Developing and Implementing a Useful Outcome Measurement Process for ABA

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NASEM Committee Areas Addressed

2. An assessment of the methods used under the demonstration project to measure the effectiveness of applied behavior analysis in the treatment of autism spectrum disorder

Relevance to:

9. The development of a list of recommendations related to the measurement, effectiveness, and increased understanding of the demonstration program and its effect on beneficiaries under the TRICARE program.

Outline

- Challenges for ABA Outcome Assessment
- Determining what to measure
  - FDA guidance and modern measure development methods
  - Example
- Choosing the right measures
  - Psychometric characteristics
  - Practical considerations
- Current Limitations of the DoD / TRICARE Approach
  - Recommendations

Current Challenges in ABA Intervention Monitoring

- BCBAs want to provide great ABA service to patients
  - Assessment activities are not a major focus of training
  - Service requests conflate clinical with business interests

- Assessment processes lack standardization, are cumbersome, prone to error, and legacy measures were not purpose built

- ABA businesses tend to be break-even, with substantial turnover, and clinicians and families carry substantial burdens
  - Need for automation, burden reduction, clinical decision support, etc.

Identifying What Matters to Patients / Families

Most currently-available and currently-used clinical measures were not specifically developed for ASD / NDD populations

Many did not use concept elicitation or cognitive interviewing processes or stakeholder engagement

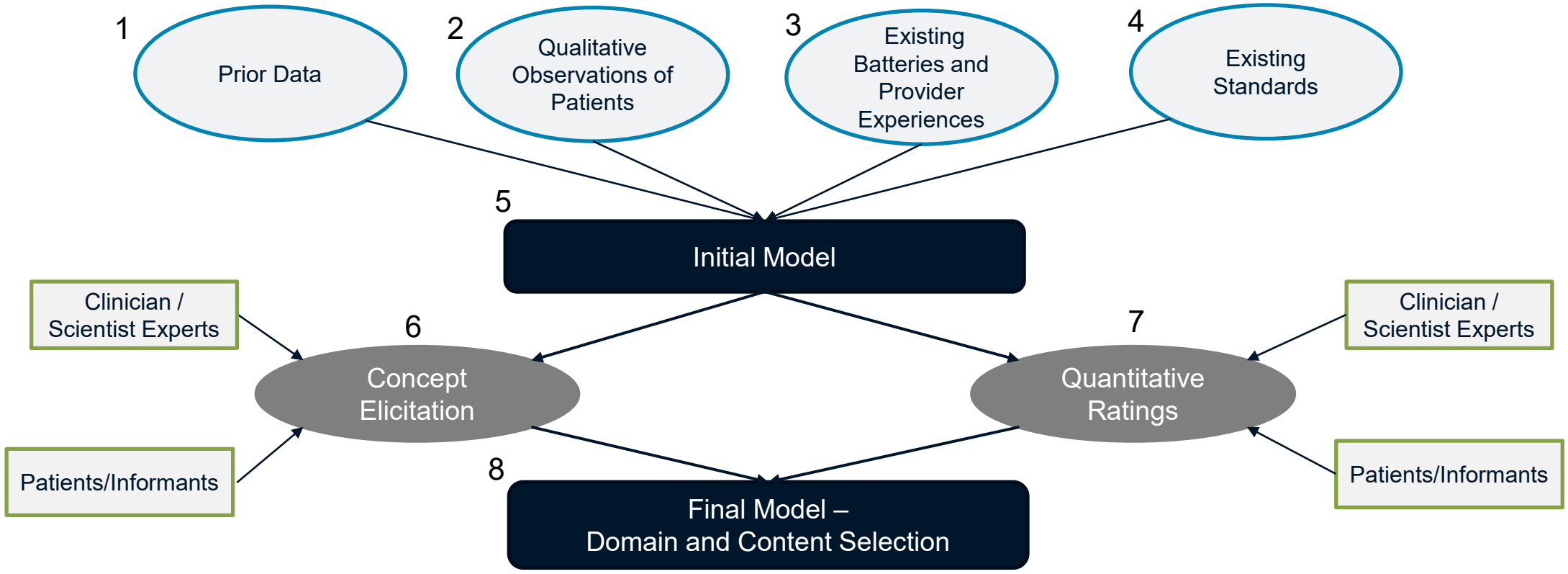
Boateng GO, Neilands TB, Frongillo EA, Melgar-Quinonez HR, Young SL. Best Practices for Developing and Validating Scales for Health, Social, and Behavioral Research: A Primer. *Front Public Health. 2018;6:149.*

Many include items / scales that are not relevant to the full population and/or represent domains or areas of treatment excluded from the TRICARE ACD policy

