

Measuring Participation Outcomes in Individuals with Communication Disorders

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- NIH planning grant “Developing a Scale of Communication Participation;” PI Yorkston
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Our Team

- **Psychometry**
 - **Dagmar Amtmann**
 - **Alyssa Bamer**
 - **Jiseon Kim**
- **Speech-Language Pathology**
 - **Tanya Eadie**
 - **Lena Hartelius**
 - **Megan McAuliffe**
 - **Robert Miller**
 - **Michael Burns**
- **OT**
 - **Brian Dudgeon**
 - **Jean Deitz**

Coulter Lecture: Baum, 2011

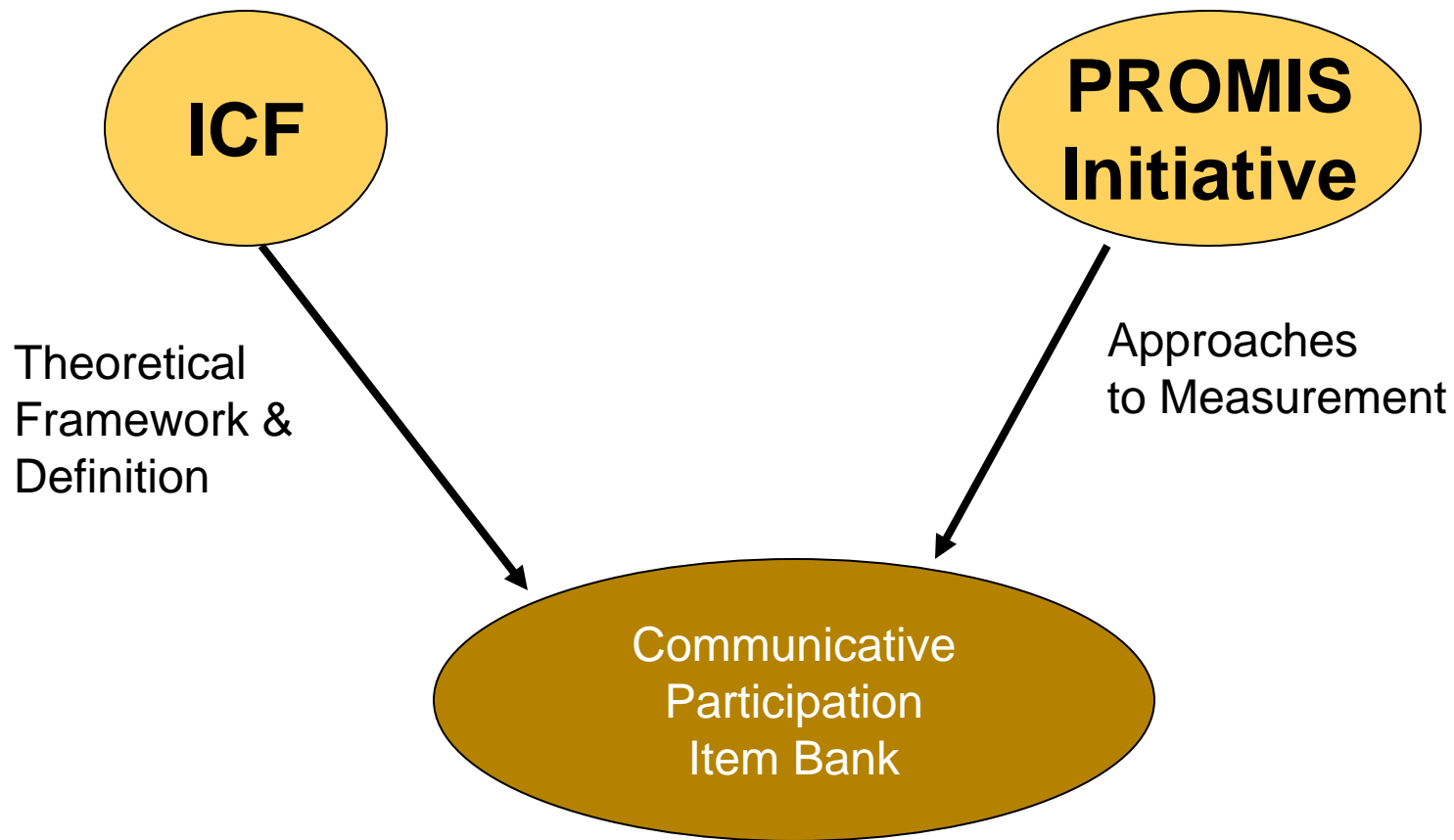
- I still meet rehabilitation professionals who believe that people can put their lives on hold until they have recovered.
- A focus on participation challenges us to find ways for people to do the things that they need to do while they recover.
- Participation itself, may foster this recovery because it brings focus to motivation, competency, and self-efficacy, all of which are psychologic concepts that are known to support growth and thus plasticity.

Enhancing Social Function

“ If intervention does not address the social aspects of communication, it may succeed in the narrow setting of the therapy room, but fail to bring about important changes in the lives of people with motor speech disorders.”

Yorkston, Beukelman,
Strand & Hakel, 2010

Origins of the Project



NIH PROMIS

- Patient Reported Outcomes Measurement Information System
- Started in 2004
- Mission: use measurement science to create a state-of-the-art assessment system for self-reported health, e.g. fatigue, pain interference, self-efficacy
- Website: NIHpromis.org

