Evaluation, Communication, and Facilitation of ASD

A Light Overview for Practitioners

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Disclosures

- Charles Galyon is a licensed psychologist working in private practice and with some academic affiliations at the University of Tennessee
- No commercial conflicts to report with respect to the tools and techniques described in this workshop
- Considered neurodiverse
  - It has provided a lifetime of interesting experiences
  - Very argumentative and stubborn by nature

Soap Box

- Neurodiversity – let's serve all as individuals
  - Diversity by its nature does not conform to conceptualization or expectation
- Respecting all, not just the vocal
- Around half of individuals with ASD experience profound impact and may be unable to communicate
- Respecting that what works for one may not work for another
- Transdiagnostic model vs Categorical model

Overview

Evaluation of ASD

- Evaluating quality of measures
- How to build a battery
- Modifying and customizing for examinees

Interpreting and Communicating Neurodiversity

- Diagnosis describes but does not change
- Reframing as differences as opposed to rankings/hierarchy
- Teaching how to identify strengths and challenges
- Deficits are opportunities

Reviewing Research to Plan Next Steps

- Identifying evidence-based practice
- Respecting and utilizing practices that lack evidence
- Treating as people rather than problems

Evaluating Quality of Measures

Lots of measures now but not all have strong evidence

Should have large samples of individuals

- At least hundreds and ideally thousands
- Include “typical” population as well as diagnosed populations
- Ideally include different diagnostic populations (e.g., ASD, Anxiety, ADHD, Intellectual Disability, Second Language Learners…)
- Demographic Diversity essential (good representations of male/female, cis/LGBTQ, SES levels, ethnic backgrounds…)
- Represent diversity of individuals with ASD, not just one subgroup (e.g., HFA)

Credibility of Measures

- Should have many studies:
- Norming – establishing results typical of those with and without diagnoses
- Reliability – meaning that results are consistent
- Validity – comparing with others, should produce similar results
- **Specificity – accurately says “No” when diagnostic criteria not met**
- **Sensitivity – accurately says “Yes” when diagnostic criteria are met**

Heterogenous Disorder (Neurodiversity)

"Spectrum" is not linear

- There is a severity scale (Level 1 to 3) indicating amount of support that would be appropriate
- Cluster of traits and characteristics that have been observed by others
- More like a big circle with lots of dots in it

Characterized by being more heterogenous than rest of population

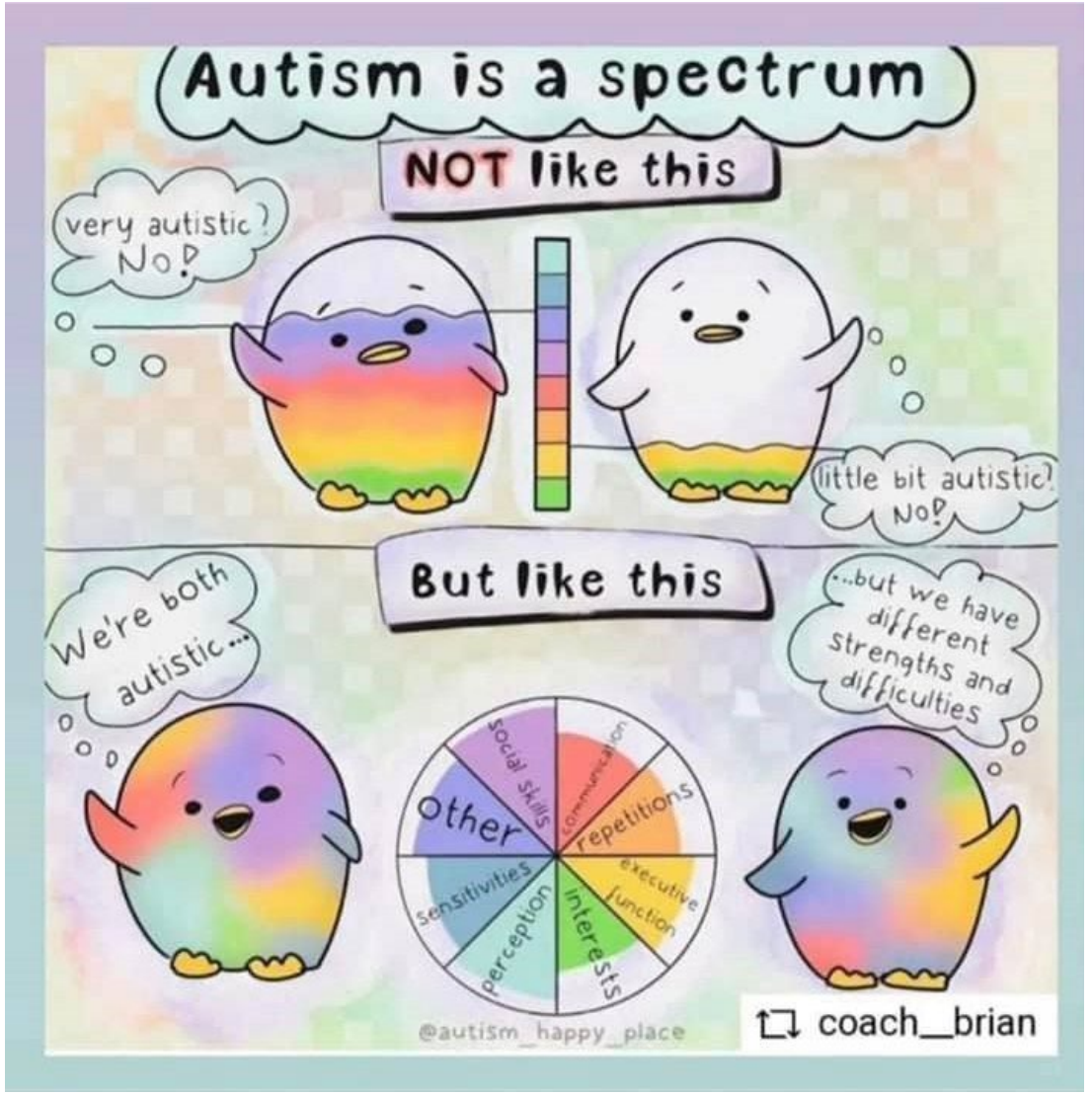
- Characteristics and traits of ASD show up to varying degrees
- May be present or completely absent between individuals

