

Autism Diagnosis in Adulthood

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SPARK

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Outline for Today

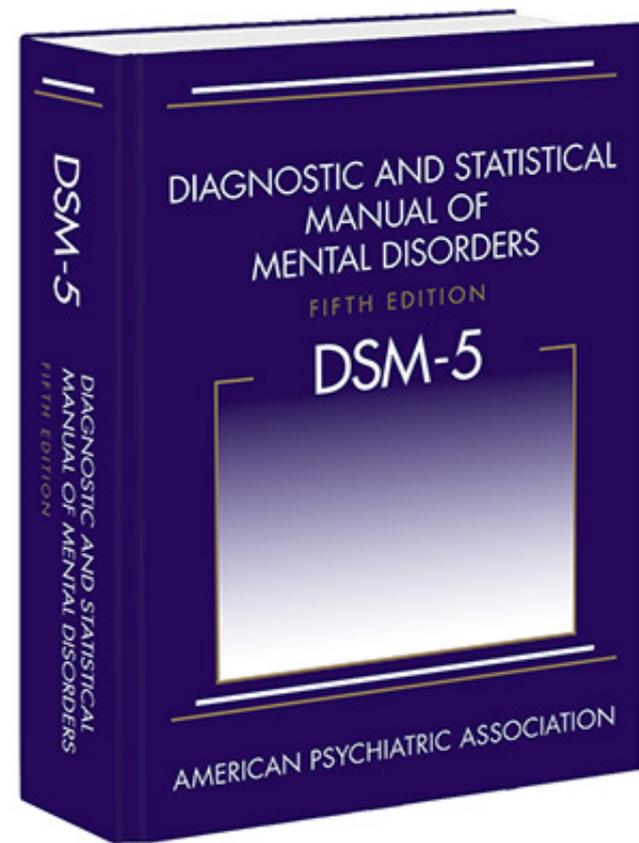
- ASD in adults
- Assessment of Adults
- Considerations
 - Deciding to pursue a diagnosis
 - Post-Diagnosis
- Info about *LifeSPAN* ASD research at Rutgers

A note about terminology

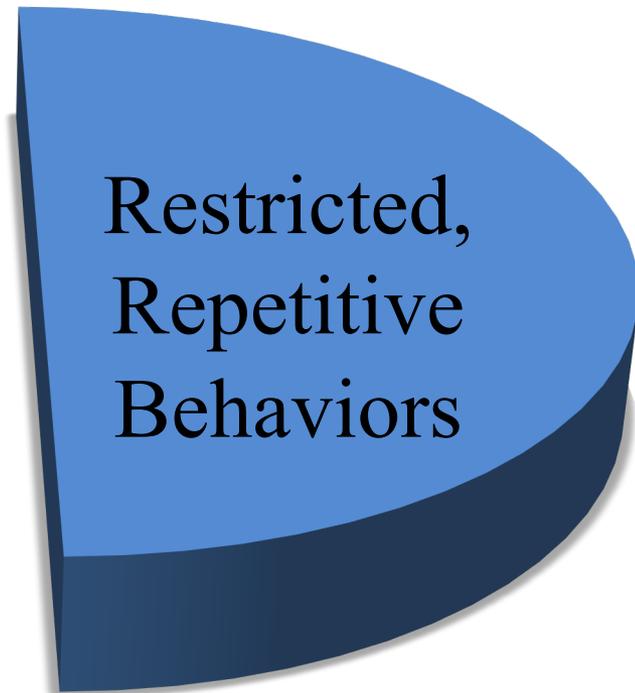
- Identity first language (i.e., autistic adult)
- Terms such as “symptom” or “impairment” are used throughout, but with acknowledgement of the importance of environmental adaptations and supports to promote acceptance, understanding and inclusion

What is Autism Spectrum Disorder?

- A **diagnostic term** used to describe a syndrome. i.e., set of behavioral symptoms that occur together and *cause impairment*
- There is NOT a medical test for ASD
 - Genetic syndromes \neq ASD... only associations