ICF Framework

Health Condition

Impairment

Activity Limitation

Participation Restriction

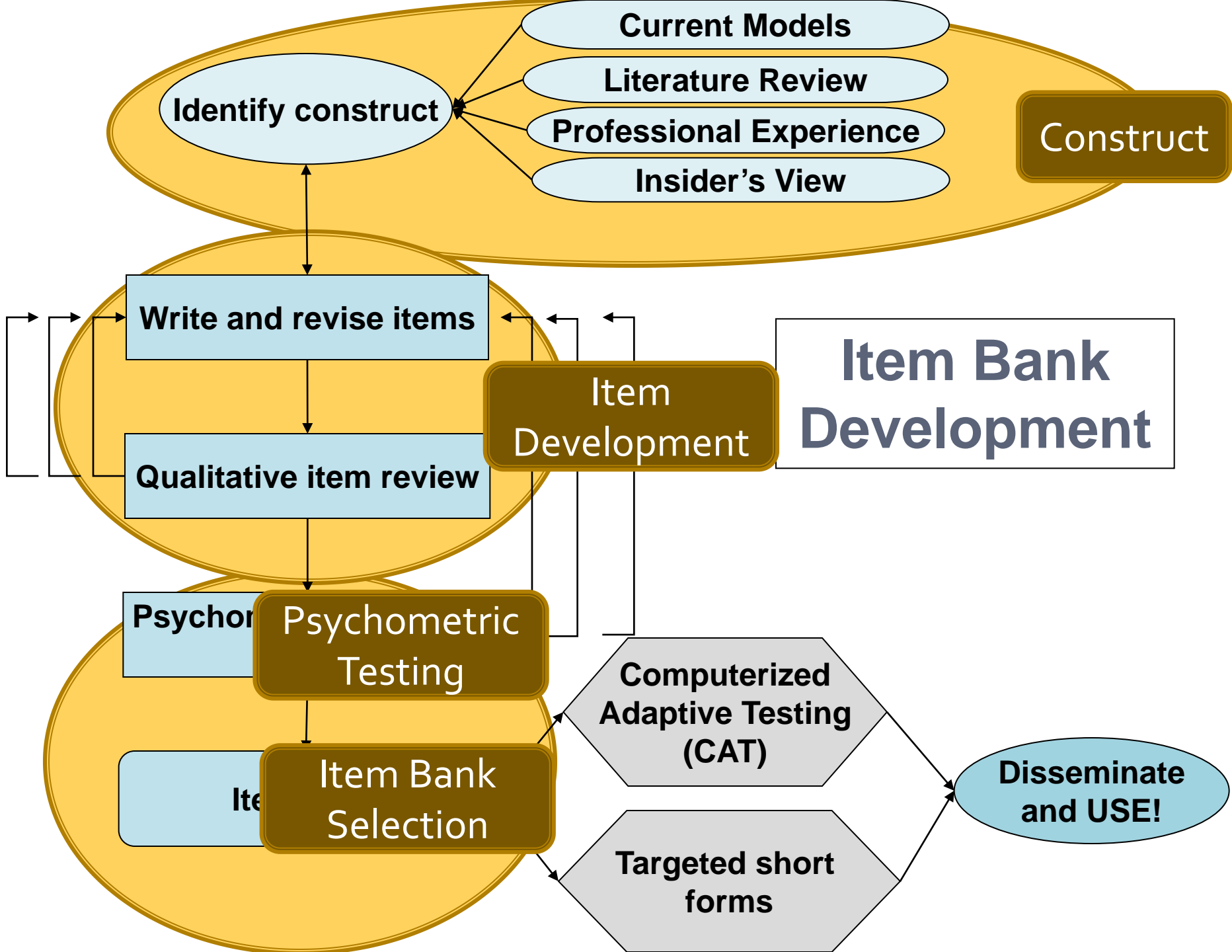
e.g. respiration for speech

Changes in speech intelligibility

Restrictions in involvement in life situations

Environmental Factors

Personal Factors



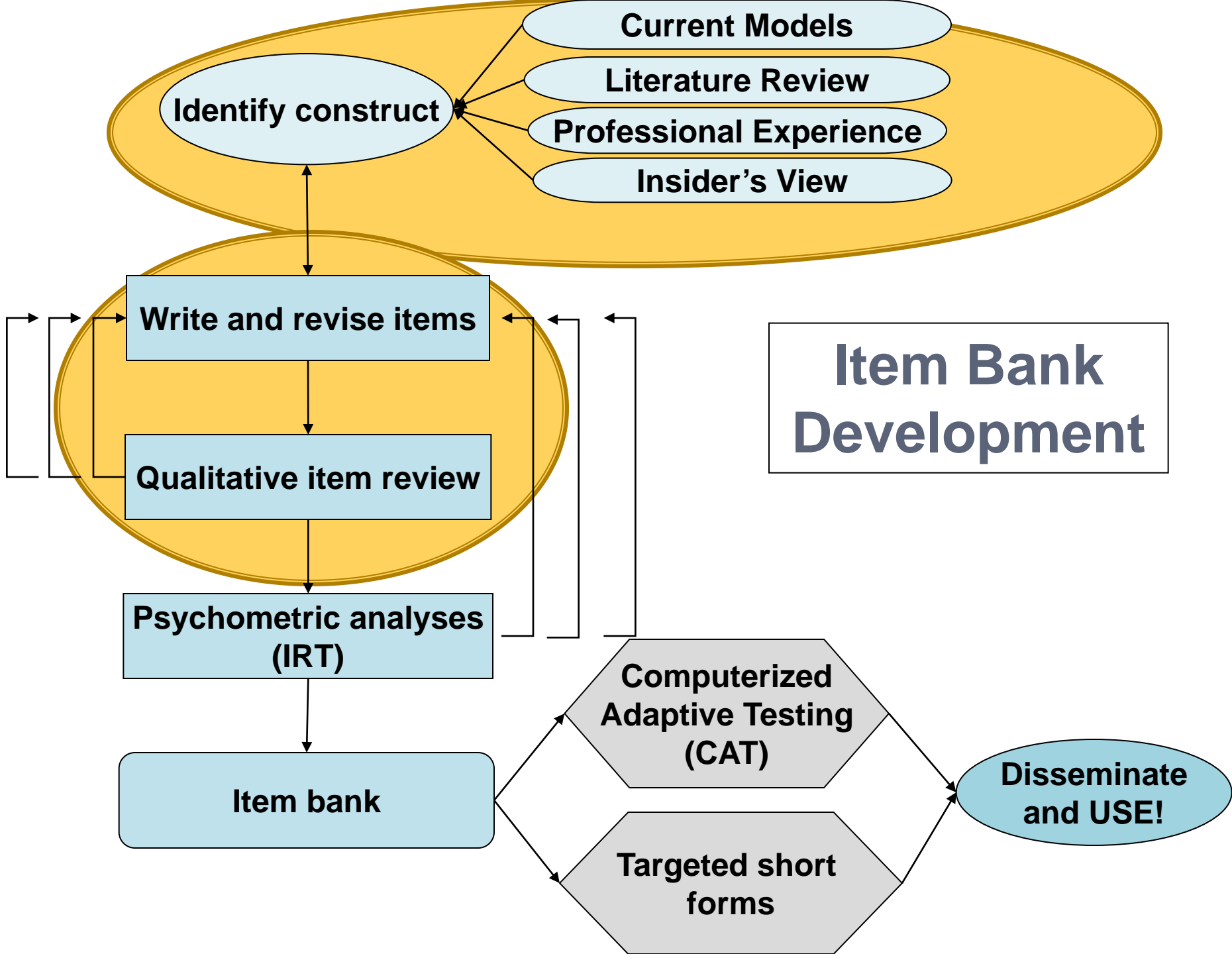
Communicative participation:

Involvement in **life situations**
where knowledge, information,
ideas or feelings are **exchanged.**

Interaction of Person, Task & Environment

- What the person can do
- What the person wants to do
- What the person has the opportunity to do
- What the person is not prevented from doing by the environment.

- Reframing the question to move from ability to involvement (Mallinson and Hammel, 2010)
- Choice and control may be more important than performance (Mallinson and Hammel, 2010)
- Success as defined by the individual – not some 'normative standard as to what participation should be.' (Brown et al., 2004; Law, 2002)



Construct **Item
Development**

Psychometric
Testing

Item
Bank

- Existing scales
- Qualitative interviews of people with disorders
- Focus group of rehab professionals
- For coverage, conceptual models of roles & responsibilities
- Items universal to community dwelling adults

Construct	Item Development	Psychometric Testing	Item Bank
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Burden of Stroke Scale (BOSS)	Stroke	Difficulty communicating	7/15
ASHA Quality of Communication Life (QCL)	General communication disorders	Difficulty communicating	8/19
Voice Handicap Index (VHI)	Voice disorders	Frequency of interference	7/30
Voice-Related Quality of Life (V-RQOL)	Voice disorders	Degree of interference	3/10
Voice Symptom Scale (VoiSS)	Voice disorders	Frequency of interference	4/30
Voice Activity and Participation Profile (VAPP)	Voice disorders	Frequency and degree of interference	5/28

Candidate Items Characteristics

- Low level of NA
- Represent a single factor
- A range of difficulty
- Ask about a single issue
- Are unambiguous
- Fit the mathematical model

Decisions

- Appropriate for community-dwelling adults
- Variety of life domains (home, work, leisure, community, personal relationships...)
- Range of communication disorders
- Focus on speech communication
- Ask about overall satisfaction for a global rating of participation (then the clinician's task is to dig deeper in the clinical interview)

Examples of candidate items:

- ...having a casual conversation with someone you do not know well
- ...communicating in situations where there is a small group of people
- ...talking with people you live with about things that need to get done around the house
- ...making a phone call to schedule a personal appointment (dentist, haircut)

Cognitive Interviews: A qualitative approach to evaluating sources of response error in survey questionnaires. What cognitive processes are used to answer questions?

1. What does the question mean to the respondent?
2. How well does the respondent recall information to answer the question?
3. How does the respondent choose from the response options?

(Willis, 2005)

Interviews

- 13 Spasmodic dysphonia
- 12 Stroke
- 7 Parkinson's disease
- 7 Multiple sclerosis
- 3 Laryngectomy
- 1 ALS
- 1 Stuttering

Baylor et al, 2011

From Cognitive Interview

- Item: Does your condition interfere with using the telephone?
- Problem: Not enough context
- Modification: Add multiple items specifying communication partner, purpose, & so on.

- Item: Does your condition interfere with using humor in a conversation?
- Problem: Double-barreled items
- Modification: Split into two items:
 1. Telling a funny story or joke
 2. Making a witty or funny comment

Problem: “Offensive” or unappealing wording

Items: “Yelling to someone outside”

“Jumping into a conversation”

Modification:

“Calling out to get someone’s attention”

“Getting a turn in a fast-moving conversation”

Selecting a Response

- What are you doing? (Diversity)
- How often? (Frequency)
- How much? (Intensity)
- With whom? (Social network)
- How difficult? (Performance ability)
- What assistance? (AT or people)

See King et al, 2004

Global Satisfaction

- **Comfort**
 - Ease
 - Confidence
- **Success of outcome**
 - Function is achieved
 - A connection is made
- **Personal meaning**
 - Personal preferences
 - Comparison with the past
 - Thinking about one's own communication