Neuroimaging studies show low consistency in how brain organizes

- Most people show consistent ways of brain organizing (visual area, motor area, association areas…)
- With ASD there is NOT a consistent difference; some look exactly like "typical" people neurologically, others are simply different
- These differences do not appear to explain well the characteristics in a diagnostic way

Spectrums are not inherently linear!

- It’s not just severity (Level 1, 2, 3)
- Many characteristics - not always problematic
- More characterized by variety
- Core feature: Social difficulty
  - Lower insight
  - Lower awareness
  - Leads to atypical response
- People are not socks!



How to Build a Better Battery

Some tests are overly sensitive and do not discriminate well (Screeners)

- Examples: Gilliam Scales (GARS, GADS), M-CHAT…
- Provide the first step of saying “We should look further”
- **Not intended to be diagnostic**

No single measure is enough to identify ASD and not intended to be

- ADOS-2 is great, but not enough
- E.g., To measure volume requires multiple measurements

Goal is to assess as a Whole Person

- Want to know where they struggle
- And understand emotional impact
- So can provide help where it matters most

Components: Cognitive (IQ) Test

First: Please understand IQ tests do not measure “intelligence” but are intended to predict acquisition of academic and life skills!

- ASD more commonly characterized by inconsistent subscale scores
- Often significant differences between verbal and nonverbal reasoning
- Presence or absence of difference is NOT diagnostic by itself
- Provides information to aid with planning
- Helps understand some experiences with frustration/challenges
  - Expectations vs Experience
  - Example: Like/Hate Math or Writing

Components: Social, Emotional, Behavioral Scales

General behavioral, social, and emotional rating scales

- Captures other areas worthy of attention
  - Attention, Hyperactivity, Conduct Problems
  - Anxiety, Depression, Self-Esteem
  - Social Engagement, Peer Difficulties
- Highlights patterns to support diagnosis
  - Certain combinations flag for ASD (“Hey, maybe take a look here!”)
  - Provides a broader picture of a person
  - Focusing only on evidence for ASD makes more likely to find ASD
- Includes things like the BASC-3, MASC-2, CDI-2

Components: Adaptive Behaviors

Adaptive Rating Scales (such as Vineland-3 or ABAS-3)	• Behaviors for day-to-day living
May identify areas that need additional support and teaching	• A deficit in a skill is not a deficit in a person
Skills that may be helpful	• Recognize can help teach a skill and makes life easier
Helps others adjust their expectations and understand	• Understanding can reduce frustration (a bit)

