## Gina Green, PhD, BCBA-D ggreen3@cox.net

Presentation to the National Academies Committee Conducting an Independent Analysis of Department of Defense's Comprehensive Autism Care Demonstration Program Virtual Public Session – November 22, 2024



# **Disclosures**

- Semi-retired, self-employed consultant
- Current paid consulting:
  - Partners Behavioral Health (private company)
  - California Association for Behavior Analysis (nonprofit professional association)
- Royalties:

Johnston, J.M., Pennypacker, H.S., & Green, G. (2020) Strategies and Tactics of Behavioral Research and Practice (4<sup>th</sup> ed). New York: Routledge



# **Disclosures**



- Other affiliations (all **volunteer** roles with **nonprofit** entities):
  - ABA Coding Coalition ABA Consultant
  - Autism Commission on Quality Standards Committee, Outcomes Work Group
  - Council of Autism Service Providers Executive Steering Committee, Guidelines & Standards
  - Mission Alpha Advocacy Board of Directors
  - Association for Science in Autism Treatment Advisory Board
  - B.F. Skinner Foundation Advisory Board

In this presentation I am not representing or speaking for any of the organizations listed.

# **Disclosures**



- Involvement with TRICARE Autism Care Demonstration (ACD):
  - Have been supporting military families' advocacy for appropriate coverage of ABA services under TRICARE since 2007.
    - Currently serve as volunteer member of Board of Directors, Mission Alpha Advocacy.
  - Have never been a TRICARE provider.
  - Have never been affected materially by TRICARE ACD policies.

# Acknowledgements



- Content is drawn from work of several teams:
  - Review of research and recommended best practices for assessing individuals with ASD for development of guidelines by Association of Professional Behavior Analysts (APBA) and Council of Autism Service Providers (CASP).
    - To be released in 2025.
  - Autism Commission on Quality Outcomes Work Group
  - Guidelines & Standards Executive Steering Committee and Practice Guidelines Steering Committee, CASP

#### Assessing Individuals with ASD for Treatment Planning and Progress Monitoring: General Recommendations

- No single assessment instrument or battery yields information needed to develop appropriate treatment plan for, or evaluate progress by, every member of this heterogeneous population.
- Assessment should be
  - <u>Comprehensive and individualized:</u>
    - Aim to identify unique strengths, needs, and preferences
    - Comprise thorough review of medical and developmental history and assessment of current functioning in all relevant domains:
      - Autism characteristics
      - Communication skills
      - Social interaction skills
      - Intellectual skills or developmental level
      - Self-care and other daily living skills
      - Challenging behaviors
      - Co-occurring medical and/or mental health conditions
      - Quality of life of individual and their family
      - Others depending on age (e.g., skills for participating in educational services, work, community living)



#### Assessing Individuals with ASD for Treatment Planning and Progress Monitoring: General Recommendations

- Assessment should be
  - Multimodal involve multiple sources and methods:
    - Existing records
    - Interviews
    - Standardized assessment instruments
      - Necessary for drawing comparisons across individuals, examiners, settings, time
      - Norm- and/or criterion-referenced
      - Administered to individual (direct) AND completed by caregivers and other third parties (indirect) by qualified professionals
      - Valid and reliable
      - Appropriate to individual's chronological age, developmental level, overall functioning
    - Non-standardized assessment instruments and procedures
      - Includes direct observation and recording of behaviors in multiple settings
      - With procedures to evaluate accuracy, reliability, and believability of recorded observations
  - <u>Integrated</u> -- all information synthesized in comprehensive report shared with all relevant parties.