Yorkston et al, 2007

Construct

**Item
Development**

Psychometric
Testing

Item
Bank

~~How satisfied are you using the telephone?~~

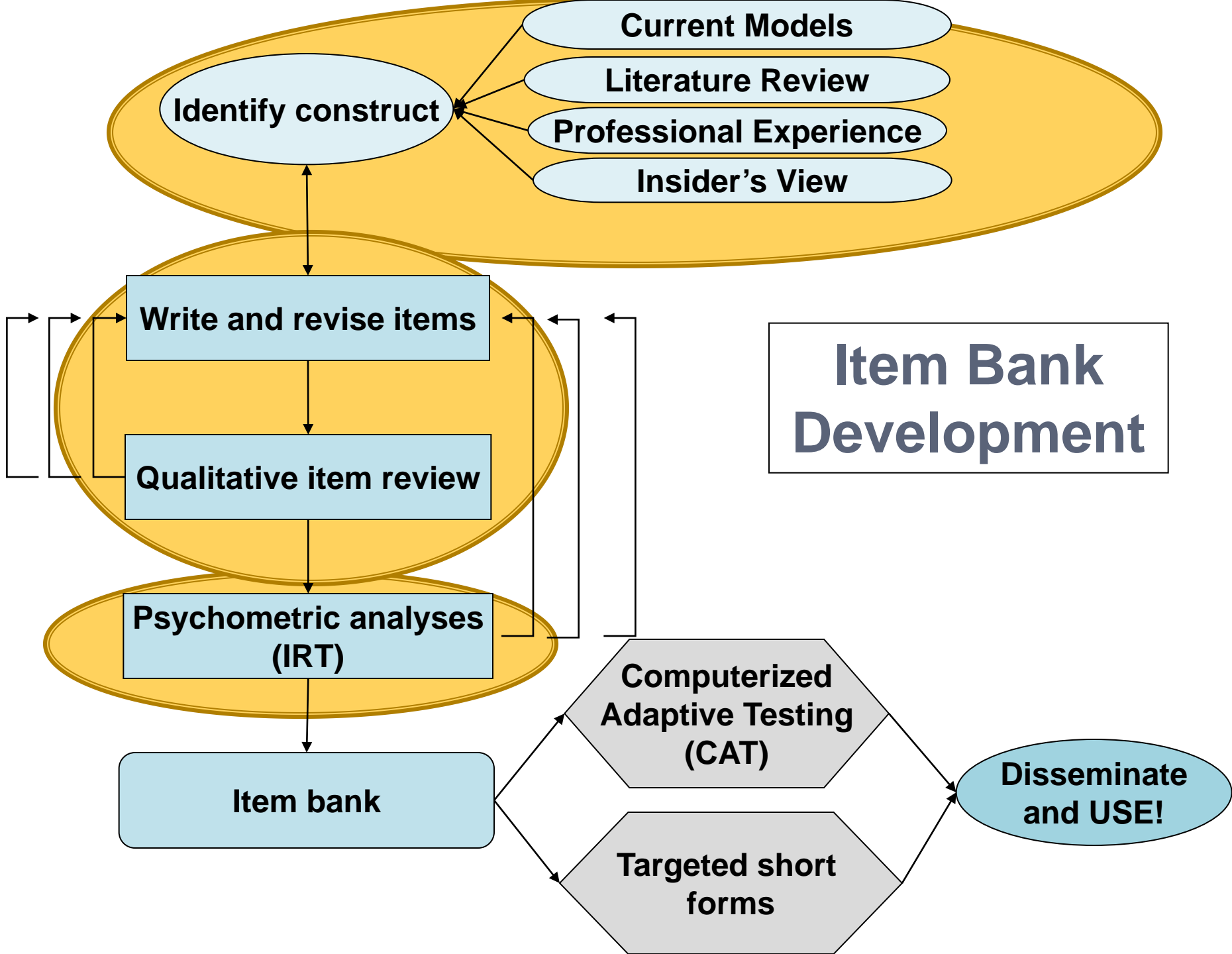
Does your condition interfere with using the telephone?

Sample early CPIB item:

Does your condition interfere with making a phone call for household business?

Score

- | | |
|--------------------------------------|---|
| <input type="checkbox"/> Not at all | 4 |
| <input type="checkbox"/> A little | 3 |
| <input type="checkbox"/> Quite a bit | 2 |
| <input type="checkbox"/> A lot | 1 |
| <input type="checkbox"/> Extremely | 0 |



Construct

Item
Development

**Psychometric
Testing**

Item
Bank

- Classical Test Theory (CTT)
 - How most of our instruments have been developed
 - Observed score = True Score + Error
- Item Response Theory (IRT)
 - “Modern measurement theory”
 - Person score derived from mathematical relationship between item characteristics and person response to the item

Item Response Theory

- Measures a Latent Trait
- Takes what it knows about:
 - Characteristics of the items
 - Way people answer those item
- Makes an estimate of a person's level of the trait being measured

Construct

Item
Development

**Psychometric
Testing**

Item
Bank

Advantages of a Logit Scale

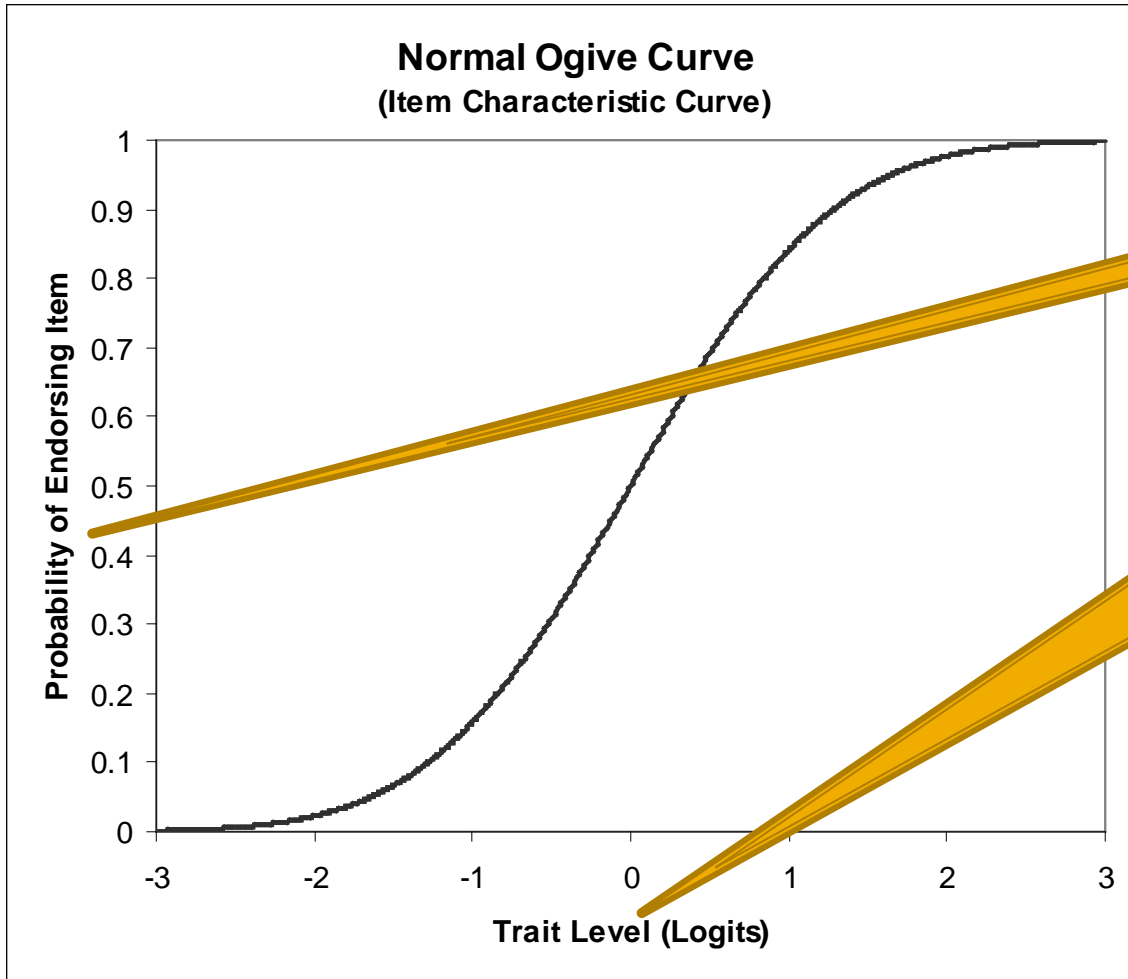
- Approximates equal intervals
- Allows mathematical operations
- Provides a common metric for equating across instruments
- Removed dependence on specific items or reference groups for interpretation