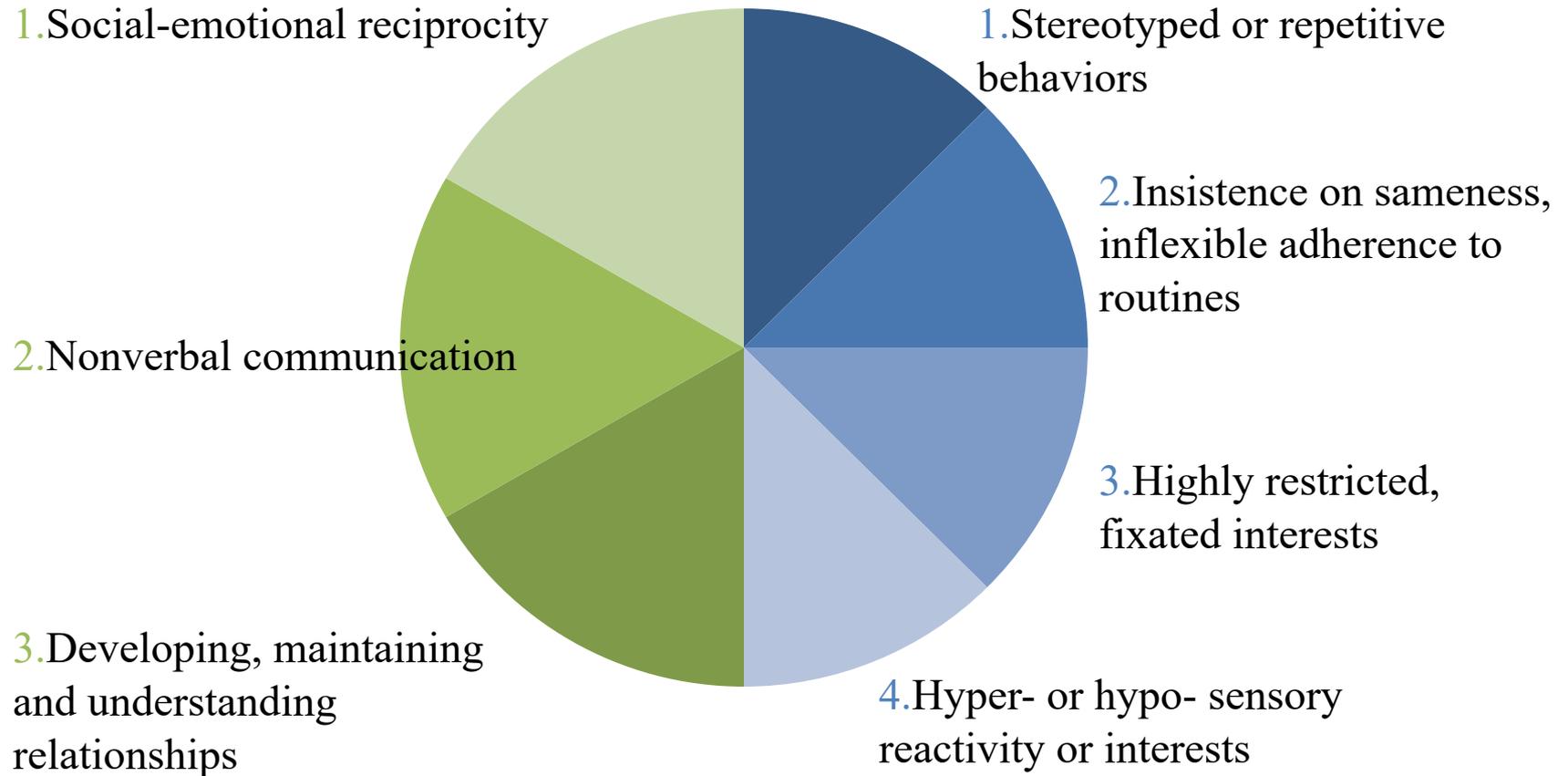


ASD in DSM-5



- Present in early developmental period
 - Clinically significant impairment
- Not accounted for by ID or global DD

