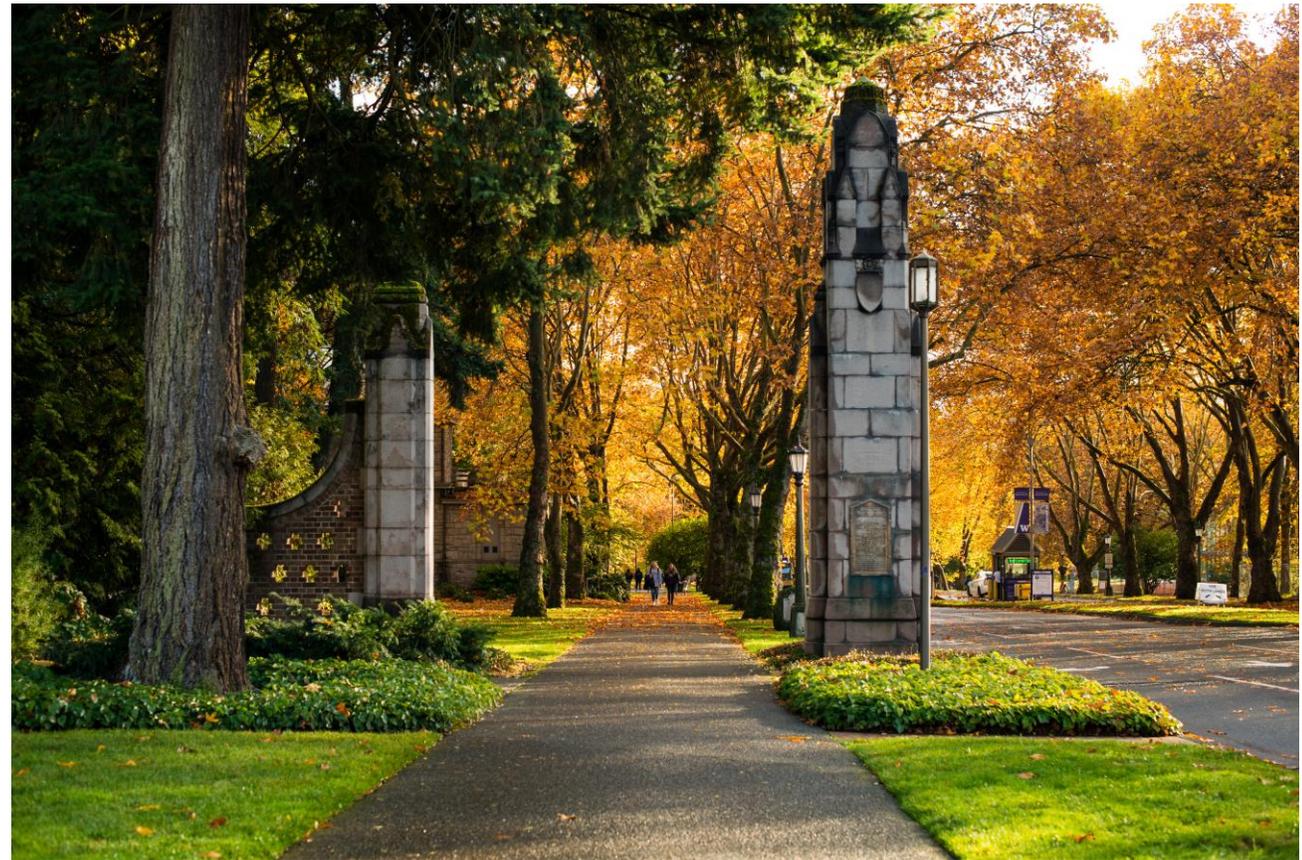
Does your condition interfere with...

Talking with people you know?



TOPIC 5

Elevate the role of PROMs in
your clinical care



Don't leave your PROM behind...when you write goals

- PROM data can be the outcomes targeted for goals!