Construct

Item
Development

Psychometric Testing

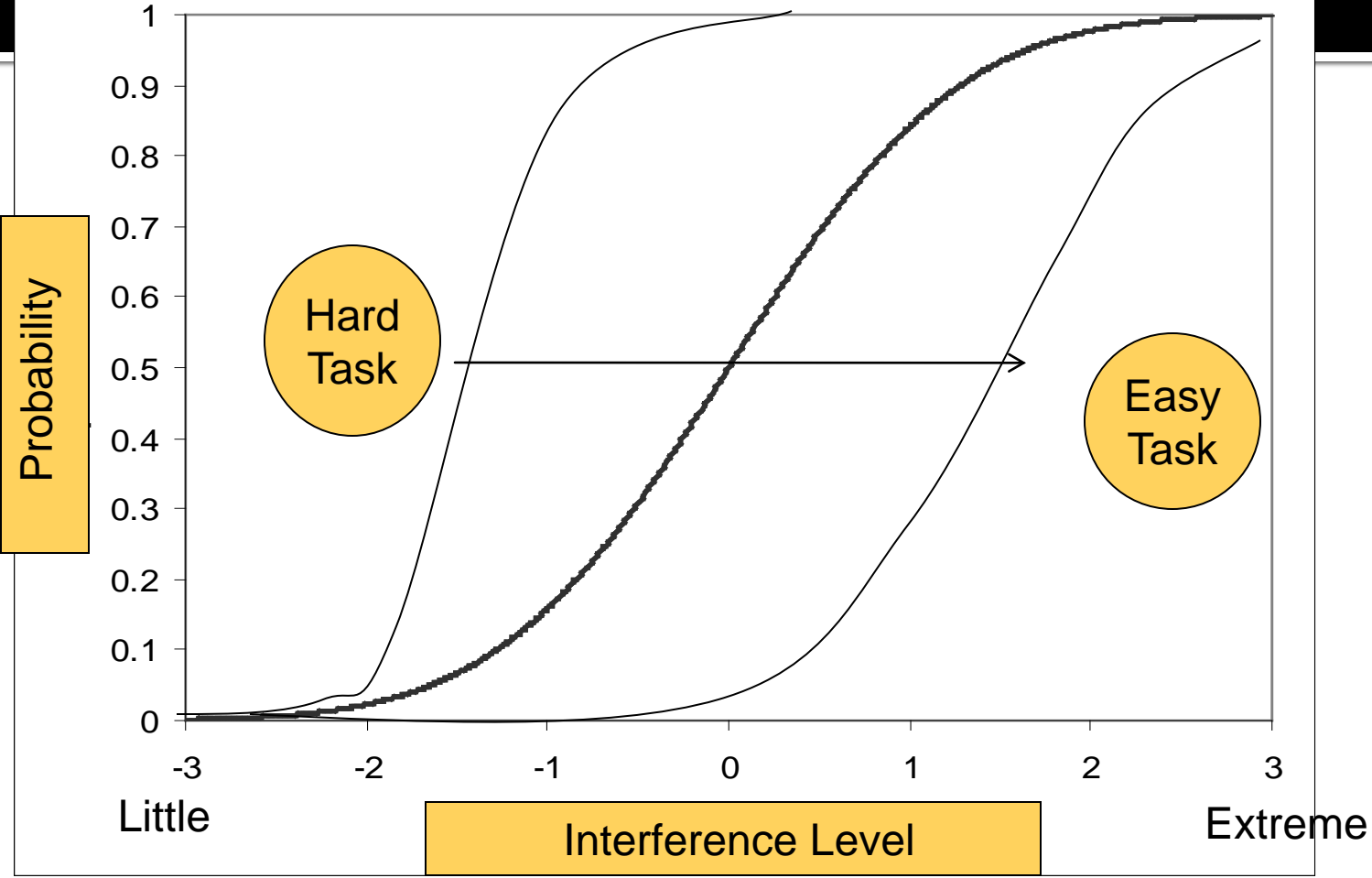
Item
Bank



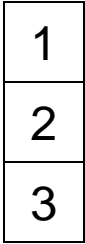
Probability of rating
high interference

Theta: Interference with
Comm. Participation

Normal Ogive Curve (Item Characteristic Curve)



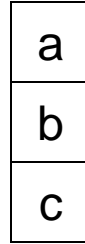
Personal



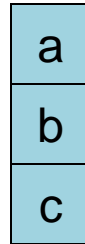
Household



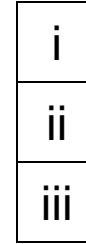
Work/Ed.



