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Addressing Quality of Life in Aphasia

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Disclosures

- Relevant Financial Disclosures
 - The presenter is being compensated for this presentation.
- Relevant Non-Financial Disclosures
 - None

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As a result of this activity, you will be able to:

- 1) define quality of life
- 2) describe at least one measure of quality of life for aphasia
- 3) describe the use of the Goal Attainment Scaling in writing goals and selecting therapy that addresses quality of life in aphasia.

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Time-ordered agenda

- 00:00 – 00:05 Introduction and Welcome
- 00:05 – 00:20 Quality of Life Measures in Aphasia
- 00:20 – 00:35 Formulating Goals that Address Quality of Life
- 00:35 – 00:50 Case Examples
- 00:50 – 00:55 Summary and Overview
- 00:55 – 01:00 Questions and Discussion

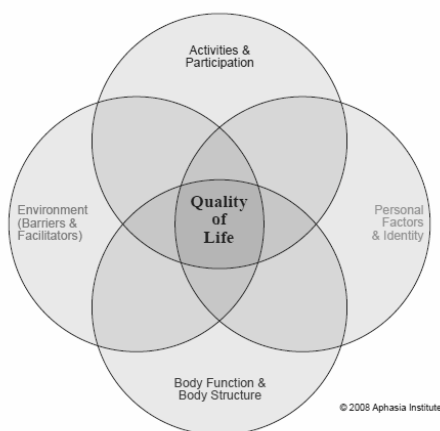
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“The overall objective of speech-language pathology services is to optimize individuals' abilities to communicate and to swallow, thereby ***improving quality of life.***” [italics mine]

Scope of Practice in Speech-Language Pathology, ASHA.
<http://www.asha.org/policy/SP2016-00343/>

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Framework for Outcome Measurement (FROM)



<http://www.asha.org/PRPSpecificTopic.aspx?folderid=8589934663§ion=Treatment>

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Limited relationships between activity measures and QOL

(Ross & Wertz, 2002)

TABLE 4
Relationships between communication activity limitation and quality of life measures

Measures	Relationship within non-brain-injured group	Relationship within aphasic group	Difference in strength of relationships between groups** (difference between Fisher zs =)
CADL-2/WHOQOL Total	$r_s = (.15)$	$r_s = .45$	(1.74)
CADL-2/WHOQOL QOL-GH	$r_s = (.33)$	$r_s = .05$	(1.08)
CADL-2/PWI	$r_s = (.39)$	$r_s = .24$	(1.80)
FACS CID/WHOQOL Total	$r = .41$	$r = .26$	0.47
FACS CID/WHOQOL QOL-GH	$r = .39$	$r = (.06)$	1.29
FACS CID/PWI	$r = (.15)$	$r = .15$	(0.83)
FACS CD/WHOQOL Total	$r = .37$	$r = .25$	0.36
FACS CD/WHOQOL QOL-GH	$r = .34$	$r = (.15)$	1.38
FACS CD/PWI	$r = (.13)$	$r = .25$	(1.06)

* $z_{\text{critical}} = 1.96$.

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Limited relationships between change on impairment and activity/participation measures (Ross & Wertz, 1999)

Table 5. Correlations between change in performance on outcome measures

Outcome measures	PICA OA	WAB AQ	CADL	WPM	CIU/min	%CIU	%ACMC
PICA OA	1.000						
WAB AQ	0.419	1.000					
CADL	0.242	0.447*	1.000				
WPM	0.071	0.225	0.156	1.000			
CIU/min	0.041	0.454*	0.168	0.731**	1.000		
%CIU	0.316	0.174	0.209	0.030	0.325	1.000	
%ACMC	0.160	0.476*	0.259	0.494*	0.668**	0.256	1.000

* Correlation is significant at the 0.05 level (two-tailed).

