Measuring Mental Health and Related Factors in Autistic People: State of the Science, Implications, and Future Directions

Hillary K. Schiltz, M.S.

Clinical Psychology Intern, Autism and Neurodevelopmental Disabilities Assessment Track, UCLA

PhD Candidate in Clinical Psychology, Marquette University

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- Alana McVey, PhD
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- I have no disclosures

A note about language

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Perspectives

Avoiding Ableist Language: Suggestions for Autism Researchers

Kristen Bottema-Beutel, PhD,[1] Steven K. Kapp, PhD,[2] Jessica Nina Lester, PhD,[3] Noah J. Sasson, PhD,[4] and Brittany N. Hand, PhD, OTR/L[5]

Identity first language (i.e., autistic person) will be used throughout this presentation to align with recent research findings identifying a preference for person first language among many stakeholders and with published recommendations to avoid ableist language in autism research.

Learning Objectives

1) Describe at least one reason why accurate measurement of mental health and related factors is important for research and clinical work with autistic individuals.
2) Identify and define qualities of a “good” questionnaire.
3) Describe at least one way researchers and clinicians can work to improve measurement among autistic people.

Outline

Background on Autism

- Diagnostic Criteria
- Mental Health & Autism

Focus on Measurement

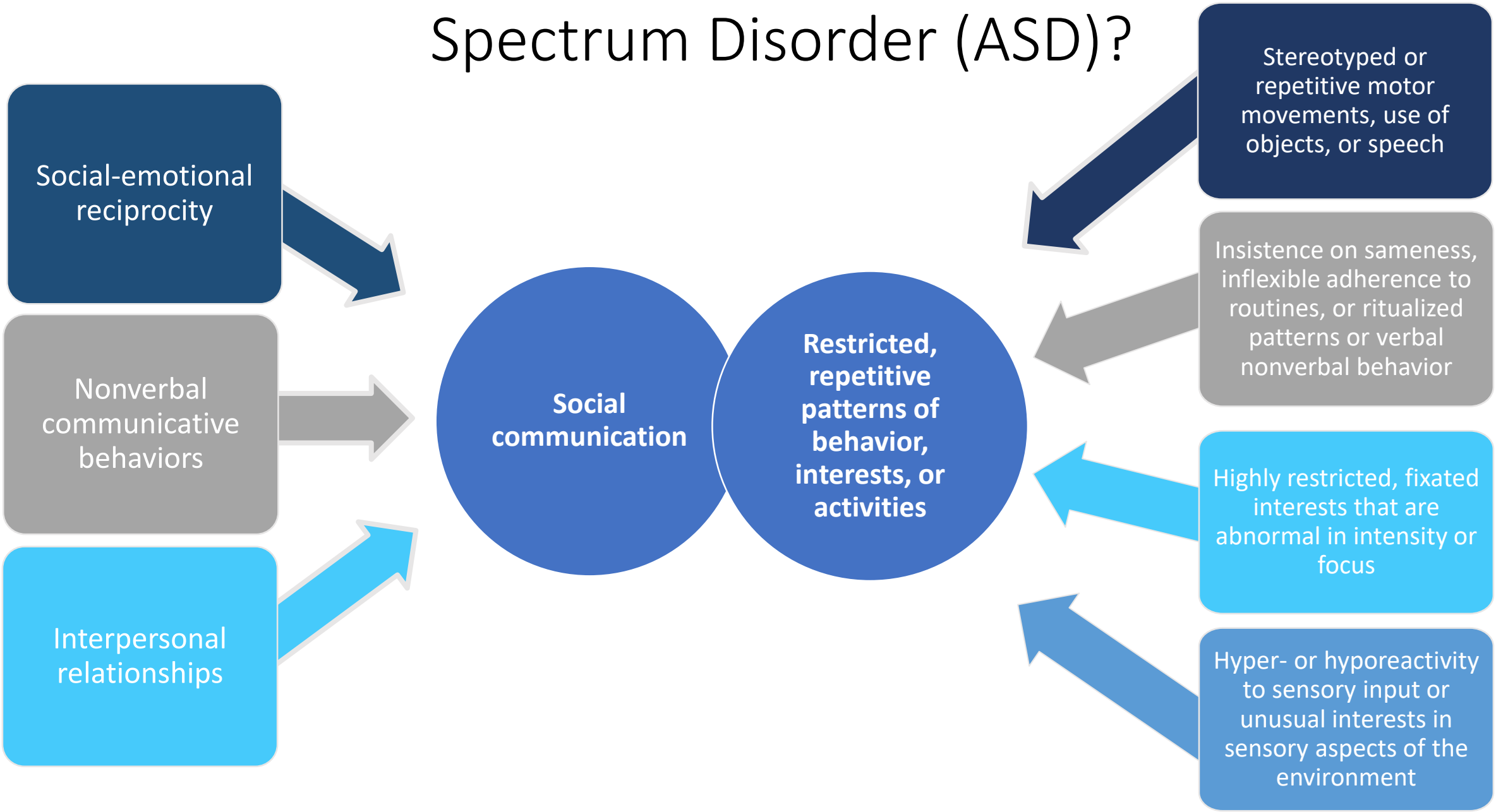
- Role of Measurement for Clinical Practice & Research
- Qualities of Good Measures
- Challenges of Measurement in Autism
- Example Questionnaires/Research Studies