Leisure



Relationships



Community



-3

-2

-1

0

+1

+2

+3

Little
Interference

Trait Level

Extreme
Interference

Construct

Item
Development

**Psychometric
Testing**

Item
Bank

Original Response Categories

- Not at all
- A little
- Quite a bit
- A lot
- Extremely

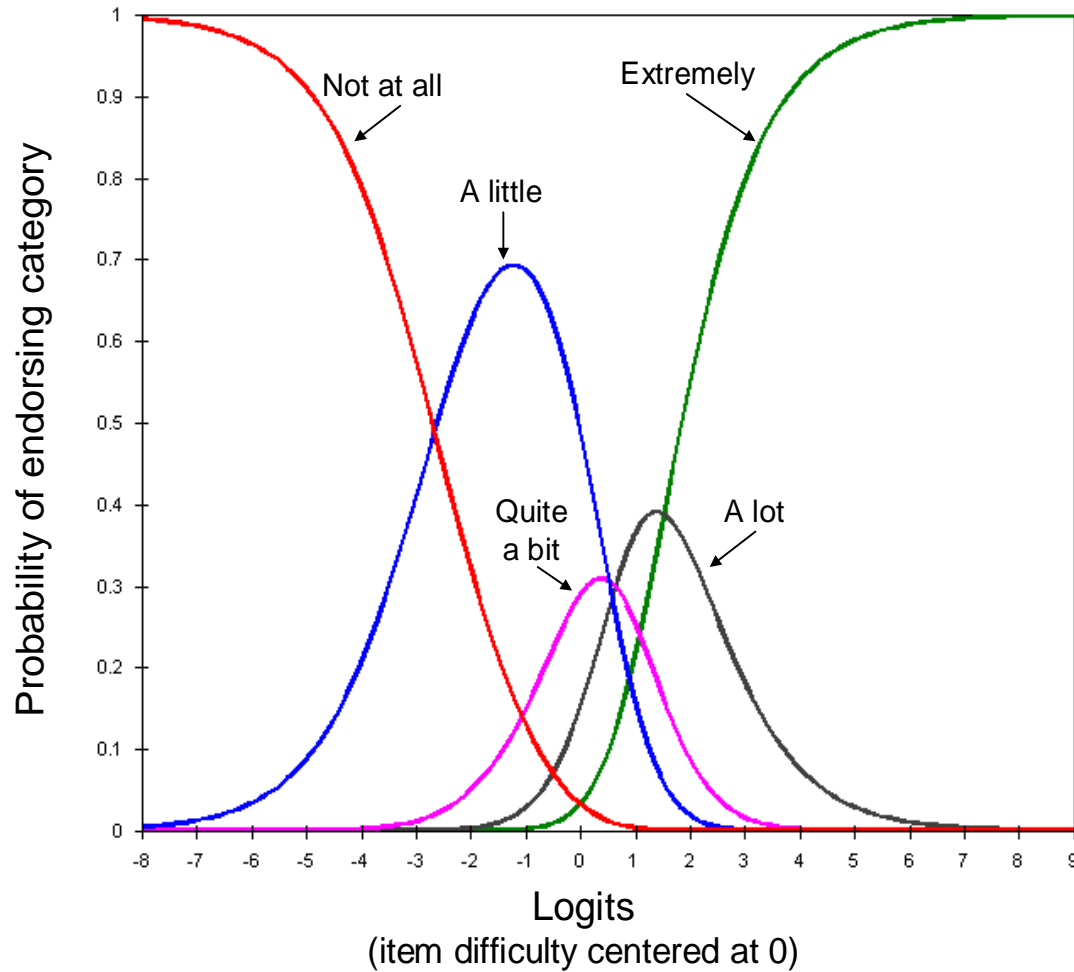
Construct

Item
Development

Psychometric Testing

Item
Bank

Original
Response
Category
Curves



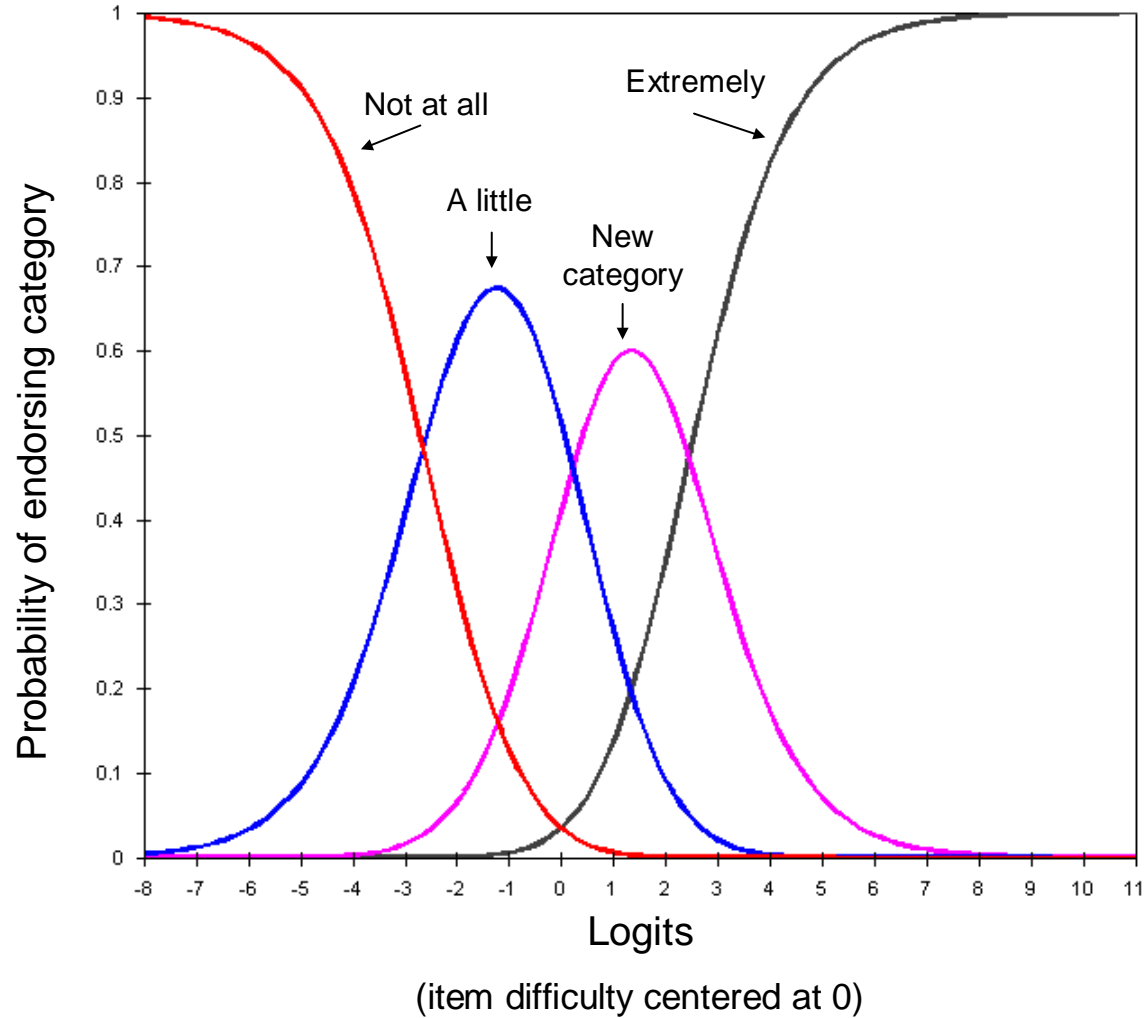
Construct

Item
Development

Psychometric Testing

Item
Bank

Revised
Response
Category
Curves



Construct

Item
Development

**Psychometric
Testing**

Item
Bank

Does your condition interfere with making a
phone call for household business?

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

Key IRT Assumptions

- Essential or sufficient unidimensionality
- Model Fit
- Local independence of items
 - Subsets of items are not correlated beyond the single construct that they measure
 - Additional evidence of no confounding variables