** Correlation is significant at the 0.01 level (two-tailed).

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	Improved QOL	Not Improved QOL
Improved Impairment		
Not improved impairment		

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	Improved QOL	Not Improved QOL
Improved Impairment	<i>Great News!</i>	
Not improved impairment		

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	Improved QOL	Not Improved QOL
Improved Impairment	<i>Great News!</i>	
Not improved impairment		<i>No response to therapy; OR wrong therapy</i>

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	Improved QOL	Not Improved QOL
Improved Impairment	<i>Great News!</i>	<i>Needs targeted life participation intervention</i>
Not improved impairment		<i>No response to therapy; OR wrong therapy</i>

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	Improved QOL	Not Improved QOL
Improved Impairment	<i>Great News!</i>	<i>Needs targeted life participation intervention</i>
Not improved impairment	<i>That's OK – QOL is what matters!</i>	<i>No response to therapy; OR wrong therapy</i>

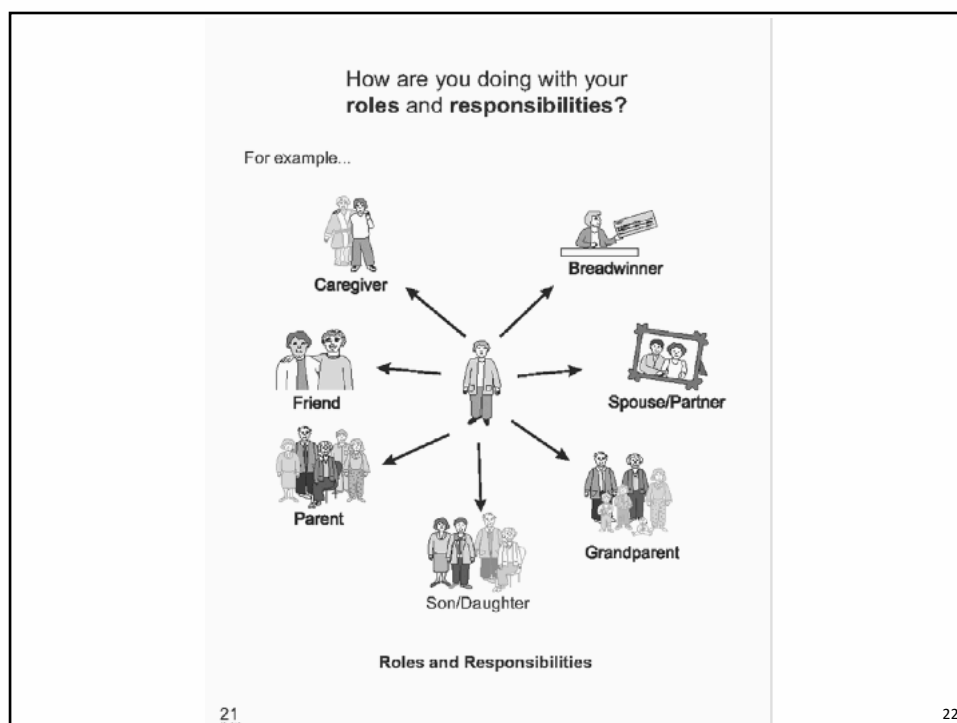
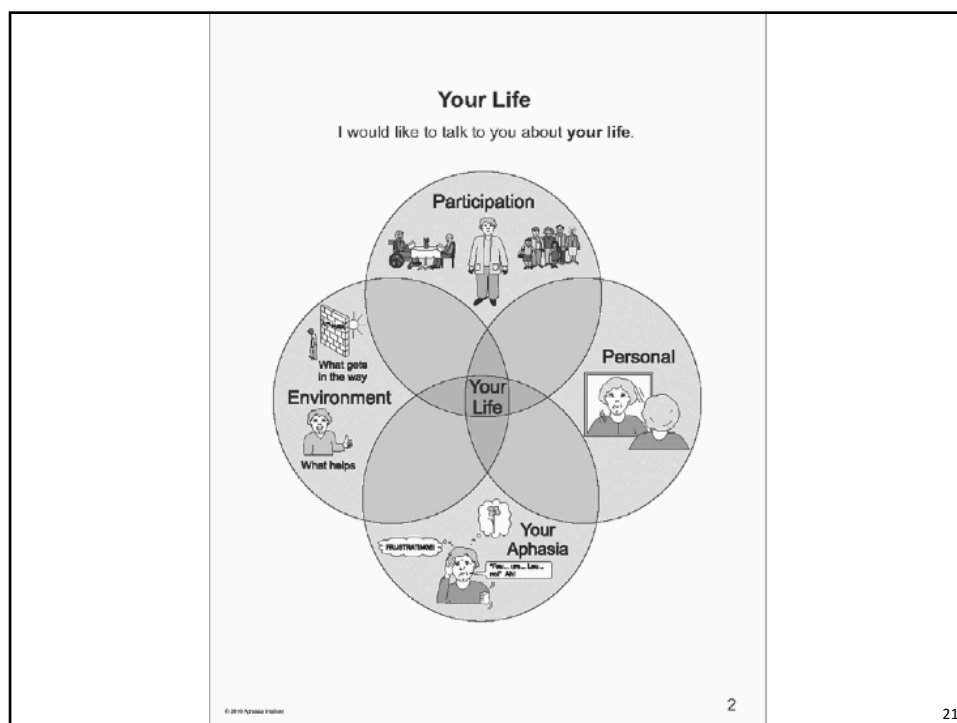
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Measuring QOL 1: Assessment for Living with Aphasia (ALA)