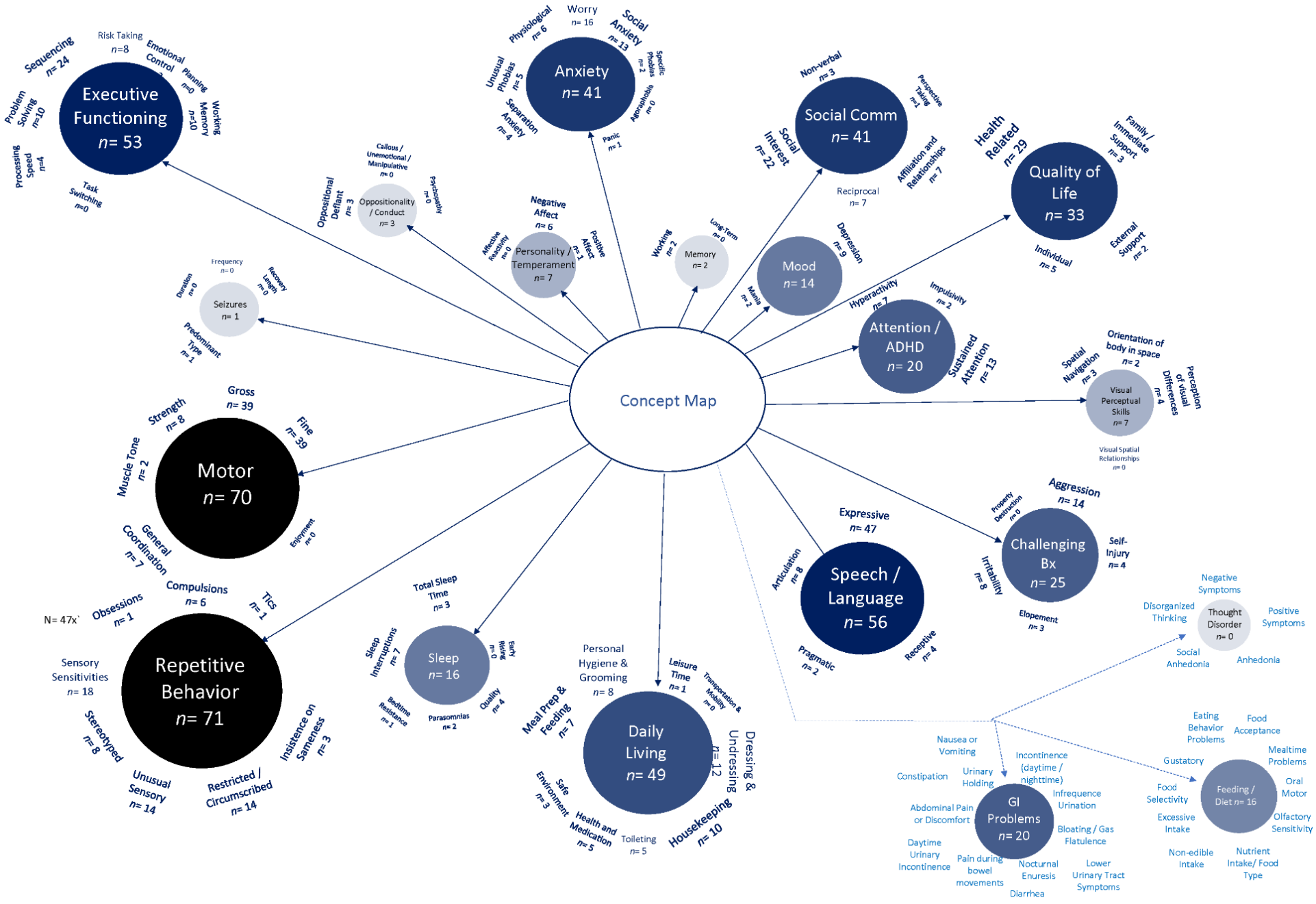
- Non-verbal / non-speaking people
- Moderate to profound cognitive impairment
- Floor is not low enough