## A note re: diagnostic assessments

- Caveats: Not a diagnostician. Diagnosing conditions is not in scope of practice of behavior analysts.
- Commentary by Somer Bishop and Catherine Lord (2023) codevelopers of Autism Diagnostic Observation Schedule (ADOS)
  - Intended use of ADOS and other standardized diagnostic tools:
    - "...to formalize the procedures through which clinicians and researchers gather information about autism-related symptoms in patients referred due to concern for autism spectrum disorder."
    - by professionals with expertise in diagnosing ASD
    - using standardized procedures for eliciting and observing behaviors in combination with reports from parents and other caregivers



#### **Diagnostic assessments -- Bishop & Lord (cont'd)**

- "Standardized diagnostic instruments were developed to aid the expert, to structure the assessment to ensure that diagnostically relevant information would be available for making diagnostic judgments. Never were they meant to prevent access to appropriate services. And yet, healthcare delivery and funding systems are increasingly trying to mandate the use of specific tools in the diagnostic assessment of ASD. This can be extremely damaging in situations when standardized instruments cannot be validly administered. In addition, blanket requirements directly contradict best practice recommendations for individualizing assessment procedures." (p. 835).
  - "...given the extreme heterogeneity that characterizes this population, the ASD diagnosis itself is less likely to guide treatment planning or provide meaningful information about prognosis than information about an individual's profile of cognitive, language, and adaptive behavior skills, as well as medical and psychiatric symptoms." (p. 836)



The Council of Autism Service Providers

#### Applied Behavior Analysis Practice Guidelines for the Treatment of Autism Spectrum Disorder

Guidance for Healthcare Funders, Regulatory Bodies, Service Providers, and Consumers



- CASP: independent nonprofit trade association for organizations that provide ABA services
- Most recent edition of guidelines initially published by nonprofit Behavior Analyst Certification Board in 2012 and 2014
- Derived from reviews of research and best practices by scores of subject matter experts in behavior analysis, psychology, medicine, healthcare law and other public policies, and consumers of ABA services

#### Available at

https://www.casproviders.org/sta ndards-and-guidelines

- Section 4.1 Assessment
  - Goal: Determine patient baseline skills, develop treatment goals and plan, identify measures of progress
  - Standards
    - Conduct at regular intervals -- annually or semi-annually for comprehensive assessment
    - Use multiple sources and processes:
      - Record review
      - Interviews patient, caregivers, other relevant stakeholders
      - Direct observation and recording of target behaviors in everyday environments
        - Include functional behavior assessment to identify environmental events that influence challenging behaviors
        - Graphed data reviewed frequently throughout treatment by behavior analyst responsible for case

- Section 4.1 Assessment Sources & processes (cont'd)
  - Standardized assessments
    - Norm- and/or criterion-referenced
    - Valid and reliable
    - Individualized to patient characteristics, characteristics of instrument, scope of treatment (*comprehensive* [multiple behaviors in multiple domains] or *focused* [small number of discrete behaviors]),
    - Direct and indirect
      - Indirect measures (completed by parents and other third parties) should not be sole or main sources of information for determining medical necessity, treatment dosages, continuation or termination of services, or other critical decisions.
    - Results of standardized assessments should not be sole or primary basis for determining medical necessity of ABA services or patient's response to treatment.

- re
- Section 4.1 Assessment Sources & processes (cont'd)
  - Risk assessment
    - Screen for emergence of challenging behaviors (e.g., self injury, property destruction, aggression, pica, elopement) every 6 – 18 weeks
    - If challenging behavior occurs, assess further:
      - Evaluation for medical issues, comorbid conditions
      - Functional behavior assessment
      - Direct observation and recording in everyday situations
      - Caregiver interviews, questionnaires, rating scales
  - Periodic assessments from and collaboration with other professionals



- Section 4.4 Progress and Outcome Measures
  - Complex process; many factors contribute to outcomes
  - It is "...unlikely that a single set of metrics will be sensitive to treatment outcomes across the entire patient population."
  - Instruments and procedures for measuring progress and outcomes should
    - Be valid and reliable
    - Be tailored to
      - Patient characteristics
      - Treatment scope (comprehensive or focused), domains, and goals
    - Use multiple methods and sources
    - Evaluate proximal (short-term) and distal (long-term) outcomes



- Section 4.4 Progress and Outcome Measures (cont'd)
  - Cautions:
    - Currently no consensus or standard for determining "successful" treatment based on percentage of treatment goals mastered.
    - If outcome measures required by funder or provider organization are not appropriate for the patient, behavior analyst or organization should say so and select additional measures.
    - Selection of instruments and other sources must be driven by evidence of appropriateness for patient rather than what is familiar to or popular with clinicians.