(Simmons-Mackie et al, 2014)

- Available from the Aphasia Institute:
www.aphasia.ca
- Based on the A-From (Kagan et al, 2008)
- Integrates measures of all four areas

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In general, are **you in charge** of your life?

For example...



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Measuring QOL 2: Stroke and Aphasia Quality of Life Scale (Hilari et al, 2003)

- Stroke and Aphasia Quality of Life Scale
 - “Aphasia-friendly” adaptation of the Stroke Quality of Life Scale

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SAQOL Example Items

- “This past week, how much trouble did you have...”
 - “...getting dressed”
 - “...speaking”
 - “...writing”
- “During this past week, did you...”
 - “...find it hard to make decisions?”
 - “...feel you were a burden to your family?”
 - “...feel discouraged?”

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Sample of filled in form
 Name: S. Smith d.o.b.: 15 Feb 1937 A: L MCA CVA Date: 10 May 2000
 SAQOL-39 Scoring Sheet

DURING THE PAST WEEK (Repeat as in SAQOL-39)							Domain scores			
Item ID	How much trouble did you have (Repeat before each item or as necessary)	Couldn't do it at all	A lot of trouble	Some trouble	A little trouble	No trouble at all	Physical	Comm.	Psycho- social	Energy
SC1.	preparing food?	1	2	3✓	4	5	3			
SC4.	getting dressed?	1	2	3	4✓	5	4			
SC5.	taking a bath or shower?	1✓	2	3	4	5	1			
M1.	walking? (If respondent can't walk, circle 1 and go to question M7)	1	2	3✓	4	5	3			
M4.	keeping your balance when bending over or reaching?	1	2	3	4✓	5	4			
M6.	climbing stairs?	1	2	3	4✓	5	4			
M7.	walking without stopping to rest or using a wheelchair without stopping to rest?	1	2✓	3	4	5	2			
M8.	standing?	1	2	3	4✓	5	4			
M9.	getting out of a chair?	1	2	3	4✓	5	4			
W1.	doing daily work around the house?	1	2	3	4✓	5	4			
W2.	finishing jobs that you started?	1	2	3	4✓	5	4			
UE1.	writing or typing, i.e. using your hand to write or type?	1	2	3✓	4	5	3			
UE2.	putting on socks?	1	2	3	4✓	5	4			
UE4.	doing buttons?	1	2	3	4✓	5	4			
UE5.	doing a zip?	1	2	3	4	5✓	5			
UE6.	opening a jar?	1	2	3	4✓	5	4			
L2.	speaking?	1	2	3✓	4	5		3		
L3.	speaking clearly enough to use the phone?	1	2	3✓	4	5		3		
L5.	getting other people to understand you?	1	2	3	4✓	5		4		
L6.	finding the word you wanted to say?	1	2	3✓	4	5		3		
L7.	getting other people to understand you even when you repeated yourself?	1	2	3	4	5✓		5		