Recommendation & Future Directions

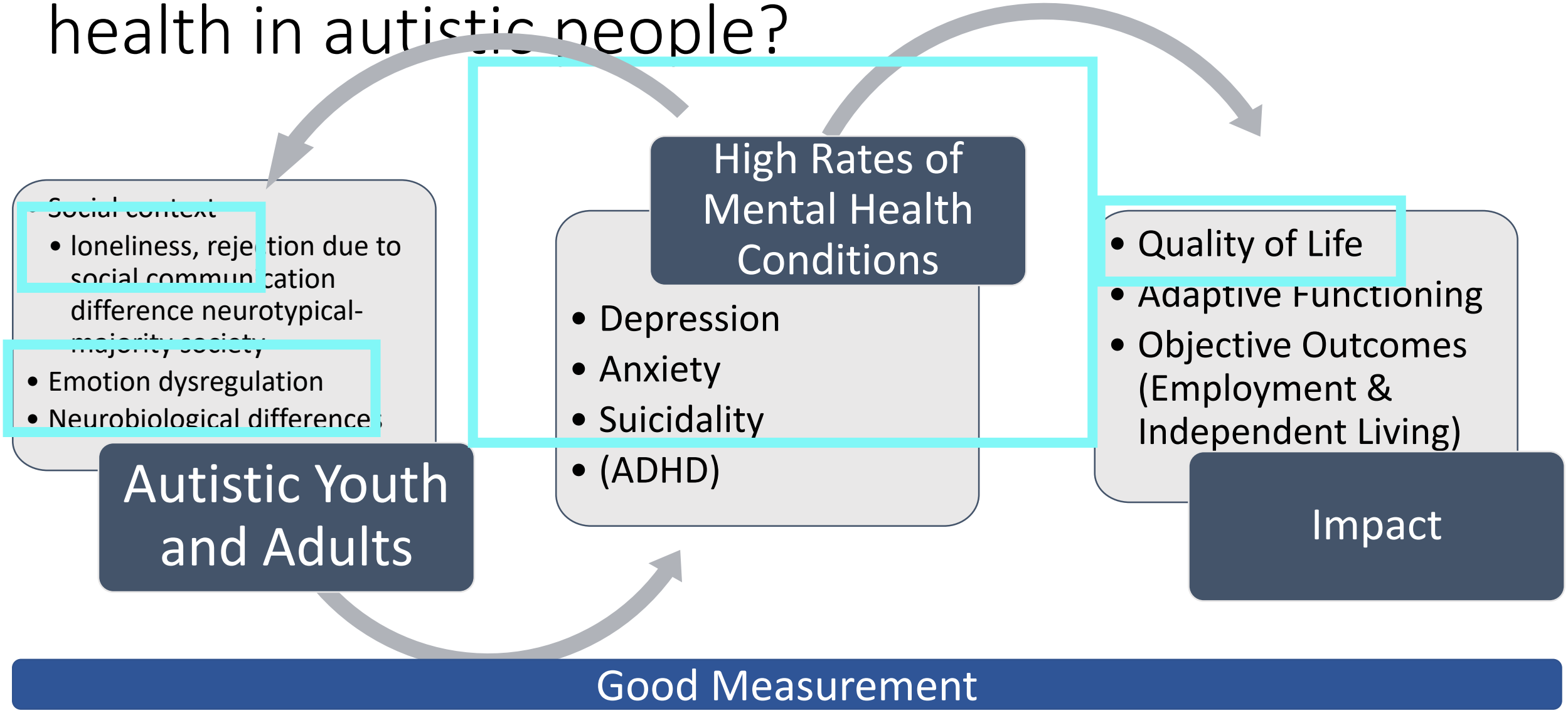
- Researchers
- Clinicians
- Stakeholders