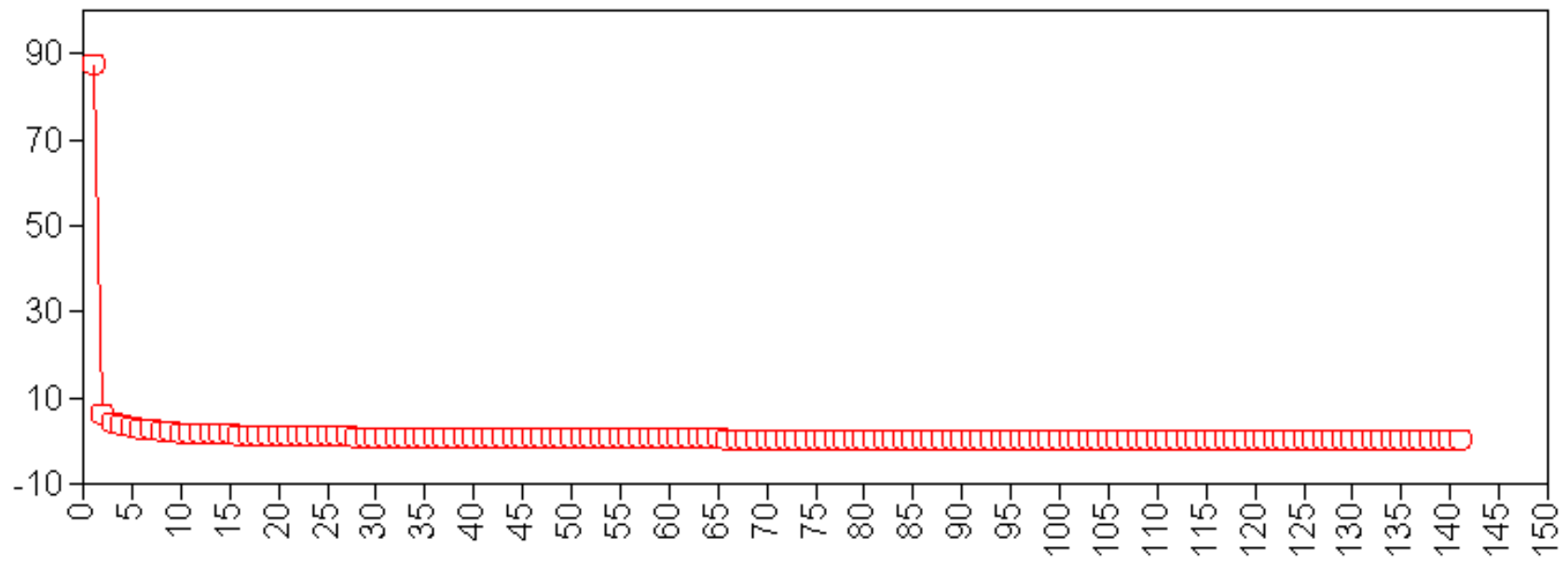
Construct

Item
Development

Psychometric
Testing

Item
Bank

Evidence of Sufficient Unidimensionality



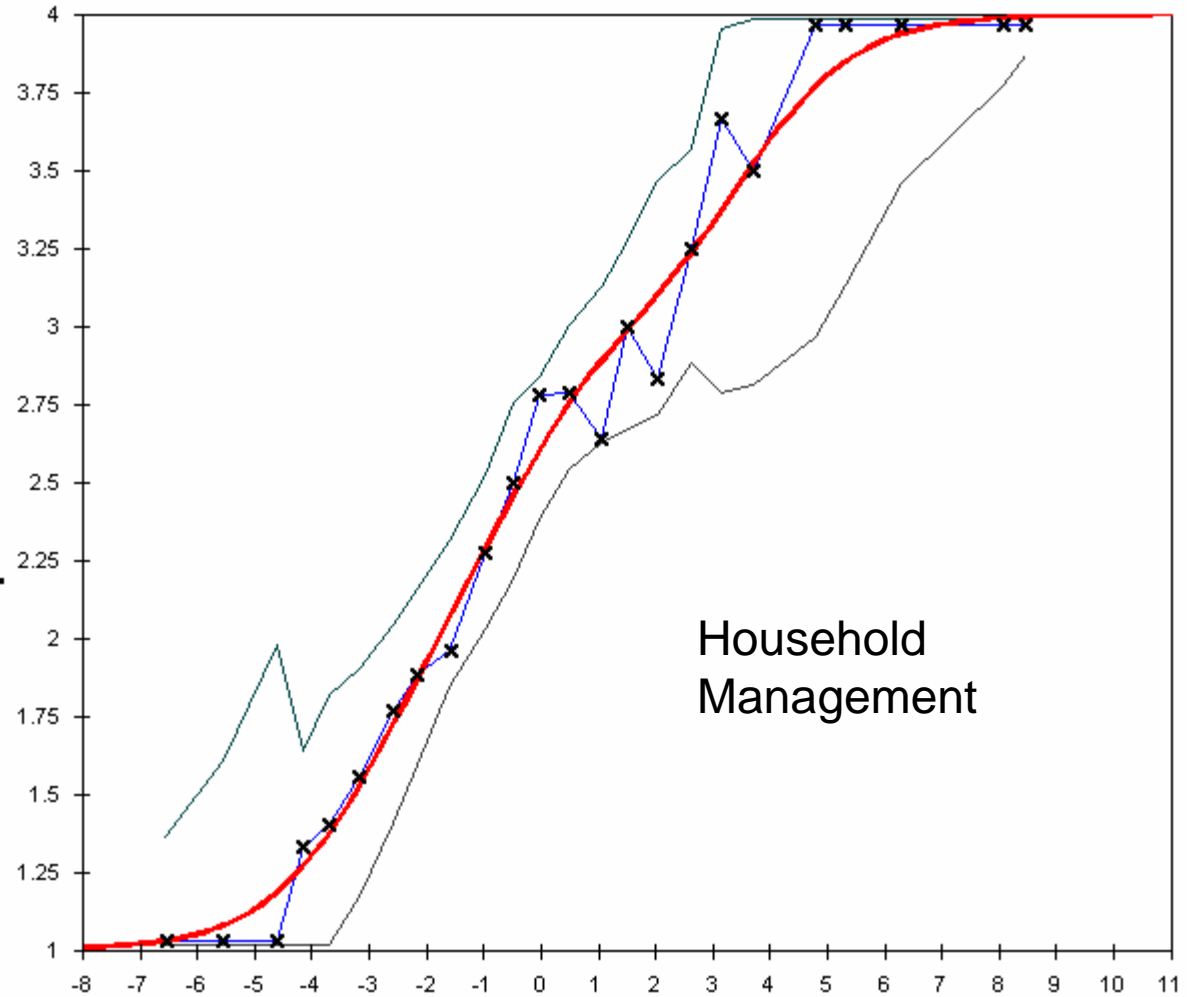
Construct

Item
Development

Psychometric Testing

Item
Bank

Item with
Good
Fit



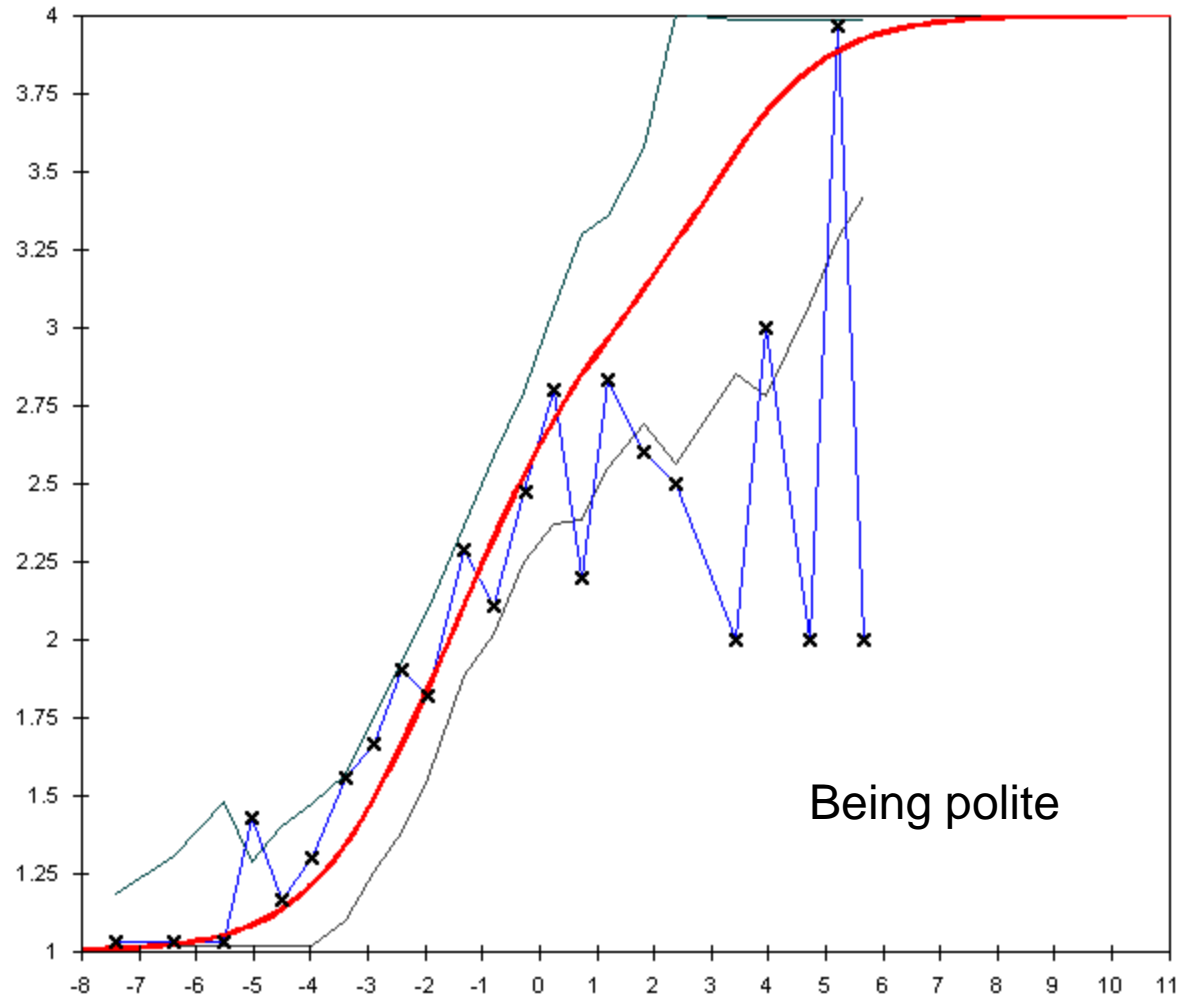
Construct

Item
Development

Psychometric
Testing

Item
Bank

Item with
Poor
Fit



Construct

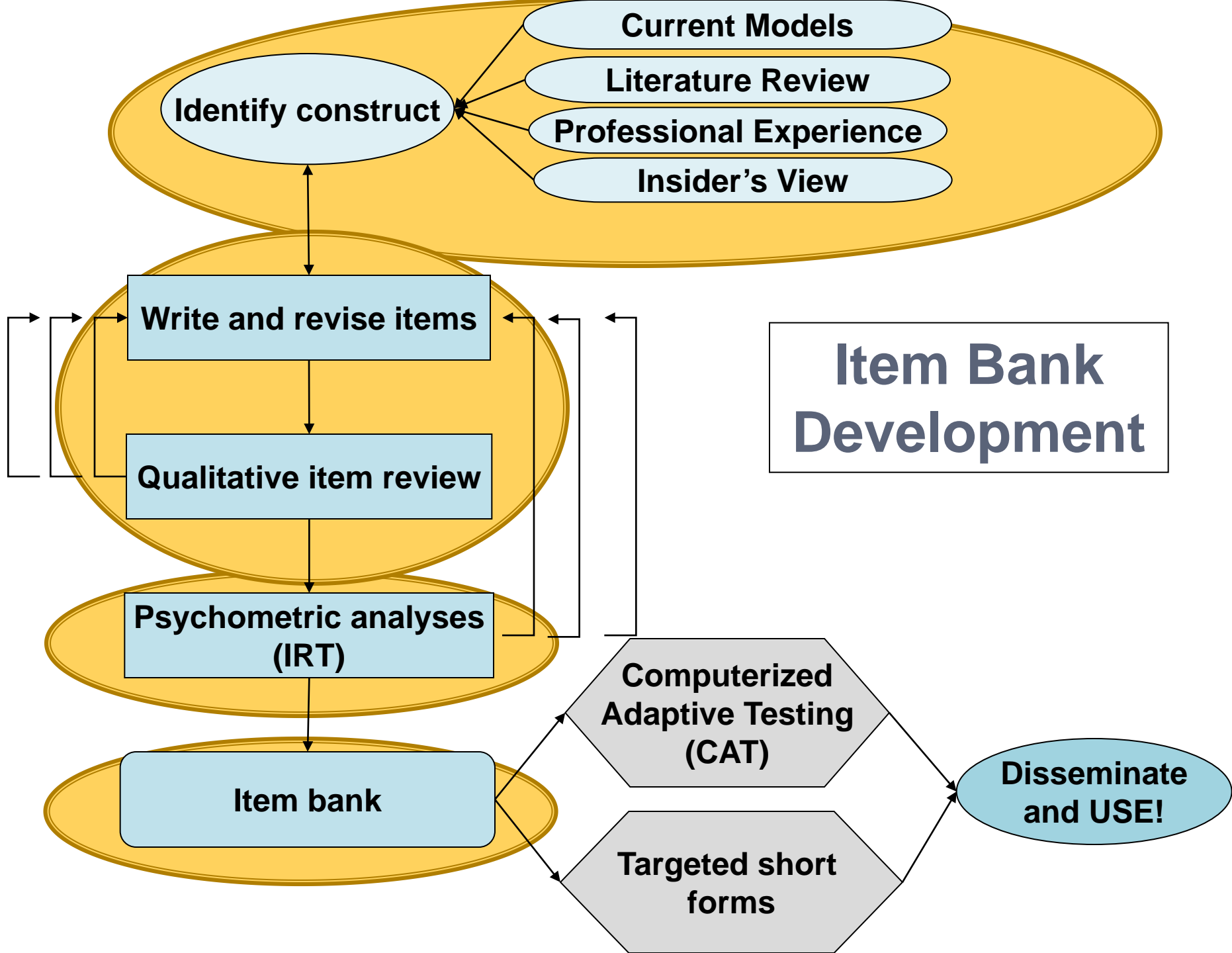
Item
Development

**Psychometric
Testing**

Item
Bank

Locally Dependent Group of Items:

- Calling out to someone far away to get their attention
- Saying something to get someone's attention
- Having conversation in noisy place
- Communicating with someone who is not paying attention to you
- Talking to someone who cannot see you
- Asking a familiar doctor or healthcare provider questions



From Candidate Items to Item Bank

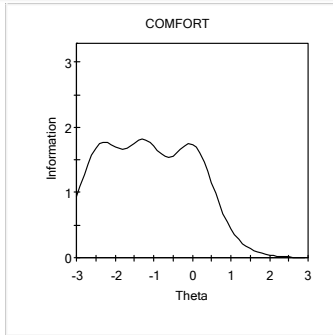
- Adequate measurement range
(Select items with appropriate information function)
- Minimize bias across populations
(Select items with minimal differential item function –DIF)