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DURING THE PAST WEEK:										
Item ID	Did you (Repeat before each item or as necessary)	Definitely yes	Mostly yes	Not sure	Mostly no	Definitely no	Physical	Comm.	Psycho- social	Energy
T4.	have to write things down to remember them, (or ask somebody else to write things down for you to remember)?	1	2✓	3	4	5				2
T5.	find it hard to make decisions?	1	2	3	4	5✓			5	
P1.	feel irritable?	1	2✓	3	4	5			2	
P3.	feel that your personality has changed?	1✓	2	3	4	5			1	
MD2.	feel discouraged about your future?	1	2✓	3	4	5			2	
MD3.	have no interest in other people or activities?	1	2	3	4✓	5			4	
MD6.	feel withdrawn from other people?	1	2	3	4✓	5			4	
MD7.	have little confidence in yourself?	1	2	3	4	5✓			5	
E2.	feel tired most of the time?	1	2✓	3	4	5				2
E3.	have to stop and rest often during the day?	1	2✓	3	4	5				2
E4.	feel too tired to do what you wanted to do?	1	2	3	4✓	5				4
FR7.	feel that you were a burden to your family?	1	2✓	3	4	5			2	
FR9.	feel that your language problems interfered with your family life?	1	2✓	3	4	5		2		
SR1.	go out less often than you would like?	1	2✓	3	4	5			2	
SR4.	do your hobbies and recreation less often than you would like?	1	2✓	3	4	5			2	
SR5.	see your friends less often than you would like?	1	2✓	3	4	5			2	
SR7.	feel that your physical condition interfered with your social life?	1✓	2	3	4	5	1			
SR8.	feel that your language problems interfered with your social life?	1✓	2	3	4	5		1		
SAGOL-39 Mean score		Add all items and divide by 39					3.08			
Physical score		(SC Items+M Items+W Items+UE Items+SR7)/17					3.41			
Communication score		(L Items+FR9+SR8)/7						3.00		
Psychosocial score		(T5+P Items+MD Items+FR7+SR1+SR4+SR5)/11							2.82	
Energy score		(T4+E Items)/4								2.5

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Tools: Community Integration Questionnaire

- The CIQ consists of 15 items
 - home integration (H),
 - social integration (S),
 - and productive activities (P).
- Subtotals for each of these, as well as for community integration overall.
- The basis for scoring is primarily frequency of performing activities or roles, with secondary weight given to whether or not activities are done jointly with others.

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Example: Home Integration Scale from CIQ

COMMUNITY INTEGRATION QUESTIONNAIRE

Subject: _____ **Date:** _____

1. Who usually does the shopping for groceries or other necessities in your household?	<input type="radio"/> Yourself alone <input type="radio"/> Yourself and someone else <input type="radio"/> Someone else
2. Who usually prepares meals in your household?	<input type="radio"/> Yourself alone <input type="radio"/> Yourself and someone else <input type="radio"/> Someone else
3. In your home who usually does the everyday housework?	<input type="radio"/> Yourself alone <input type="radio"/> Yourself and someone else <input type="radio"/> Someone else

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Example: Social Integration Scale from CIQ

11. Do you have a best friend with whom you confide?	<input type="radio"/> Yes <input type="radio"/> No
12. How often do you travel outside the home?	<input type="radio"/> Almost every day <input type="radio"/> Almost every week <input type="radio"/> Seldom/never (less than once per week)

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Example: Productivity Scale from CIQ

13. Please choose the answer that best corresponds to your current (during the past month) work situation:

- ☐ Full-time
(more than 20 hours/week)
- ☐ Part-time
(less than or equal to 20 hrs/week)
- ☐ Not working,
but actively looking for work
- ☐ Not working,
not looking for work
- ☐ Not applicable,
retired due to age

14. Please choose the answer that best corresponds to your current (during the past month) school or training program situation:

- ☐ Full-time
- ☐ Part-time
- ☐ Not attending school,
or training program
- ☐ Not applicable,
retired due to age

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Social Network Analysis

- A social network is a social structure that results from all of the ties and relationships between individuals.
- Social network analysis refers to methods that are used to analyze the purposes, functions, and frequency of contact between individuals.
- An organized approach to identifying the nature of different social interactions that occur in a client's daily life, and who might be good targets for communication partner training.

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Social Network Analysis

- Most social network approaches involve interviews to identify characteristics such as the number and types of relationships, frequency of contact, importance of each contact to the person, settings where contact occurs or the amount of time spent.