Background on Autism & Mental Health

What are the diagnostic criteria for Autism Spectrum Disorder (ASD)?



What does existing research tell us about mental health in autistic people?



(Conner et al., 2020; Farley et al., 2009; Hollocks et al., 2018; Lawson et al., 2020; Schiltz et al., 2021)

Focus on Measurement

Measurement Matters

Mental Health Across the Lifespan

autism

Autism
2020, Vol. 24(4) 822–833

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Listening to the autistic voice: Mental health priorities to guide research and practice in autism from a stakeholder-driven project

Teal W Benevides[1], Stephen M Shore[2], Kate Palmer[3], Patricia Duncan[3], Alex Plank[3], May-Lynn Andresen[4], Reid Caplan[3], Barb Cook[5], Dena Gassner[2], Becca Lory Hector[3], Lisa Morgan[3], Lindsey Nebeker[3], Yenn Purkis[3], Brigid Rankowski[6], Karl Wittig[3] and Steven S Coughlin[1]

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Guest Editorial

Measuring What Matters in Autism Research and Practice

Teal W. Benevides, PhD, MS, OTR/L,[1] and Sarah A. Cassidy, PhD[2]

Journal of Autism and Developmental Disorders (2018) 48:925–934
https://doi.org/10.1007/s10803-017-3320-0

ORIGINAL PAPER

CrossMark

Priorities for Advancing Research on Youth with Autism Spectrum Disorder and Co-occurring Anxiety

Roma A. Vasa[1] · Amy Keefer[1] · Judy Reaven[2] · Mikle South[3,5] · Susan W. White[4]

Published online: 21 November 2017

Measurement: What role does measurement play in **autism research** on mental health?

Identifying prevalence of co-occurring conditions

Exploring how co-occurring mental health conditions emerge over time

Examining patterns of co-occurring conditions (who is most at risk)

Evaluating efficacy of treatment

Measurement: What role does measurement play in **clinical practice** with autistic people?

Assessment

- Differential diagnosis and diagnostic clarity
- Guiding recommendations

Therapy

- Identifying treatment targets
- Monitoring treatment progress & outcomes

Measurement Methods: What tools do we have?

- Questionnaires
  - Self-Report
  - Caregiver/Other Report
- Interviews
  - Structured
  - Semi-structured
  - Unstructured
- Observation

Measurement: What makes a good measure?

Measures what it is supposed to (Validity)

Works generally the same each time we use it (Reliability)

Tells us when there is change (Sensitivity)

Good Measure

Strong Psychometric Properties

Measurement: What makes a good measure?

Validity

It measures what it is supposed to

- Does it measure the construct we want to measure? (Construct)
  - Associations with related/unrelated constructs (Convergent & Divergent)
  - Multiple aspects of construct and how these are related to each other (Structural; Dimensionality)
- Coverage of construct (Content)

Measurement: What makes a good measure?