Construct

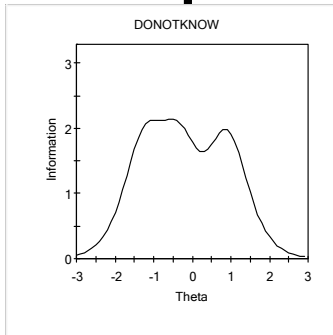
Item Development

Psychometric Testing

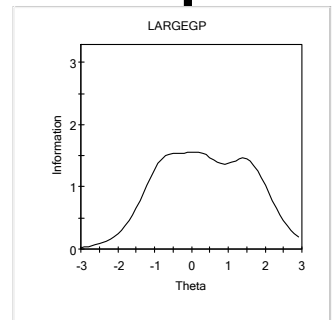
Item Bank



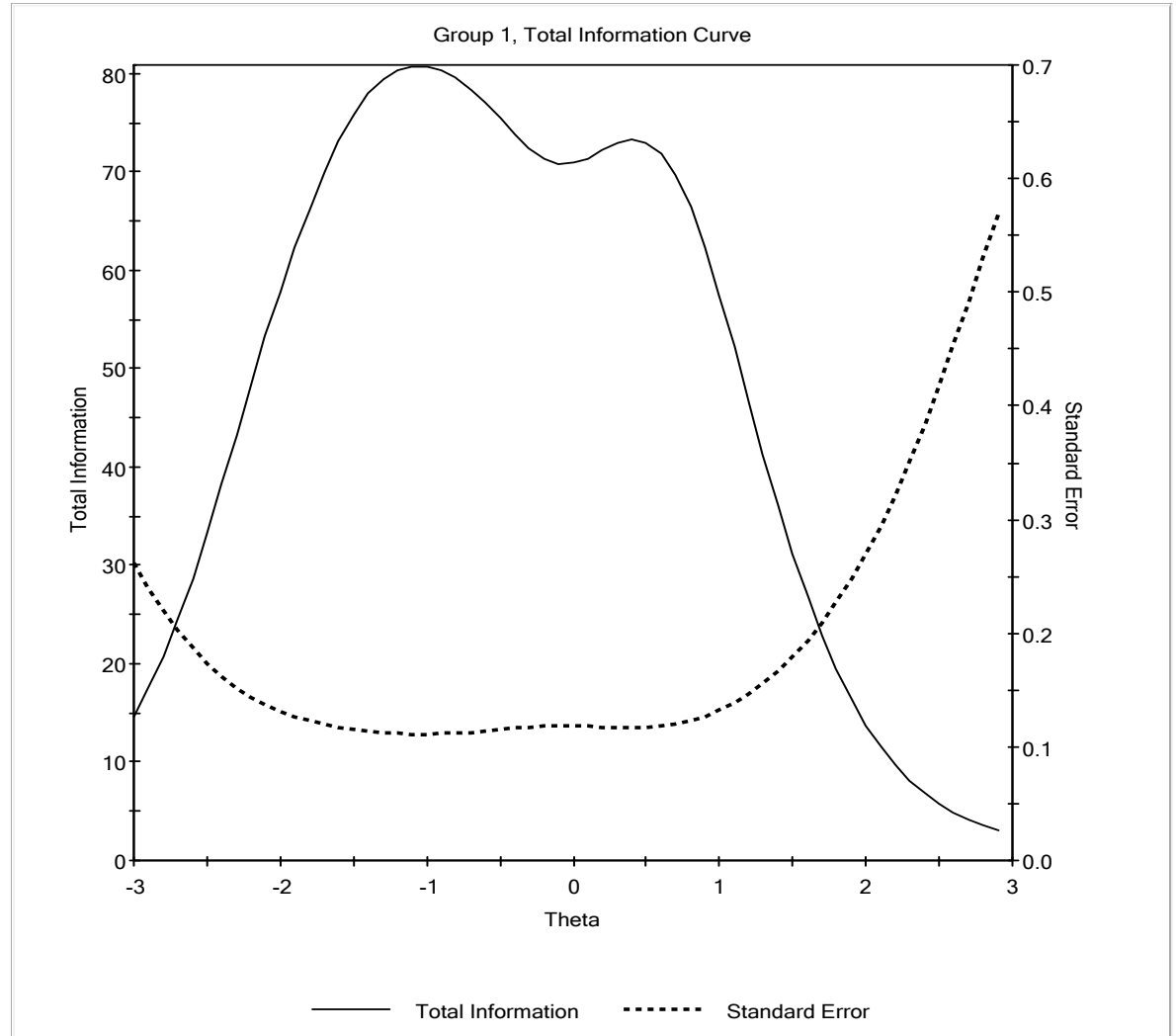
+



+



=



Construct

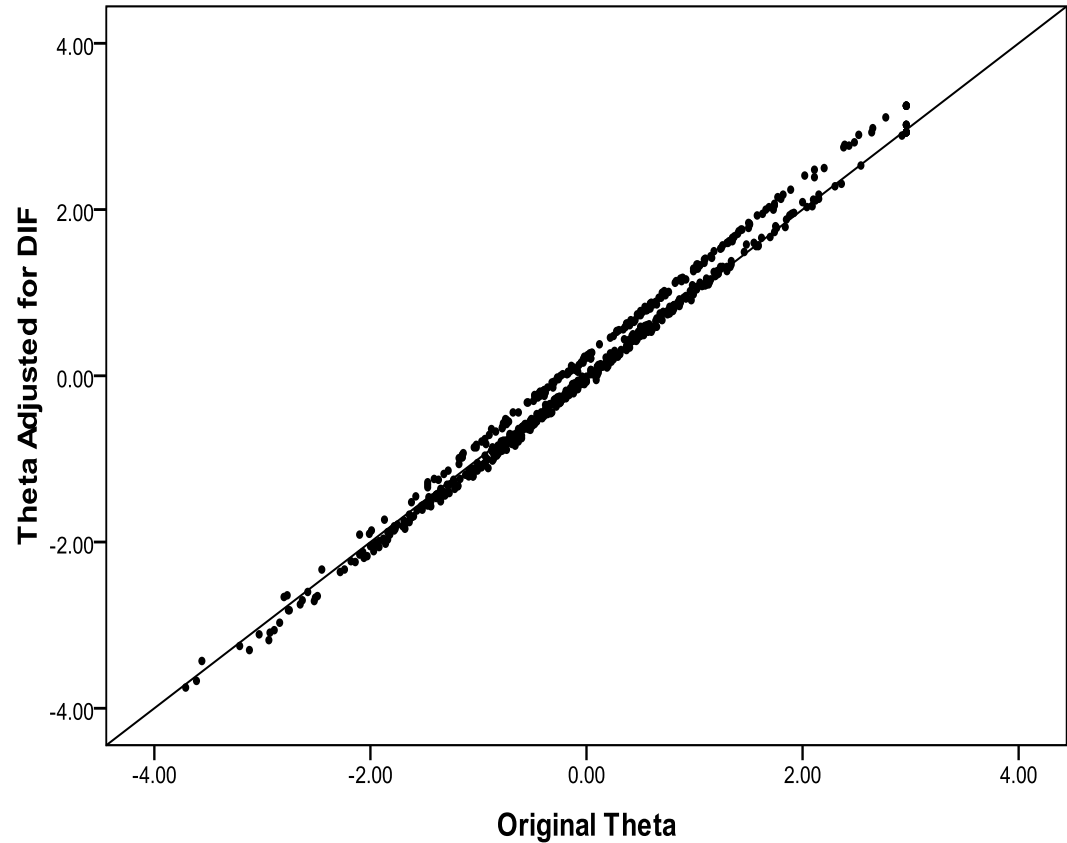
Item
Development

Psychometric
Testing

Item
Bank

Differential
Item
Function

Original vs Purified Theta - Beta Change .05



Construct

Item
Development

Psychometric
Testing

Item
Bank

Insuffient #'s

No
DIF

Populations	Men	Women	Total
MS	39	176	215
PD	119	99	218
HNCA	121	76	197
ALS	41	29	70
Total	320	380	700

Construct

Item
Development

Psychometric
Testing

Item
Bank

CPIB 10-Item General Short Form Scoring Table

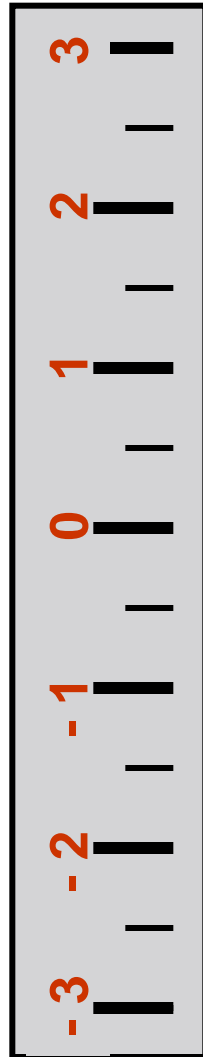
Scoring
Conversion
10-Item
General
Short Form