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Social Network Analysis of Aphasia Profile (SNAP) (Code, 2003)

The SNAP consists of seven sheets headed with each of the days of the week, with four columns entitled Name/Initials/Time (e.g., Mrs J, 8–11am), Place (e.g., church, shop), Purpose of Contact (e.g., shopping, hairdresser), Relationship (e.g., son, doctor, nurse). Participants are also asked to provide information on who completed the SNAP (the person with aphasia, their partner, or both), dates of Completion, age, occupation, physical mobility, months post-onset of aphasia, whether the aphasic person was a car driver, and whether the spouse or carer of the aphasic person owned a car and drove.

(The SNAP should be completed for all activities for 7 consecutive days. Each sheet of paper should correspond to a different day of the week)

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Example: Social Network Analysis

MONDAY

Name/Initials/Time	Place	Purpose of Contact	Relationship
Mrs. J., 8-11AM	Shop	Shopping	Son

Date of completion:

Who filled out this SNAP? Person with Aphasia? Carer? Both?

Age of person with aphasia:

Occupation:

Physical Mobility:

Months post onset of aphasia:

Person with aphasia car driver?

Spouse or carer of person with aphasia car driver? Own Car?

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Setting Goals for QOL

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Goal Attainment Scaling

Goal Attainment Scaling is a goal-setting procedure that has the strongest empirical support for its validity and effects (Hurn, Kneebone, & Cropley, 2006)

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Goal Attainment Scaling

(from Malec, 1999)

TABLE 1
Six Steps for the Development and Implementation of GAS

1. Goal selection
2. Weighting goals
3. Designation of follow up time period
4. Articulation of the "expected" level of outcome in objective behavioural terms
5. Articulation of other outcome levels
6. Assessment of GAS level on admission and at follow up

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Goal Attainment Scaling – evaluation

- Most favorable outcome
- More than expected outcome
- Expected outcome
- Less than expected outcome
- Least favorable outcome

+2, +1, 0, -1, -2

OR

0, 1, 2, 3, 4

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Goal Attainment Scaling Example – Adult Aphasia (Worrall, 2000)

	Goal 1: Catching the bus
Most favorable outcome	Able to use the bus without assistance without error all of the time
More than expected	Able to use the bus with the help of his wife without error all of the time
Expected outcome	Able to use the bus with the help of his wife with some errors some of the time
Less than expected	Too much help required and too many errors made for continued use of the bus
Least favorable	Unable to use the bus at all

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Advantages of Goal Attainment Scaling

- Focused on life participation
- Provides evaluative component
- Provides time limit
- Can be customized to particular social environments
- Structure and process could be internalized by clients to facilitate autonomous goal-seeking

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If you focus on activity goals, then...

- Client sees improvements on something important to him/her more quickly
- Client is able to do something, which will increase willingness to go out and do the activity, which will support social engagement and continued improvement
- Activity-focused practice (catalog-ordering, menu-ordering, conversation, script training) transfers to “downstream” skills like word-finding (Hinckley, Patterson & Carr, 2001; Hinckley & Carr, 2005; Boyle, 2011)
- Finally, activity-focused practice may be most effective when treatment time is limited (Hinckley & Carr, 2005)

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Principled task decomposition

(Fredericksen & White, 1989)

- Top-down, goal-oriented task decomposition
 - Example: ordering in a restaurant
 - Goal : Get the food/drink.
 - SubGoal: Tell the waitperson what you want
 - Seen in this way, there are multiple ways to get food in a restaurant:
 - Have someone else order for you
 - Say what you want
 - Point to what you want
 - Use a device to communicate what you want

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Principled task decomposition

Ask three questions to find the optimal strategy to achieve the ultimate task goal:

1. Does the strategy help to achieve the goal without making it harder to achieve some other goal?
2. Does the execution of the strategy reduce or increase the cognitive load of achieving the goal?
3. Does the strategy require the acquisition of complex skills or concepts?