Validity

It measures what it is supposed to

Does it work the same for:

- all autistic as well as non-autistic people
- across various intersecting identities and characteristics

or are there systematic differences? (Differential Item Functioning/ Measurement Invariance Testing)

Measurement: What makes a good measure?

Reliability

It works consistently

- Does it give a similar result over time (test-retest)?
- Do people respond similarly across the items within the measure (internal)?

Measurement: What makes a good measure?

Sensitivity to Change/ Responsiveness

It detects change

- Does it tell us when something has changed, either over time or across intervention?

What are some barriers that exist to accurate measurement among autistic people?

Any-Reporter	Most measures were developed and normed with the general population.
	Autism-related experiences may not be captured by existing tools
Self-Report	Common difficulty identifying internal states in autism (alexithymia)
	Range of verbal/cognitive abilities in autism
Other-Report	Reliance on observable behaviors by caregivers and other reporters
	Misinterpretation of autism symptom as those of a different condition or vice versa (diagnostic overshadowing or overlap)

(Kinnaird et al,. 2019; Kerns et al., 2015; Nicolaidis et al., 2020;)

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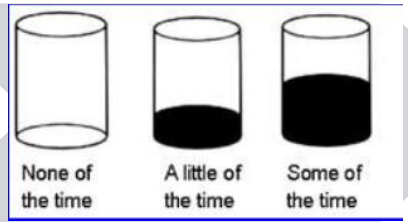
Advances in Measurement Methods

Creating Accessible Survey Instruments for Use with Autistic Adults and People with Intellectual Disability: Lessons Learned and Recommendations

Christina Nicolaidis, MD, MPH,[1–4] Dora M. Raymaker, PhD,[1,3,4] Katherine E. McDonald, PhD,[3,5] Emily M. Lund, PhD, CRC,[4,6] Sandra Leotti, PhD,[1,4,7] Steven K. Kapp, PhD,[3,8] Marsha Katz, MS ED,[4,9] Leanne M. Beers, PhD,[4] Clarissa Kripke, MD,[3,10] Joelle Maslak, BA,[3] Morrigan Hunter, MA,[3] and Kelly Y. Zhen[1,3]

Examples of Identified Issues & Recommendations (Nicolaidis et al., 2020)

Issue	Recommendation	Example
Complicated or confusing terms or phrases	substitute language or use hotlink	lonely → the feeling of being alone when you do not want to be alone
Likert scales with imprecise or vague response options	use graphics and/or percentages	
Anxiety around answering accurately	reminder to give best guess & comment boxes	please give your best guess from the provided answers
Inability to fully capture construct	add items as necessary	items about sensory sensitivities or communication skills

Examples of measures that have been **developed/adapted for** autistic people

Emotion Dysregulation Inventory
(Mazefsky et al., 2018)

- Caregiver-report of youth
- Used PROMIS guidelines

Set of guidelines developed by an NIH Roadmap Initiative with leading experts in the field

Key PROMIS Steps:
- define target concept and make a model; get feedback on model
- develop item pool based on existing measure and new items
- see how people interpret/respond to items using cognitive interviews
- perform pilot testing followed by larger scale testing using IRT

World Health Organization Quality of Life–Brief Version with autism spectrum QoL Supplement
(Rodgers et al., 2016)

- Adults self-report
- Developed autism-specific quality of life (ASQoL) questions to add to WHOQoL-BREF
- ASQoL may underestimate QoL in autistic women

Examples of measures that have been **developed/adapted for** autistic people

Parent-Rated Anxiety Scale for ASD (PRAS-ASD)
(Scahill et al., 2019)

- Parent-report of youth
- Developed using focus groups and IRT

Anxiety Scale for Children with Autism Spectrum Disorder (ASC-ASD)
(Rodgers et al., 2016)

- Parent- and self-report of youth
- Adapted from: Revised Child Anxiety and Depression Scale
- Re-worded items, new items

Examples of measures that have been **evaluated/tested among** autistic people

Suicidal Behaviour Questionnaire-R

- Self-report measure of suicidality for **adults**
- Measurement invariance & cognitive interviews indicate need for adaptations