Your client's
intervention program

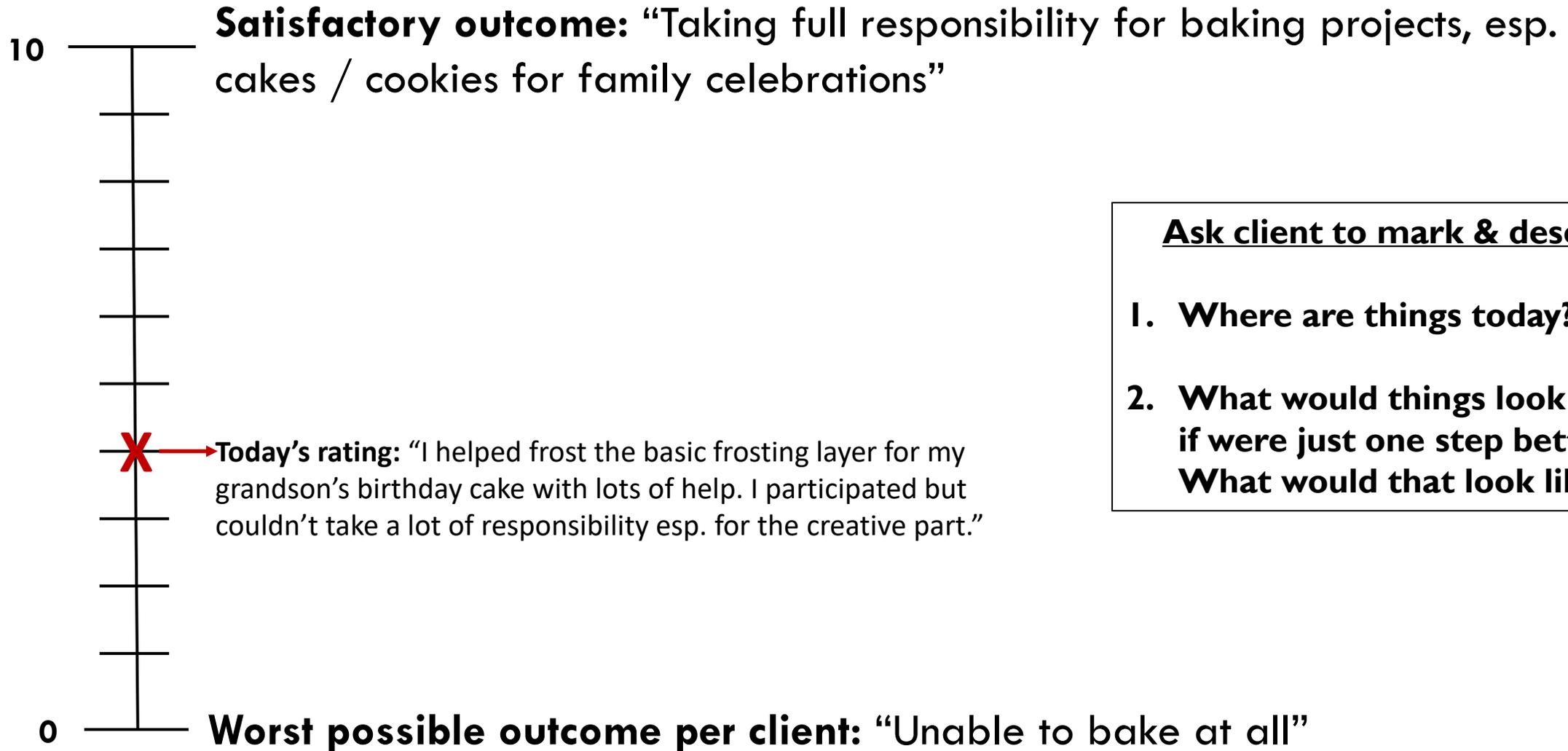
PROM data



shutterstock.com · 716967601

REVISITING an Example: Client working on kitchen function / safety

(Fox, 2012)



Ask client to mark & describe:

1. **Where are things today?**
2. **What would things look like if we were just one step better?
What would that look like?**

Let's turn our PROM into a short-term goal:

On a self-anchored rating scale of 0 – 10 (0 = not at all satisfied; 10 = completely satisfied), the client will rate their satisfaction with their participation in their valued life situation of baking with/for family as a 8 by the end of 10 weeks.