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Principled task decomposition

1. Does the strategy help to achieve the goal without making it harder to achieve some other goal?
 - In other words, does the communication strategy get the food without making it harder to achieve independence?
 - ~~Have someone else order for you~~
 - Say what you want
 - Point to what you want
 - Use a device to communicate what you want

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Principled task decomposition

2. Does the execution of the strategy reduce or increase the cognitive load of achieving the goal?
 - Which of these requires the lowest cognitive load?
 - Point to what you want
 - Say what you want
 - Use a device to communicate what you want

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Principled task decomposition

3. Does the strategy require the acquisition of complex skills or concepts?
 - Which of these requires the least complex skills?
 - Point to what you want = OPTIMAL STRATEGY
 - Say what you want
 - Use a device to communicate what you want

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Principled task decomposition: From activity to goal

Client's desired activity: Ordering independently in a restaurant

Sample goal: Client will point to words and pictures *to request desired items* with XX% accuracy

Maps directly to outcome measures such as:

- ordering lunch on the CADL-2
- QOL items relevant to making one's own choices

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Example

- Client's priority activity is talking about travel with friends and visitors
 - Sample goal: "Client will maintain conversation about selected personal topic for xx minutes using communication supports"
 - "with trained/untrained partners"
- Compare:
- "Client will name travel words with xx% accuracy"
- OR
- "Client will correctly label travel photos with XX% accuracy"

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Example

- Client's priority activity is talking about travel with friends and visitors
 - Sample goal: "Client will maintain conversation about selected personal topic for xx minutes using communication supports"
 - "with trained/untrained partners"
- Stroke and Aphasia
Quality of Life Scale:
- "Did you...do your hobbies less often than you would like?"

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Case Illustration 1: Mr. F

- Mr. F is a 63-year old right-handed gentleman who was admitted to the hospital 3 days ago with a left hemispheric stroke. He had no previous medical history of stroke, brain injury, communication disability, or psychiatric condition. His wife is at his bedside most of the day.

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Mr. F: Background Info

- Based on the administration of a standardized language assessment and consistent with informal observation, Mr. F. is diagnosed with a fluent, Wernicke's-type aphasia of moderate severity. Mrs. F. complains about the hospital food, indicating that if she is not there when the food service staff comes to take his order, he ends up with food he does not like and won't eat. She is worried that he is not getting enough to eat and that will hamper his recovery.

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Goal Attainment Scaling Example – Mr. F

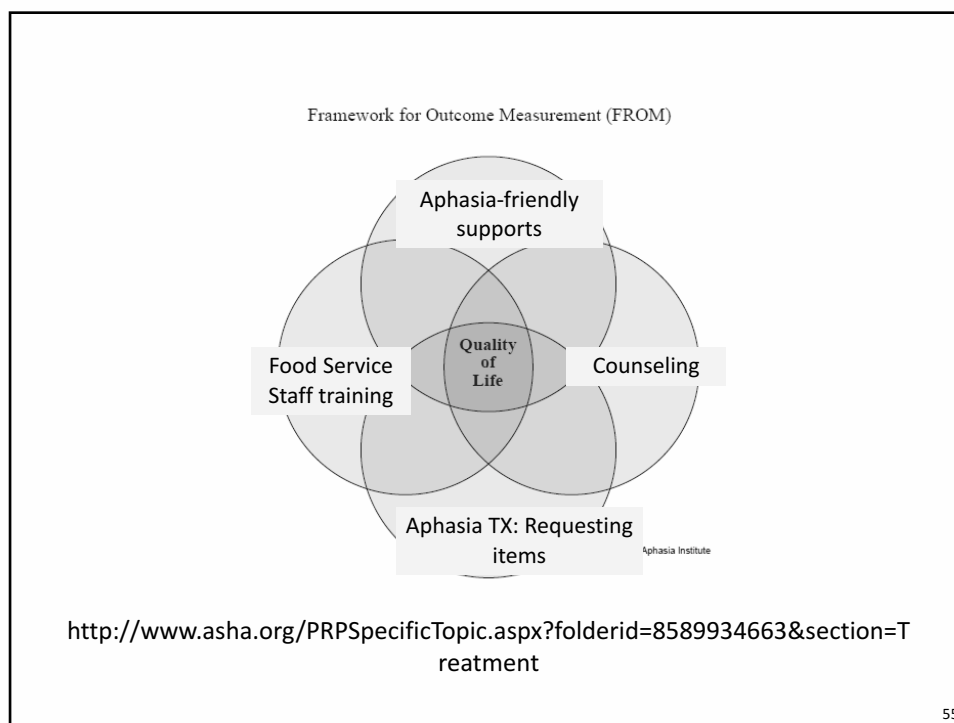
	Goal 1: Ordering preferred food
Most favorable outcome	Able to order preferred food without assistance without error all of the time
More than expected	Able to order preferred food with the help of his wife without error all of the time
Expected outcome	Able to order preferred food with the help of his wife (or other) with some errors some of the time
Less than expected	Too much help required and too many errors made to make own order
Least favorable	Unable to order own food