Components: Social Behavior Scales

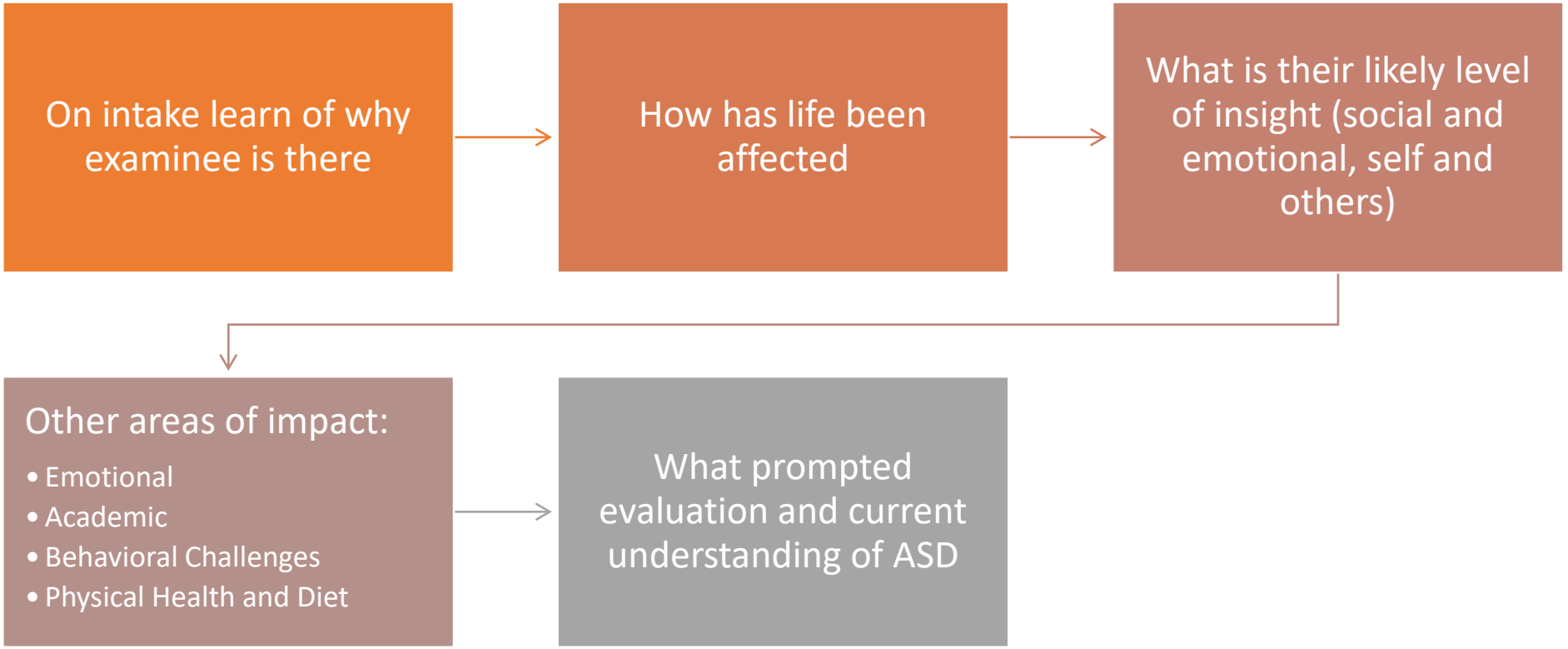
Specifically intended to assess for level of social difficulties

Should examine multiple aspects of social behavior

- Social communication
- Social response
- Social insight
- Social interest

Some useful tools: ADOS-2, SRS-2, RAADS-R

Modifying and Customizing



Selection of Measures

Ensure developmentally appropriate

- Assess level of verbal skill and insight
- Select appropriate activities (amount of play, conversation)

Structuring evaluation sessions

- Consider attention span and motivation level
- More, shorter chunks vs fewer, longer chunks
- Use of intermittent reinforcement and breaks

Providing Results

Who will results be communicated to?

- If child, may talk with parents but not child
- Practice empathetic perspective while writing report
- Prepare for unanticipated questions
  - Acknowledging anxiety and uncertainty for self
  - Allowing pause
  - Conceding limits of own knowledge (models that it's ok to not know)
- Time and Space:
  - Allow time for questions
  - Allow space for emotions

Talking with Parents

Despair, grief, worry, anger, frustration, relief, hope

- Because child is not what they imagined would be
- Because they blame themselves
- Because they don't know who to blame and feel a need to
- "Knowing" may feel better
- Hope that it provides direction

Diagnosis describes but does not change the child

- "Your child is exactly the same as before the evaluation"
- Sit with parents so they can process this and then ask questions
- Results sessions can run longer than expected
- Invite delayed questions – email or subsequent appointments

Differences not Hierarchies

- Neurodiversity is a difference and has real effects
- A difference is neither better nor worse
- *It does have an impact on how one lives though*

Example:

- Impaired vision is a difference. Can choose to wear glasses or not. If not, life will be different and sometimes harder. World assumes one can see and doesn't/can't/won't accommodate otherwise.