Specific? Measurable? Achievable? Relevant? Timely?

Another example of turning our PROM into a short-term goal:



On a 100-mm visual analog scale of 0 – 100 (0 = not at all confident; 100 = completely confident), the client will rate their confidence with their communication in their valued life situation of running team meetings at work as a 80 by the end of 10 weeks.

...AND A COUPLE IDEAS FOR KIDS



Ways to assess communicative participation in specific situations

(Proxy report for children younger than elementary school-aged)

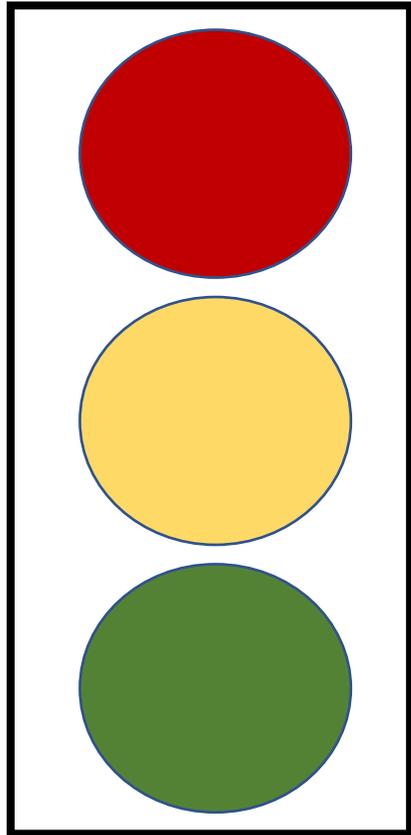
“How engaged does your child seem to be communicating with peers at play group?”

Likert Scale



Transition to child self-report of their own feelings as they move through elementary school.

Possible self-rating scale for children (early elementary)



I DON'T like talking in _____ (situation) _____

I REALLY like talking in _____ (situation) _____

Questions / Discussion / Suggestions

Thank you for
spending this time
with me today!

Carolyn Baylor: cbaylor@uw.edu

Lab email: speaclab@uw.edu

Research interest inquiry: <https://redcap.link/speaclabresearch>

Three Studies: Open Anywhere in the US!

1. Survey for people with any of the following (and family):
 - Parkinson's disease
 - Mild Cognitive Impairment / early Dementia
 - Head and Neck Cancer
2. Study for people with Stroke and communication difficulties (aphasia and/or motor speech)
3. SLPs working with people with stroke and use the CPIB



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QUESTIONS?



Scoring the CPIB: Using Item Response Theory (IRT)

Item Banks

- What is an item bank?
 - The CPIB has 46 items in its bank...
 - But you don't need to administer them all
- What is the advantage of item banks?
 - Measurement precision
 - Measurement efficiency





Physical Ability



Can you run 10 miles?

Can you run 1 mile?

Can you walk 1 mile?

Can you walk a block?

Can you walk from room to room in your house?

Can you get out of bed by yourself?



Adaptive Assessment Example

While this difficulty hierarchy is probably logical, the statistical calibration performed during instrument development creates the actual hierarchy based on statistical item parameters.