#### Standardized Measures Commonly Used in ABA Treatment Outcome Studies with Autistic Individuals

- Comprehensive, intensive ABA for young children (ages  $\leq$  7 yrs)
  - <u>Direct</u>
    - Intellectual skills Bayley Scales of Infant Development, Mullen Scales of Early Learning, Wechsler Preschool and Primary Scale of Intelligence or Intelligence Scale for Children, Stanford-Binet, Psychoeducational Profile, Differential Abilities Scale
    - Autism core symptoms ADOS
    - Communication skills Reynell Developmental Language Scales, Peabody Picture Vocabulary Test, Expressive One Word Picture Vocabulary Test, Preschool Language Scale
  - Indirect
    - Adaptive functioning Vineland Adaptive Behavior Scales, Child Behavior Checklist, Developmental Profile
    - Autism core symptoms Autism Diagnostic Interview, Childhood Autism Rating Scale, Gilliam Autism Rating Scale, Social Responsiveness Scale
    - Maladaptive behavior Vineland Maladaptive Domain, Child Behavior Checklist, Repetitive Behavior Scale-Revised
    - **Caregiver wellbeing** Parental Stress Index

#### Standardized Measures Commonly Used in ABA Treatment Outcome Studies with Autistic Individuals

- Focused ABA interventions (all ages)\*
  - Challenging behaviors
    - Aberrant Behavior Checklist
    - Vineland (esp. Maladaptive Domain)
    - Parental Stress Index
    - Clinical Global Impression Improvement Scale
  - Social communication skills
    - Early Social Communication Scales
    - Social Responsiveness Scale
    - Social Skills Improvement System Rating Scale
    - Behavioral Assessment System for Children
    - Vineland Communication Domain

\*NOTE: The most common measurement method used in studies and clinical practice is direct observation and recording of specific target behaviors. Few standardized assessments detect changes in the small numbers of discrete behaviors that are targeted in focused ABA <sup>17</sup> interventions.



## Resources

American Educational Research Association, American Psychological Association, & National Council on Measurement in Education (2014) *Standards for Educational and Psychological Testing.* Washington, DC: American Educational Research Association. <u>https://www.testingstandards.net/uploads/7/6/6/4/76643089/standards\_2014edition.pdf</u>

Behavior Analyst Certification Board (2020). *Ethics Code for Behavior Analysts*. <u>https://bacb.com/wp-content/ethics-code-for-behavior-analysts/</u>

Bishop, S.L. & Lord, C. (2023). Commentary: Best practices and processes for assessment of autism spectrum disorder – the intended role of standardized diagnostic instruments. *Journal of Child Psychology and Psychiatry, 64(5),* 834 -838. doi: 10.1111/jcpp.13802

Boateng, G.O., Neilands, T.B., Frongillo, E.A., Melgar-Quinones, H.R., & Young, S. (2018). Best practices for developing and validating scales for health, social, and behavioral research: A primer. *Frontiers in Public Health, 6,* 1 – 18. doi: 10.3389/fpubh.2018.00149

Bolte, E.E., & Diehl, J.J. (2013). Measurement tools and target symptoms/skills used to assess treatment response for individuals with autism spectrum disorder. *Journal of Autism and Developmental Disorders, 43,* 2491 – 2501. doi: 10.1007/s10803-013-1798-7

Brugha, T.S., Doos, L., Tempier, A., Einfeld, S., & Howlin, P. (2015) Outcome measures in intervention trials for adults with autism spectrum disorders: A systematic review of assessments of core autism features and associated emotional and behavioural problems. *International Journal of Methods in Psychiatric Research, 24(2), 99 –* 115 doi: 10.1002/mpr.1466

Cooper, J.O., Heron, T.E., & Heward, W.L. (2019). Applied behavior analysis (3rd ed.) Upper Saddle River, NJ: Pearson.

Council of Autism Service Providers (2024) Applied Behavior Analysis Practice Guidelines for the Treatment of Autism Spectrum Disorder: Guidance for Healthcare Funders, Regulatory Bodies, Service Providers, and Consumers (3<sup>rd</sup> Ed.). https://www.casproviders.org/standards-and-guidelines

Goldstein, S. (2018) Historical perspective and overview. In S. Goldstein & S. Ozonoff (Eds.), *Assessment of autism spectrum disorder* (2<sup>nd</sup> ed., pp. 1 – 25). New York: Guilford Press.