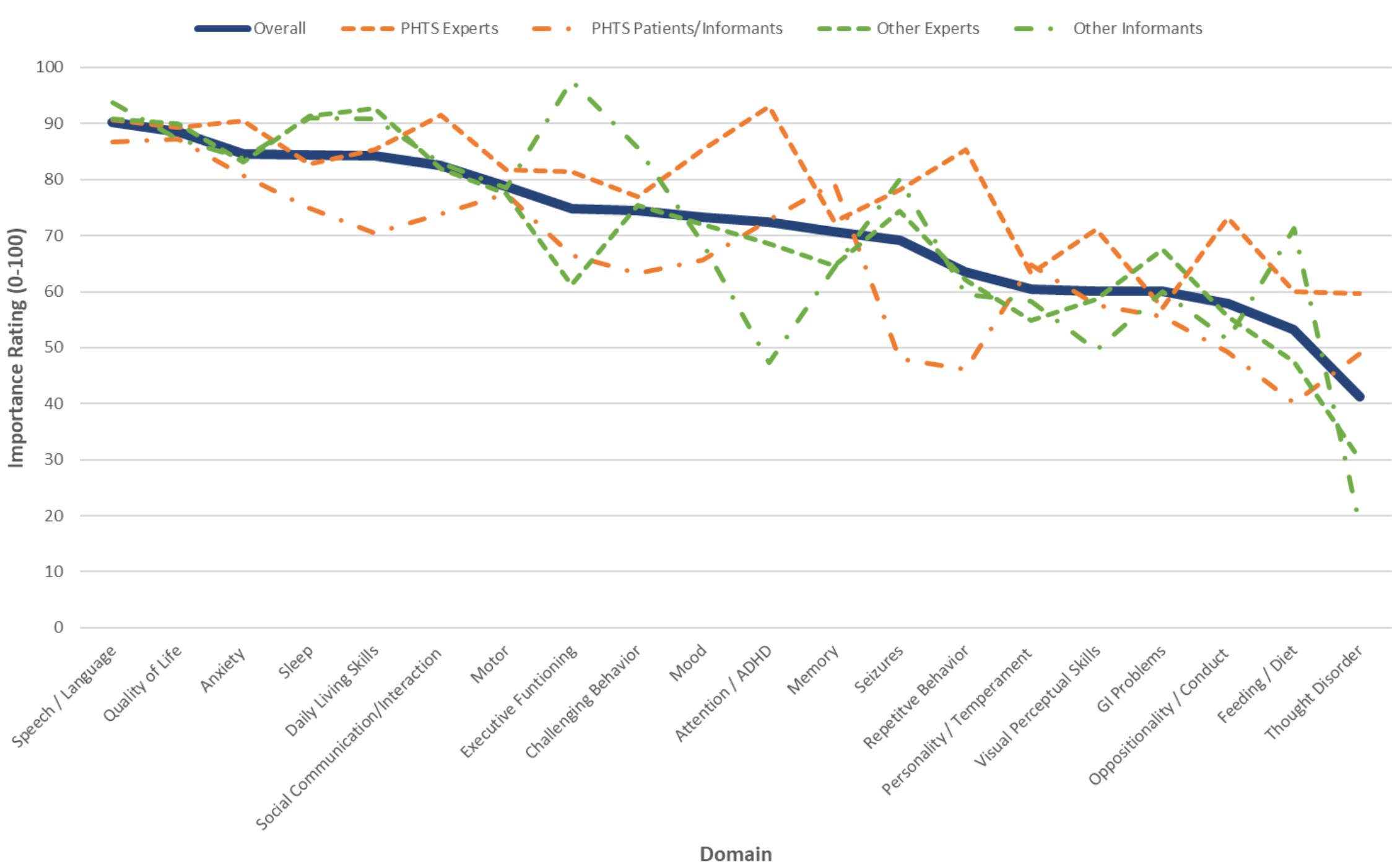
FDA. (2009). *Patient-reported outcome measures: use in medical product development to support labeling claims. (United States Food and Drug Administration, Guidance for Industry.* https://www.fda.gov/downloads/drugs/guidances/ucm193282.pdf