Communicative Participation



**Sample from
Communicative Participation
Item Bank (CPIB)**

Getting your turn in a fast-moving conversation

Having a conversation while riding in a car

Giving someone detailed information

Communicating in a small group of people

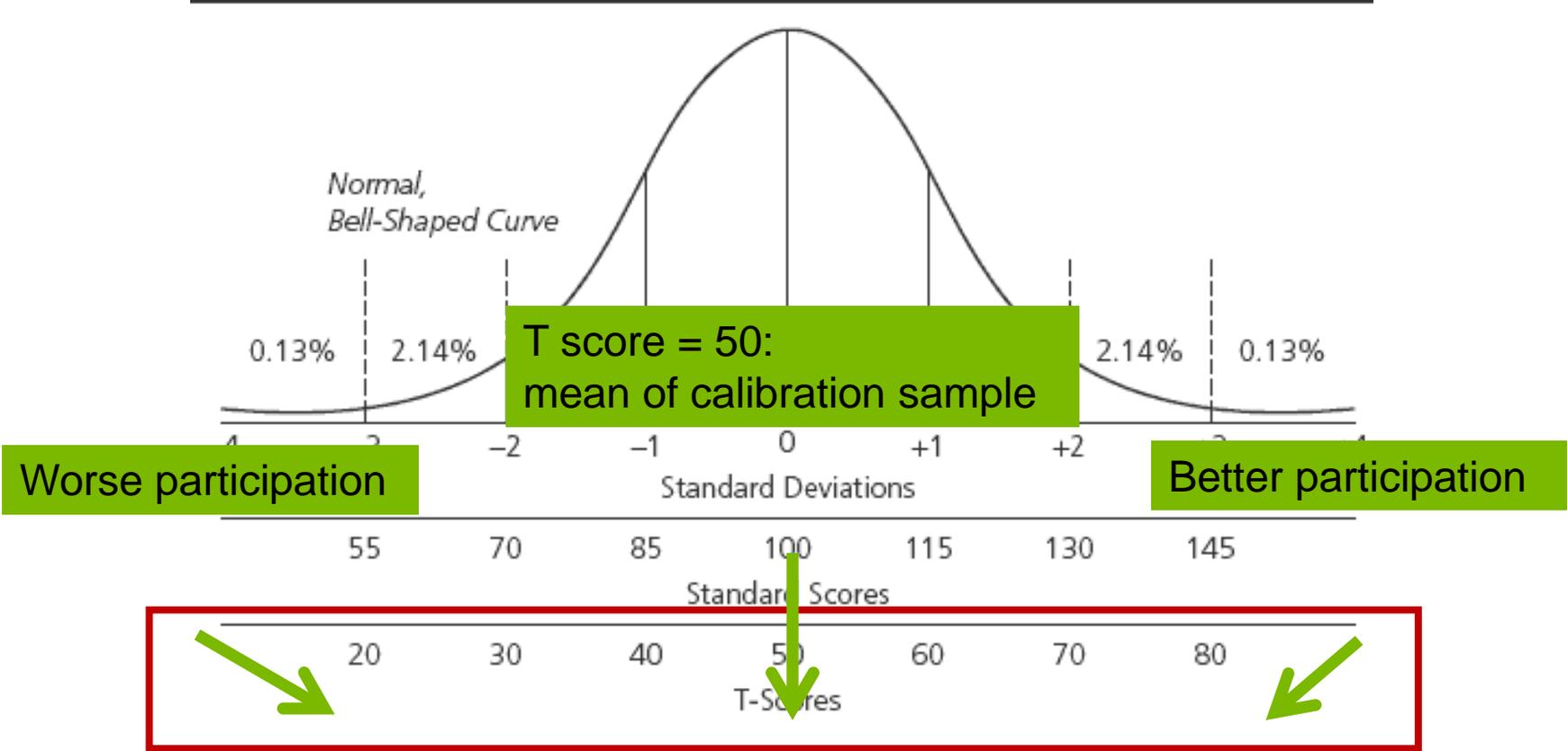
Talking with people you know

Communicating at home



What is the “ruler” in IRT-based instruments?

FIGURE 9.2 Standard Normal Distribution and T-Scores



www.education.com



CPIB Website for paper download or Computerized Adaptive Testing:

<http://www.depts.washington.edu/cpib/>

CPIB Resource
ePortfolio

Home

ONLINE CPIB LINK

CPIB General Short Form
(Paper Version) and
Scoring Table

References for CPIB
Development

CPIB for People with
Hearing Loss

Information about
Computer Adaptive
Testing and Item
Response Theory

CAT Administration for the Communicative Participation Item Bank (CPIB): A Resource ePortfolio for Speech- Language Pathologists

This site provides access to the Computerized Adaptive Testing (CAT) administration for the Communicative Participation Item Bank (CPIB), access to the paper short form, and additional information about the CPIB. For a quick start, follow these instructions for the CAT administration and follow the link below for the CAT website:

- When you enter the CAT website, use the "default" settings.
- When you have received the message that the administration is complete, click on the "generate report" button to get the score. When the score page comes up at the end, please write down or record your client's score elsewhere. For