## Resources

Grzadzinski, R., Janvier, D., & Kim, S.H. (2020). Recent developments in treatment outcome measures for young children with autism spectrum disorder (ASD). *Seminars in Pediatric Neurology*, *34*, 100806. doi.org/10.1016/j.spen.2020.100806

Hanratty, J., Livingstone, N., Robalino, S., Terwee, C.B., Glod, M., Oono, I.P., et al. (2015) Systematic review of the measurement properties of tools used to measure behaviour problems in young children with autism. *PLoS ONE 10(12):* e0144649. doi:10.1371/journal.pone.0144649

Hayden-Evans, M.,Milbourn, B., D'Arcy, E., Chamberlain, A., Afsharnejad, B., Evans, K., Whitehouse, A.J.O., Bölte, S., & Girdler, S. (2022) An evaluation of the overall utility of measures of functioning suitable for school-aged children on the autism spectrum: A scoping review. *International Journal of Environmental Research and Public Health, 19,* 14114. doi.org/10.3390/ijerph192114114

Hedges, S.H., Shea, V., & Mesibov, G.B. (2018) Age-related issues in the assessment of autism spectrum disorder. In S. Goldstein & S. Ozonoff (Eds.), *Assessment of autism spectrum disorder* (2<sup>nd</sup> ed., pp. 130 - 146). New York: Guilford Press.

Johnston, J.M., Pennypacker, H.S., & Green, G. (2020). *Strategies and Tactics of Behavioral Research and Practice (4th ed)*. New York: Routledge. ISBN 9781138641594

McConachie, H., Parr, J.R., Glod, M., Hanratty, J., Livingstone, N., Oono, I.P., et al. (2015) Systematic review of tools to measure outcomes for young children with autism spectrum disorder. *Health Technology Assessment, 19(41).* doi: 10.331/hta19410

Melanson, I.J. & Fahmie, T.A. (2023). Functional analysis of problem behavior: A 40-year review. *Journal of Applied Behavior Analysis*, *56*, 262-281. doi: 10.1002/jaba.983

Naglieri, J.A., Chambers, K.M., McGoldrick, K.D., & Goldstein, S. (2018). Psychometric issues and current scales for assessing autism spectrum disorder. In S. Goldstein & S. Ozonoff (Eds.), *Assessment of autism spectrum disorder* (2<sup>nd</sup> ed., pp. 96 – 129). New York: Guilford Press.

Powell, K.K., Heymann, P., Tsatsanis, K.D., & Chawarska, K. (2018). Assessment and diagnosis of infants and toddlers with autism spectrum disorder. In S. Goldstein & S. Ozonoff (Eds.), *Assessment of autism spectrum disorder* (2<sup>nd</sup> ed., pp. 26 – 71). New York: Guilford Press

#### Resources

Padilla, K.L., Weston, R., Morgan, G.B., Lively, P., & O'Guinn, N. (2023). Validity and reliability evidence for assessments based in applied behavior analysis: A systematic review. *Behavior Modification*, *47(1)*, 247-288. doi:10.1177/01454455221098151

Ridout, S., & Eldevik, S. (2024) Measures used to assess treatment outcomes in children with autism receiving early and intensive behavioral interventions: A review. *Review Journal of Autism and Developmental Disorders, 11,* 607-619. doi.org/10.1007/s40489-023-00355-9

Santhanam, S.P. & Hewitt, L.E. (2016) Evidence-based assessment and autism spectrum disorders: A scoping review. *Evidence-Based Communication Assessment and Intervention, 9,* 140 – 181. doi.org/10.1080/17489539.2016.1153814

Smith, I.C., Pugliese, C.E., Corbett, B.A., & White, S.W. (2018) Future directions in the assessment and treatment of autism spectrum disorder. In S. Goldstein & S. Ozonoff (Eds.), *Assessment of autism spectrum disorder* (2<sup>nd</sup> ed., pp. 442 - 476). New York: Guilford Press





# Thank you!