(Cassidy et al., 2020)

Beck Depression Inventory II

- Self-report measure of depression for **adults**
- Rigorous testing indicates this is a good measure for autistic adults

(Williams et al., 2020)

Screen for Anxiety Related Disorders

- Caregiver report of a measure for **children**
- Caregivers respond to some items differently depending on their child's autism features, IQ, and age

(Schiltz et al., 2021)

Difficulties with Emotion Regulation Scale

- Self-report measure for **adolescents to adults**
- Overall, performs well, with some modifications (e.g., some items loading on different factors)

(McVey, Schiltz, et al., 2021)

Social Anxiety Scale for Adolescents

- Both Adolescent report and Parent report

- Items:
  - 18 items related to anxiety
  - 4 filler items (e.g., my child/I likes to play sports)

- 5-point Likert scale:
  - 1 *Not at all* to 5 *All of the time*

- Three subscales:
  - Fear of Negative Evaluation (FNE) - I worry that others don't like me
  - General Social Avoidance and Distress (SAD-G) - I am quiet when I'm with a group of people
  - Avoidance and Distress Specific to New Situations (SAD-N) - I get nervous when I meet new people

(Schiltz et al., 2021)

SAS-A has been used to examine:

- Prevalence of Social Anxiety in ASD
- Correlates of Social Anxiety in ASD
  - Neurophysiological (EEG)
  - Behavioral (Social Abilities)

(Schiltz et al., 2021)

Psychometric Assessment of SAS-A in Autism

- Adolescent-parent item-level agreement → Poor
- Factor Structure → Two-Factors
- Measurement Invariance → Lack of Evidence
- Convergent and Divergent Validity → Some Evidence

(Schiltz et al., 2021)