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Example

- Client wants to be able to order preferred food
 - Sample goal: “Client will use pointing to pictures/words to request items with xx% effectiveness”
 - “with trained/untrained partners”
- Patient-reported QOL measure:
 “How frequently, in the last (1, 2, 3... days) did you get the food that you wanted to order?”

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Case Example: Mr. L.

Mr. L. is beginning OP therapy at your facility. During a joint interview with Mr. L. and his wife, Mr. L. indicated that he wanted to be able to use the phone, and that he missed doing business on the phone. He had been a successful entrepreneur with many social and business connections.

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Goal Attainment Scaling Example – Mr. L

	Goal 1. Use technology to place phone/Facetime call to (specific) friends/family.
Most favorable outcome	Able to place call and say "hello" without assistance without error all of the time
More than expected	Able to place call and say "hello" with the help of his wife without error all of the time
Expected outcome	Able to place call and say "hello" with some help and some errors
Less than expected	Too much help required and too many errors made to place call
Least favorable	Unable to place a call

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Goal-writing example: Mr. L

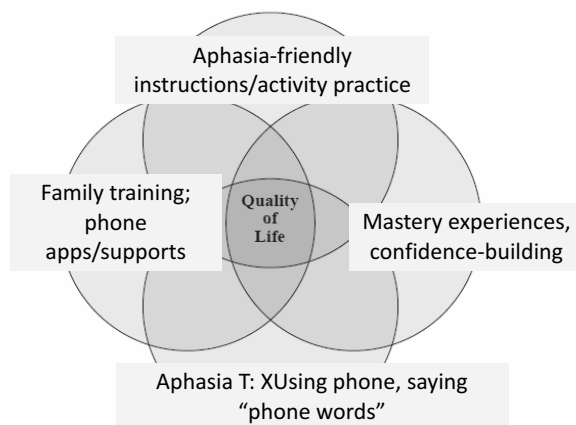
- Client wants to be able to initiate a call and say "hello"
- Sample goal: "Client will use pointing to pictures/words to request items with xx% effectiveness"
- "with trained/untrained partners"

Stroke and Aphasia
Quality of Life Measure:
"In the last week, how much trouble did you have...speaking clearly enough to use the phone?"

L2.	speaking?	1	2	3✓	4	5
L3	speaking clearly enough to use the phone?	1	2	3✓	4	5
L5.	getting other people to understand you?	1	2	3	4✓	5
L6.	finding the word you wanted to say?	1	2	3✓	4	5
L7.	getting other people to understand you even when you repeated yourself?	1	2	3	4	5✓

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Framework for Outcome Measurement (FROM)



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SUMMARY AND OVERVIEW

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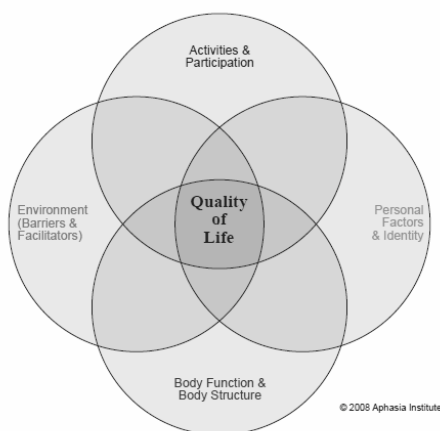
Summary/Closing Thoughts

- Consider all of the ways to document change and progress on trained items that are personally relevant to an activity
 - Frequency of successfully communicated message
 - Number of attempts prior to success/% of attempts with x number of attempts or fewer
 - Improved efficiency measured by total time required for each attempt (averaged); can be reported as % faster
 - Frequency/% of attempts using a particular strategy
- Link goals to a measure of QOL

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Thank you!

Contact me: Dr.JJHinckley@gmail.com

QUESTIONS AND DISCUSSION

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