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			

Future Directions

- CAT scoring

Item Bank & Computer Adaptive Testing

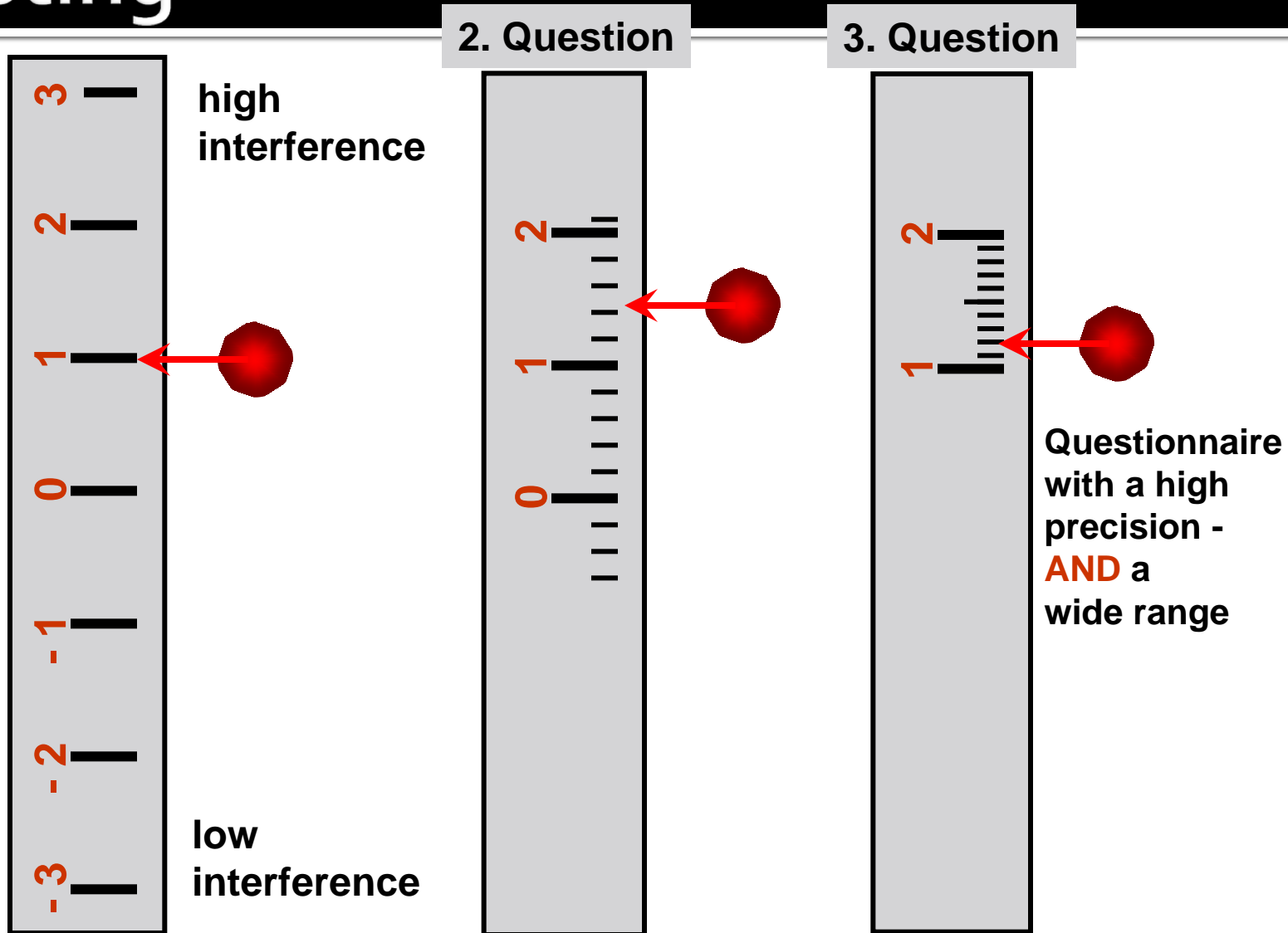


Questionnaire
with a wide
range -
but low precision



Questionnaire
with a high
precision -
but small range

Item Bank & Computer Adaptive Testing



Computerized Adaptive Testing (CAT)

More
difficult
situations

46 CPIB items

+3

Communicating in a large group of people

Giving someone detailed information

Talking with a clerk in a store about a problem with a bill or purchase

Making a phone call to get information

Having a long conversation with someone you know about a book, movie, etc.

Having a conversation while riding in a car

Sharing personal feelings with people close to you

Ordering a meal in a restaurant

Sharing your opinion with family and friends

Greeting someone you know at a social gathering

Answering a question from a doctor you know

Comforting a friend or family member

-3

Less
difficult
situations

Future Directions

- CAT scoring
- What things are associated with CPIB?

Regression Analysis

Model predicts 48.7% of variance
Baylor et al, 2010

Demographics

Age

Education

Gender

Duration of MS

Employment

Communicative Participation

Social Support MSPSS

Symptoms

Mobility EDSS

Depression
CESD

Fatigue MFIS

Pain

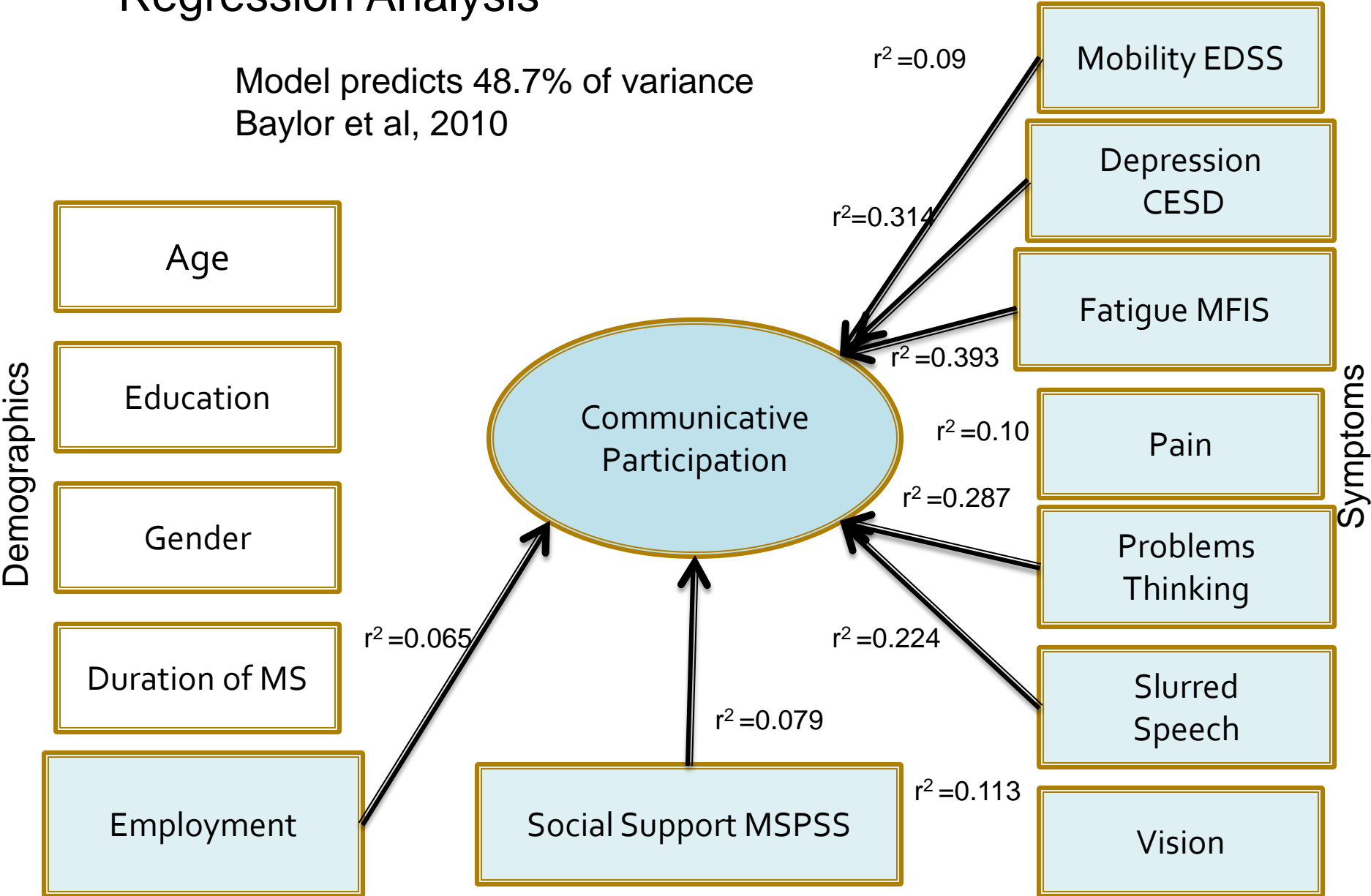
Problems
Thinking

Slurred
Speech

Vision

Regression Analysis

Model predicts 48.7% of variance
Baylor et al, 2010



Future Directions

- CAT scoring
- What things are associated with CPIB?
- More populations, e.g. aphasia
- Cultural & Language translations
- Is it sensitive to change
- How much does it need to change to be meaningful?

Lessons Learned

- There's no better way is highlight your limited understanding of something than to try to measure it.
- Team research is need
 - People with communication disorder
 - Qualitative researchers
 - Quantitative researchers
- We are not finished yet

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