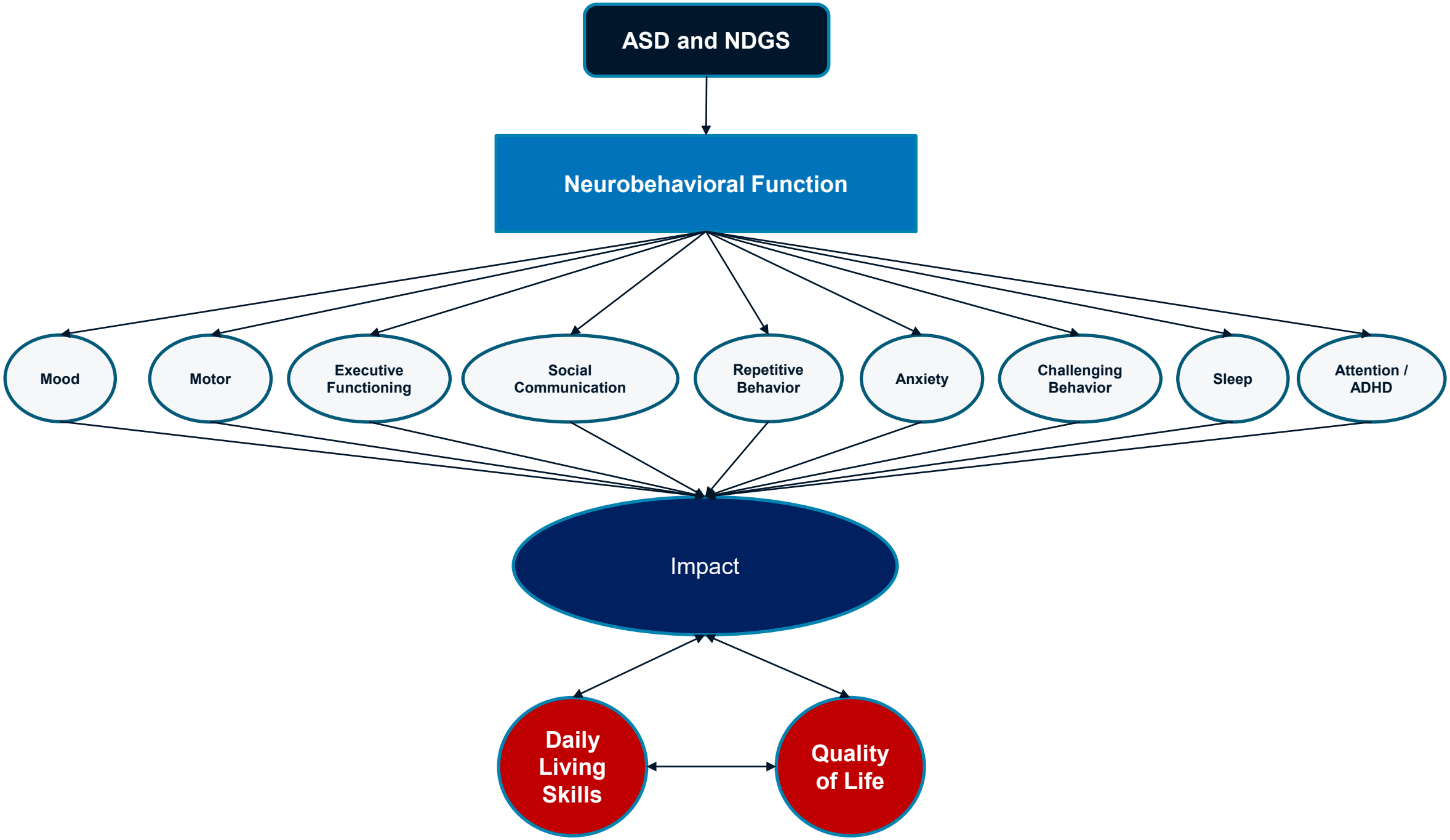
A Process for Determining What to Measure



Frazier TW et. al. Development of informant-report neurobehavioral survey scales for PTEN hamartoma tumor syndrome and related neurodevelopmental genetic syndromes. *Am J Med Genet A. 2023;191(7):1741-1757.*