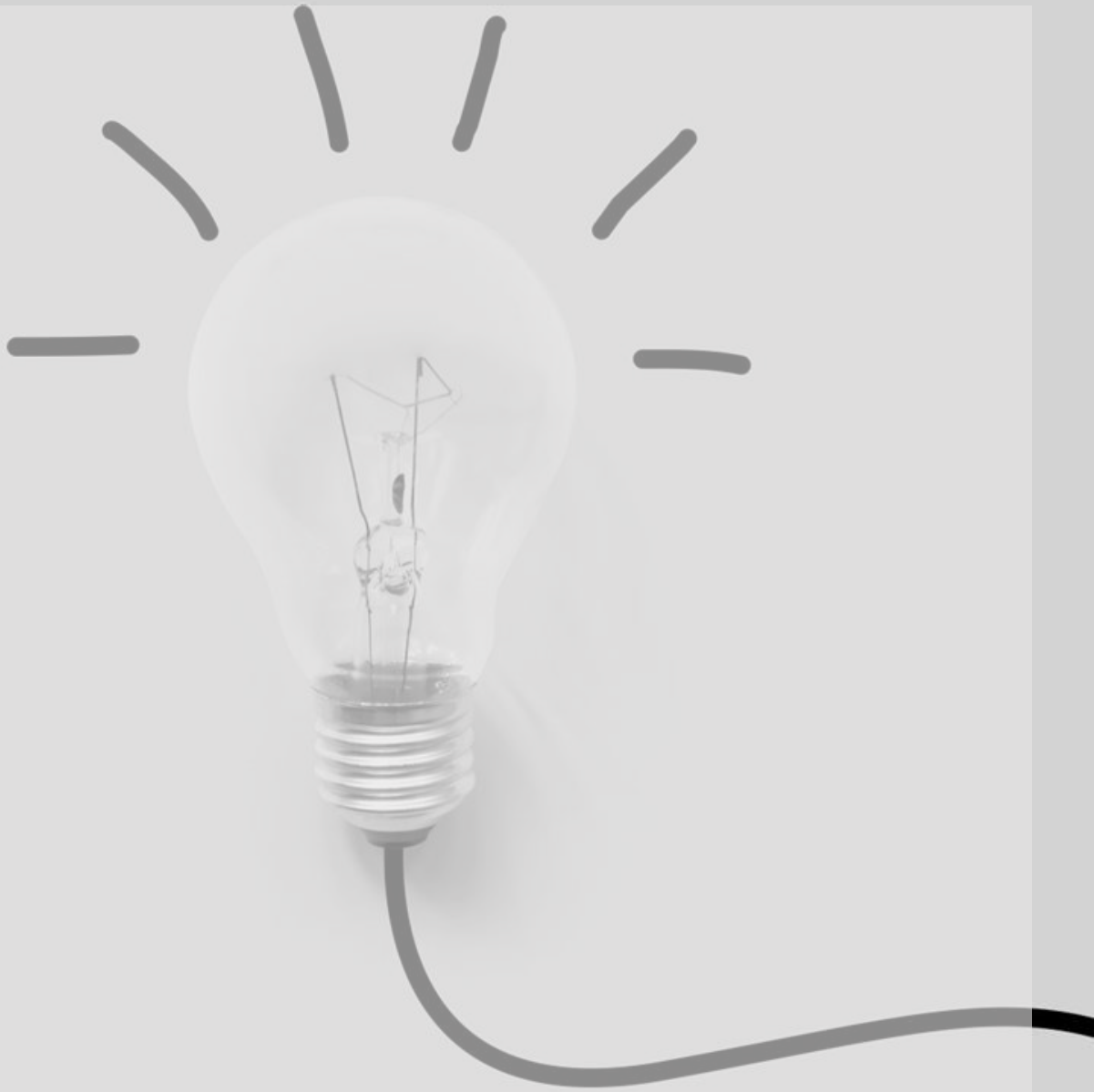
Recommendations & Future Directions

We know more about

- Anxiety
- Children
- Parent-report
- People without intellectual disability

We know less about

- Other constructs
- Adults
- Self-report
- People with intellectual disability



(Kim & Lecavalier, 2021)

Recommendations: Researchers

- Considerations for **selecting measures** for studies
  - Choose measures that have psychometric support in autism
  - Make evidenced based adaptations as necessary
  - Multi-method, multi-informant approach

Future Directions: Measurement Researchers

- Do **more research** on measurement!
  - Evaluating measures, and when necessary, adapting/developing measures for autism
  - Focus on areas with less evidence: adults, ID, self-report, other than anxiety
  - Involve stakeholders (e.g., focus groups, cognitive interviews, etc.)
  - Use advanced psychometric approaches (e.g., IRT)
    - Test measures for bias (both comparing autistic to non-autistic respondents as well as within autistic individuals – like IQ, gender, race)
  - An example approach is the PROMIS Method

Recommendations: Clinicians

- Considerations for **selecting measures** in clinical practice
  - Choose measures that have psychometric support in autism
  - Multi-method, multi-informant approach
- Considerations for **administering measures** in clinical practice
  - Complete questionnaires with clients/patients
  - Provide a visual of response options (e.g., see Nicolaidis et al,. 2020)
  - Ask clients/patients about their experience completing the questionnaire

Future Directions: Stakeholders

- Involvement in studies helping both researchers and clinicians improve measurement
  - What things should we be measuring?
  - Which aspects of your experience aren’t captured by existing measures?

Some Takeaways!

- Good measurement is the foundation of good science and clinical practice.
- There are certain qualities of measures that we can test to ensure good measurement (including validity, reliability, and sensitivity to change)
- However there are some barriers to good measurement of mental health and related factors among autistic people
- There is a need for researchers, clinicians, and stakeholders to work together to develop, test, and utilize measures with sound psychometric properties that can ultimately help to improve quality of life among autistic people.

If you're interested in this topic…

Colleagues and I will be leading a

Special Interest Group at the International Society for Autism Research Annual Meeting!

Improving Patient Reported Outcome Measures (PROMs) in Autism Research: Bridging the Gap Between Advanced Psychometric Techniques and Stakeholder Priorities

Saturday May 14, 2018 7:00AM – 8:30AM

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Q & A