Opportunities and Challenges

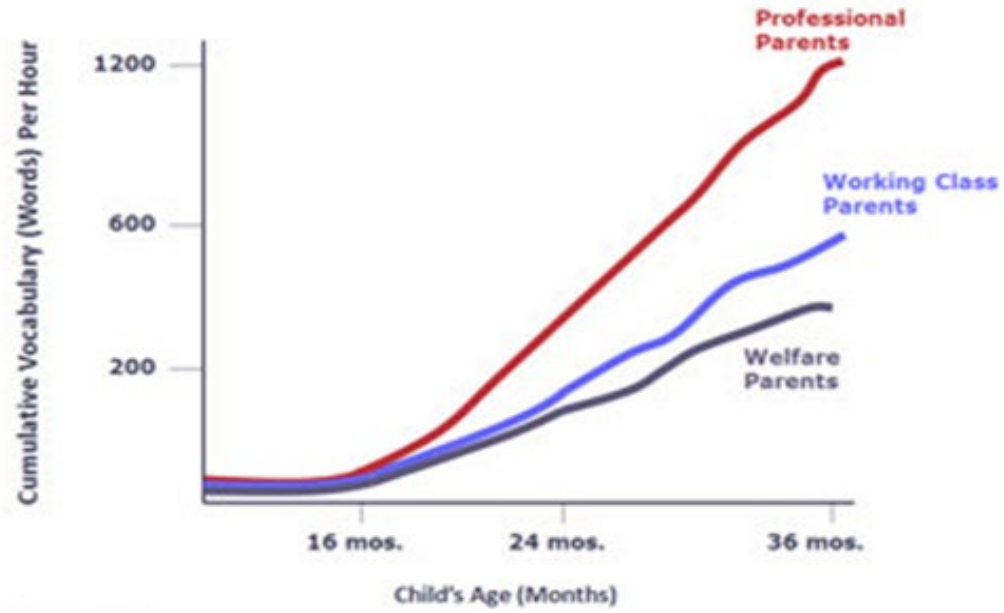
- If cannot see, it is harder to learn some skills (like hitting a baseball). Once *can* see, then can start learning to coordinate swinging. Ability to swing a bat was always there, but skill wasn't learned.
- Becoming aware of social behaviors provides opportunity, but skill is not as developed at first (hence evaluation).
- ASD does *not* mean does not have social interest or ability to see emotions and social stimuli. However, history of being unaware leaves skills less developed compared to others.

Opportunities and Challenges

- Therapy, social skills training, etc… is putting on glasses.
- Consider role of “willingness to change” as applied with skill development – respect autonomy
- Practice unconditional acceptance, take time to learn what matters to client, and tailor treatment accordingly
  - Ex: earmuffs in public – stigma vs experience
  - Does it matter? To whom? (client or therapist?)
  - Run past people when feels awkward
  - “Would you like to change it?”

Strategic Skill Building

- Think in terms of strategy and creating doors
- Acting in present to direct the future
- Once a skill is an option, then it may occur
- Once a skill occurs, it can be responded to
- Communication is fundamental for humans
  - Much of challenging behavior arises from miscommunication
  - Inability to communicate is frustrating (needs/wants not met)



What is an Evidence-Based Practice

"The good life is one inspired by love and guided by knowledge." – Bertrand Russell

- There are many people motivated to help
  - Because the world can be a wonderful place!
- There are many people who *want* help
  - There is a highly vulnerable population in parents and individuals
- There is too much information out there
  - Hard to determine what has good evidence
  - Hard to know all the mechanisms
  - No "Seal of Quality"

What Can We Look For?

Mechanism of Change

- If I am proposing A as treatment, how is it supposed to work?
- “By acting on (b, c, and e)”
- Is there good evidence that (b, c, and e) actually matter?

Randomized Control Trials

- Comparing different conditions to see if there are differences in effect
- If I am using A, then I will compare to Nothing and to someone using B
- Does A produce a significantly different result than Nothing and B?

Independent Verification

- People with no stake, no conflict of interest evaluate it
- (See Pearson’s cognitive training program…)

What to Watch Out For

Clarity and Openness

- I would prefer the author says “I have no idea if this works, but I feel like it is a helpful thing and have had some good results. So you may want to try it too.”
- Always represent speculation for what it is; don’t try to pass it off as scientific if it isn’t yet
- Clearly state limitations and what is unknown

Almost never a definite result (death is definite, but that’s about it)

- Ex: IQ tests usually are predictive, but cannot tell for whom they won’t be

As professionals we are protecting a vulnerable population

- Parents can be in tremendous pain and desperate
- Snake Oil is alive and well

The National Standards project produced a helpful resource

- State of evidence on different treatments and modalities
- https://nationalautismcenter.org/national-standards-project/phase-2/

Harm – Direct and Indirect

Some things are directly harmful

- Auditory devices for ASD
- Restricted diets
- Trauma-inducing procedures

Some things are indirectly harmful

- Loss of time spent in effective interventions
- Misinformation
- Setting false expectations for improvement

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