Concept Map
Executive Functioning n= 53
Sequencing n= 24
Risk Taking n=8
Emotional Control
Planning n=0
Working Memory n=10
Problem Solving n=10
Processing Speed n=4
Task Switching n=0
Anxiety n= 41
Worry n= 16
Physiological n= 6
Social Anxiety n= 13
Specific Phobias n= 2
Agoraphobia n=0
Panic n= 1
Separation Anxiety n= 4
Unusual Phobias n= 5
Social Comm n= 41
Non-verbal n= 3
Perspective Taking n=1
Social Interest n= 22
Affiliation and Relationships n= 7
Reciprocal n= 7
Quality of Life n= 33
Health Related n= 29
Family / Immediate Support n= 3
External Support n= 2
Individual n= 5
Mood n= 14
Depression n= 9
Mania n= 2
Hyperactivity n= 7
Attention / ADHD n= 20
Impulsivity n= 2
Sustained Attention n= 13
Visual Perceptual Skills n= 7
Spatial Navigation n= 3
Orientation of body in space n= 2
Perception of visual Differences n= 4
Visual Spatial Relationships n= 0
Memory n= 2
Working n= 2
Long-Term n= 0
Personality / Temperament n= 7
Negative Affect n= 6
Positive Affect n= 1
Affective Reactivity n=0
Oppositionality / Conduct n= 3
Oppositional Defiant n= 3
Callous / Unemotional / Manipulative n= 0
Psychopathy n= 0
Seizures n= 1
Frequency n= 0
Duration n= 0
Recovery Length n= 0
Predominant Type n= 1
Motor n= 70
Gross n= 39
Fine n= 39
Strength n= 8
Muscle Tone n= 2
General Coordination n= 7
Enjoyment n= 0
Repetitive Behavior n= 71
N= 47x`
Obsessions n= 1
Compulsions n= 6
TICs n= 1
Sensory Sensitivities n= 18
Stereotyped n= 8
Unusual Sensory n= 14
Restricted / Circumscribed n= 14
Insistence on Sameness n= 3
Sleep n= 16
Total Sleep Time n= 3
Sleep Interruptions n= 7
Early Rising n= 0
Bedtime Resistance n= 1
Parasomnias n= 2
Quality n= 4
Daily Living n= 49
Personal Hygiene & Grooming n= 8
Leisure Time n= 1
Transportation & Mobility n= 0
Dressing & Undressing n= 12
Meal Prep & Feeding n= 7
Safe Environment n= 3
Health and Medication n= 5
Toileting n= 5
Housekeeping n= 10
Speech / Language n= 56
Expressive n= 47
Articulation n= 8
Receptive n= 4
Pragmatic n= 2
Challenging Bx n= 25
Aggression n= 14
Property Destruction n= 0
Self-Injury n= 4
Irritability n= 8
Elopement n= 3
Thought Disorder n= 0
Negative Symptoms
Positive Symptoms
Disorganized Thinking
Social Anhedonia
Anhedonia
GI Problems n= 20
Nausea or Vomiting
Constipation
Urinary Holding
Incontinence (daytime / nighttime)
Abdominal Pain or Discomfort
Infrequence Urination
Bloating / Gas Flatulence
Daytime Urinary Incontinence
Pain during bowel movements
Nocturnal Enuresis
Lower Urinary Tract Symptoms
Diarrhea
Feeding / Diet n= 16
Eating Behavior Problems
Food Acceptance
Gustatory
Mealtime Problems
Food Selectivity
Oral Motor
Excessive Intake
Olfactory Sensitivity
Non-edible Intake
Nutrient Intake/ Food Type


Overall
PHTS Experts
PHTS Patients/Informants
Other Experts
Other Informants
Importance Rating (0-100)
100
90
80
70
60
50
40
30
20
10
0
Speech / Language
Quality of Life
Anxiety
Sleep
Daily Living Skills
Social Communication/Interaction
Motor
Executive Funtioning
Challenging Behavior
Mood
Attention / ADHD
Memory
Seizures
Repetitve Behavior
Personality / Temperament
Visual Perceptual Skills
GI Problems
Oppositionality / Conduct
Feeding / Diet
Thought Disorder
Domain


ASD and NDGS
Neurobehavioral Function
Mood
Motor
Executive Functioning
Social Communication
Repetitive Behavior
Anxiety
Challenging Behavior
Sleep
Attention / ADHD
Impact
Daily Living Skills
Quality of Life

Domains / Constructs to Consider for ABA Outcome Assessment

Autism Symptoms	Functioning	Other Concerns	Well-Being
Social Communication / Interaction	Daily Living Skills / Practical Functioning	Anxiety	Satisfaction with Therapy
Restricted/Repetitive Behavior	Motor Skills	Attention / ADHD	Quality of Life / Flourishing
ASD Subdomains	Leisure Skills	Irritability / Challenging Behavior	External Environmental Supports
	Executive Functioning	Mood / Affective Experience	Access to Medical and Behavioral Health Services
	Language / Speech	Sleep Problems	
	Family Functioning	GI Problems	
		Feeding Challenges	

Modern Understanding of Core ASD Symptoms

Social Communication / Interaction

- Basic social communication (verbal and non-verbal)
- Social motivation / affiliation
- Perspective taking
- Relationships

- Restricted / Repetitive Behavior
  - Repetitive motor and speech
  - Insistence on sameness
  - Restricted interests
  - Sensory interests
  - Sensory sensitivities

Phillips JM, et. al. *Mol Autism. 2019;10:48.*

Uljarevic M. et. al. *J Am Acad Child Adolesc Psychiatry. 2020;59(11):1252-1263 e1253.*

Uljarevic M. et. al. *J Clin Child Adolesc Psychol. 2021;50(5):609-618.*

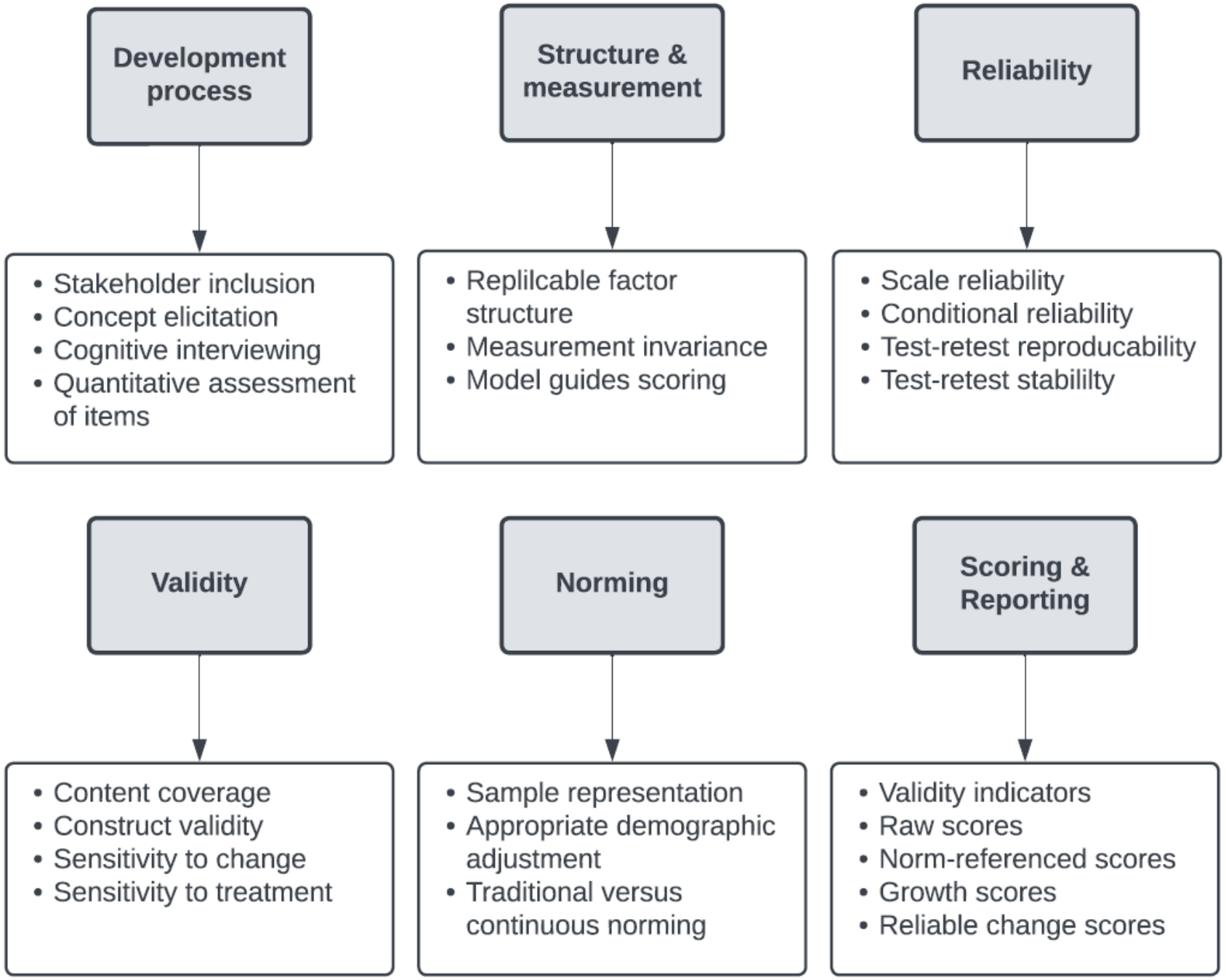
Frazier TW, et. al. *Autism. 2017;21(6):749-759.*

Uljarevic M, et. al. *J Am Acad Child Adolesc Psychiatry. 2023;62(5):568-581.*

Uljarevic M. et. al. *J Am Acad Child Adolesc Psychiatry. 2022;61(3):446-457.*

Frazier TW, *Autism. 2014;18(1):31-44.*

Proposed Psychometric Criteria for Outcome Measure Prioritization



Proposed Practical Criteria

i. Automated administration

ii. Automated scoring

iii. Visual display of measure results

iv. Automated interpretative statements, with clinician selection/modification

v. Automated connection of results with intervention target identification, with clinician selection/addition/modification

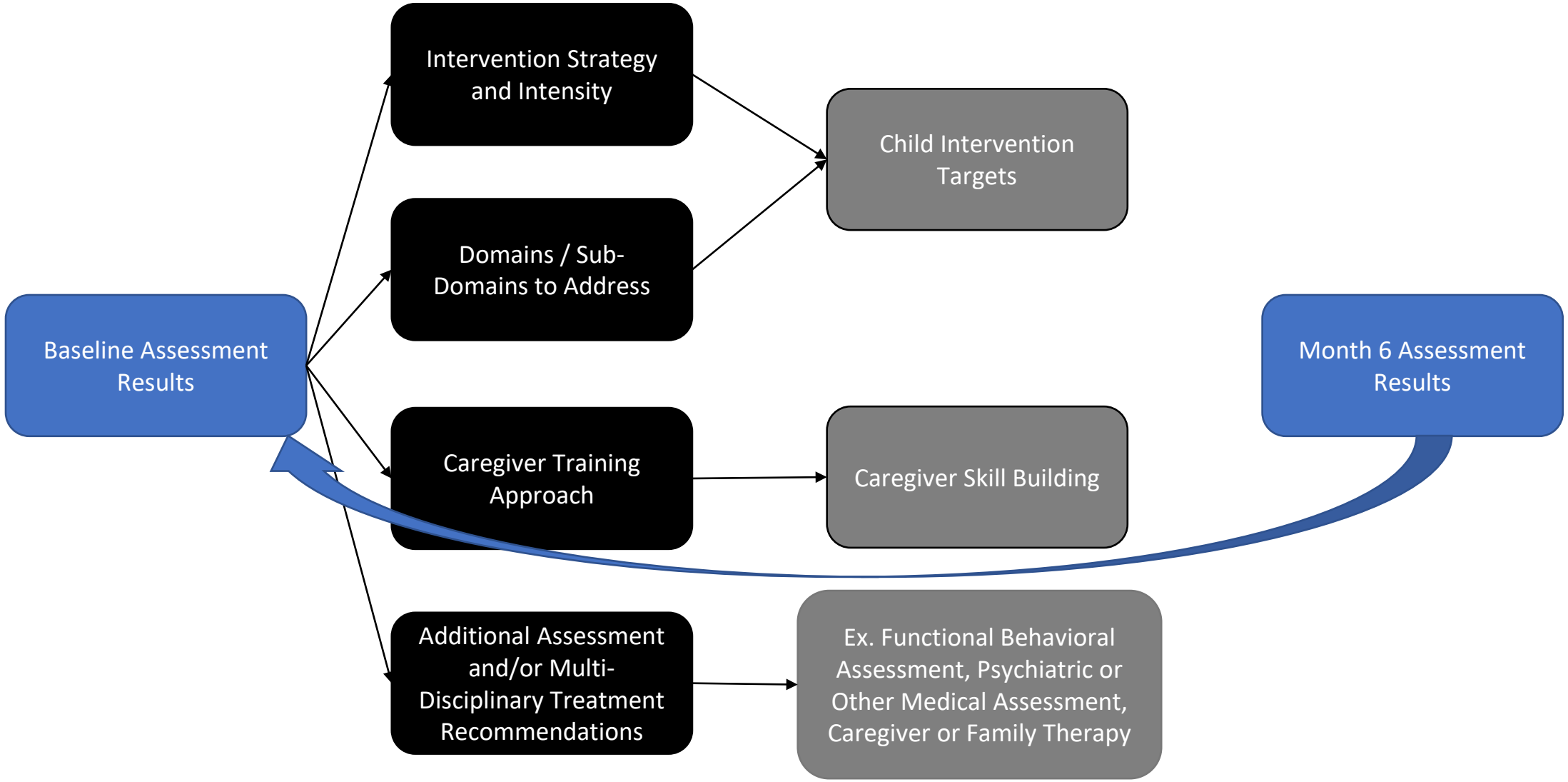
vi. Automated clinical guidance for additional assessment, intervention strategy, and referral with clinician selection/modification

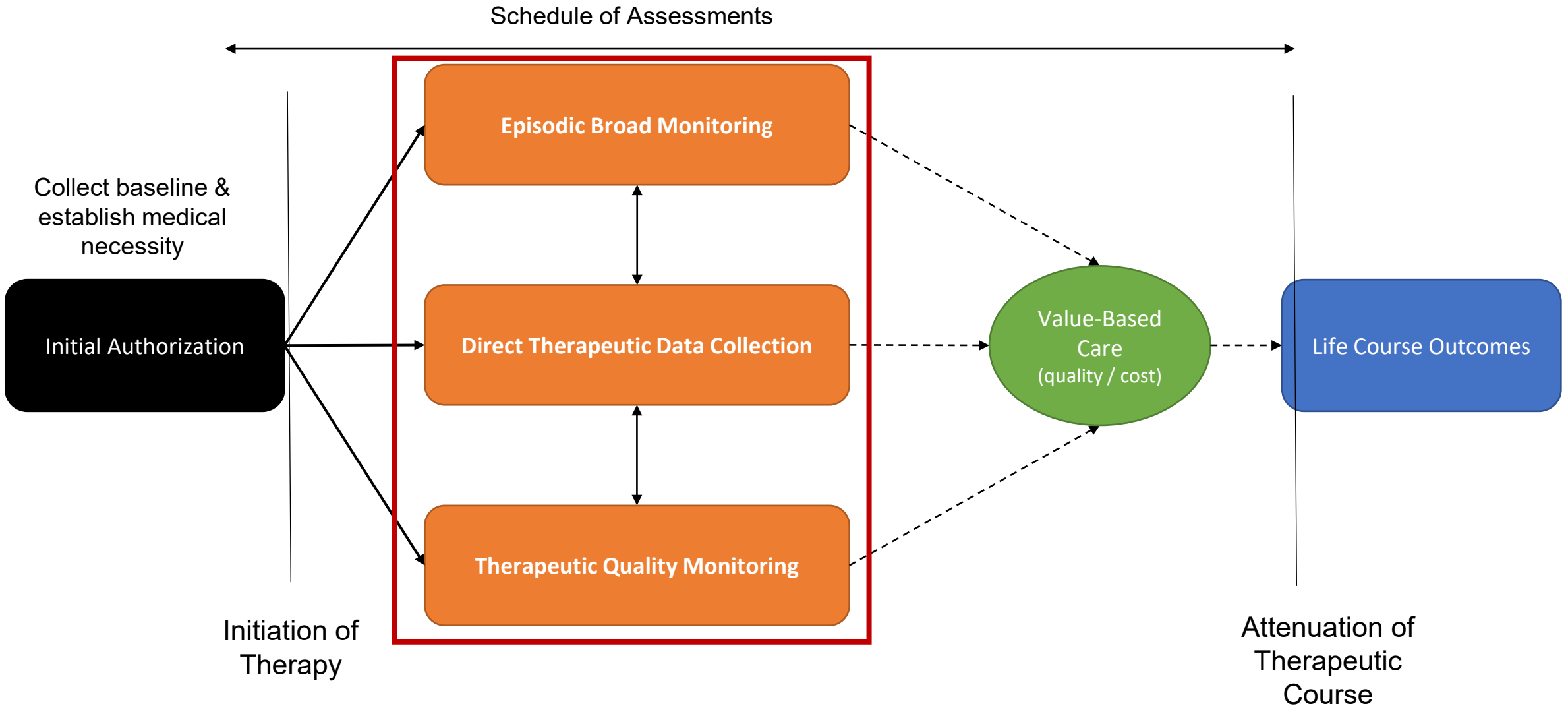
vii. Automated progress monitoring

viii. Connection of target identification with goals/objectives and teaching plan selection

ix. Aggregation of measures and reporting to facilitate clinical workflow

Assessment-Driven Treatment





To achieve value-based care, a highly-effective outcome assessment system should capture all 3 types of data to inform therapeutic progress and the clinical quality improvement process with the ultimate purpose being the enhancement of life course outcomes

Current Limitations of the DoD / TRICARE Outcome Assessment Battery

Vineland-3, PDDBI, SRS-2, PSI-4-SF/SIPA were not purpose-built for this population

- Stakeholders had limited to no involvement in their development
- Unknown or poorly replicated factor structure to inform scoring

  Farmer RL, et. al. *Assessment. 2021;28(7):1848-1864.*
- Unknown or limited evidence of measurement invariance, key for diverse patient populations

  Frazier TW, et. al. *Autism. 2014;18(1):31-44.*
- Limited construct validity evidence

  McMorris CA, Perry A. *Autism. 2015;19(3):272-280.*
- Items that are not appropriate for typical ABA patient population
  - Require speech, lack consideration of SGD use
  - Frustrating for parent/caregiver informants when ask about higher-level skills that are not relevant to the child
  - Quality of life is not a narrow construct and can be used to inform the treatment strategy

Current Limitations of the DoD / TRICARE Outcome Assessment Battery (cont.)

Battery Has Weak Construct Coverage

- Do not adequately assess all of core autism sub-domains that have been identified
  - Social motivation, sensory sensitivity, sensory interests
- Construct overlap
  - Example. Basic social communication over-sampled
- Limited neurobehavioral construct coverage
  - ADHD, anxiety, mood/irritability, challenging behavior, sleep, or quality of life domains poorly or not at all assessed

Very Few of the Practical Criteria Addressed
Difficult to Implement Assessment-Driven Treatment

Recommendations

- Identify a battery of psychometrically-sound measures appropriate for ABA population
  - Stakeholder engagement: domain -> sub-domain -> measure evaluation -> measure implementation

- Identify a processes for administration, scoring, interpretation, longitudinal monitoring, and decision-support that minimize practice variability and implements assessment-driven intervention
  - Invest in a system to ensure that practical considerations are met

- Engage in continuous quality improvement of the assessment process and system
  - Build administrator functionality to provide a real-time window into service delivery with the DoD/TRICARE network

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