Broad domains comprise diverse behaviors

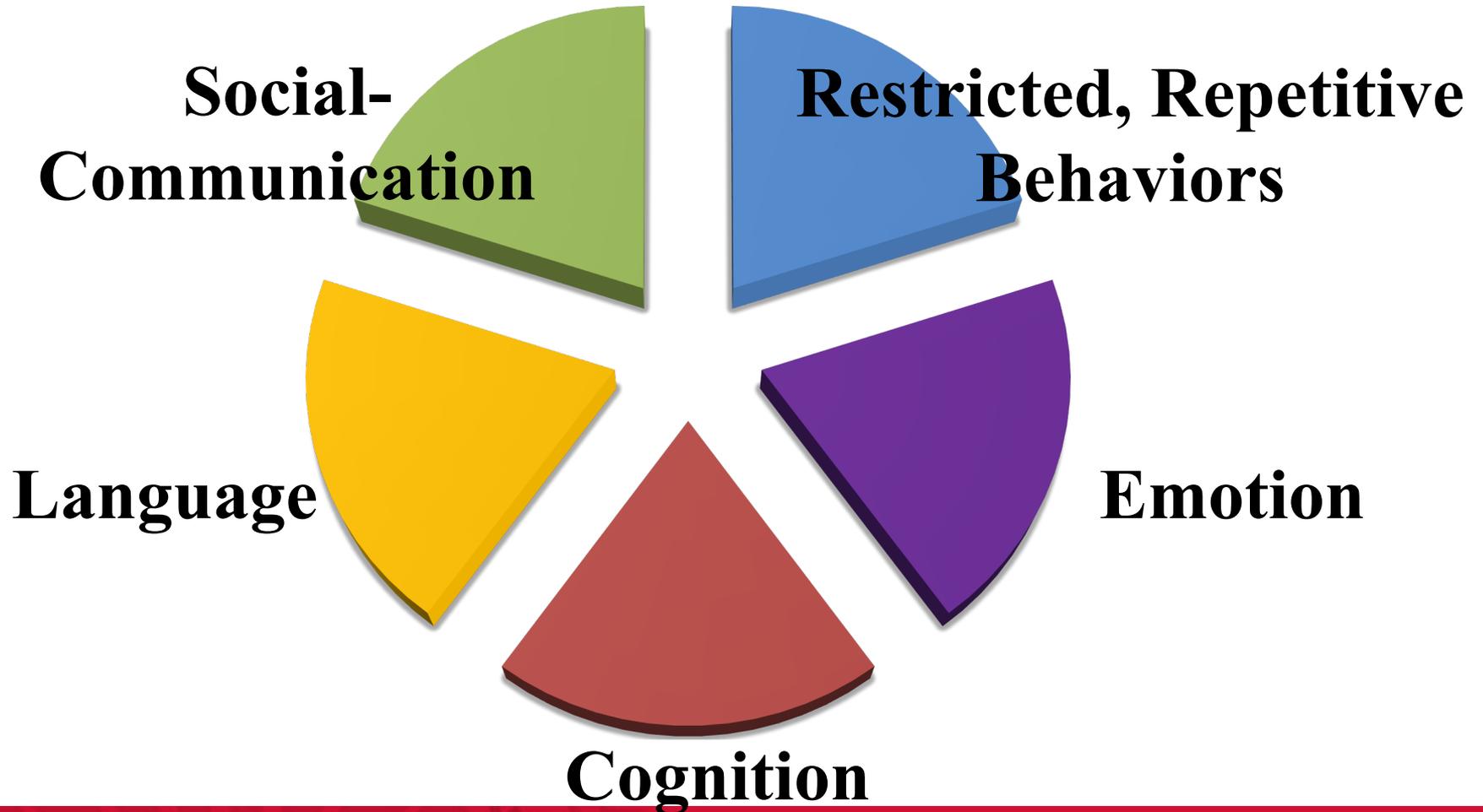


Associated conditions and challenges

- Adults with ASD have high rates of:
 - Psychiatric conditions (e.g., anxiety, depression)
 - Health problems (e.g., seizures, hypertension)
- Adults with ASD may need support with:
 - Adaptive skills (e.g., self-care, money management)
 - Executive functioning (e.g., planning, decision making)

e.g., Croen et al., 2015; Fortuna et al., 2016
Also see Murphy et al., 2016 for review

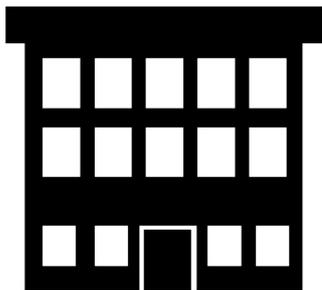
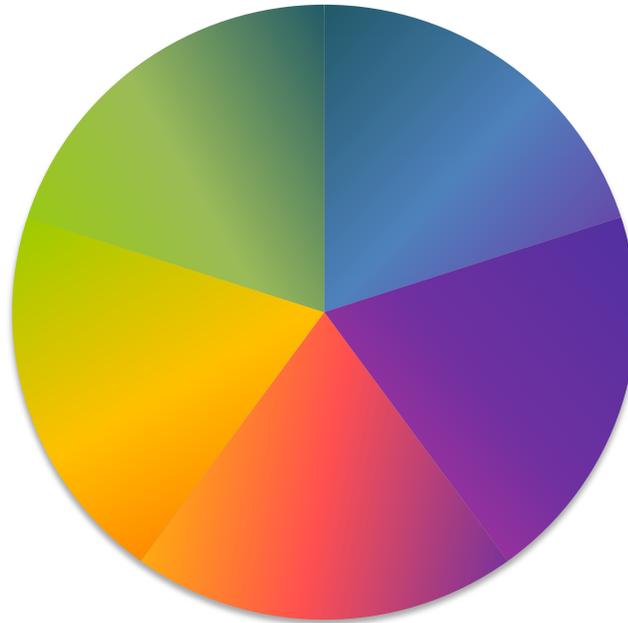
ASD+...



Heterogeneity & diversity within ASD



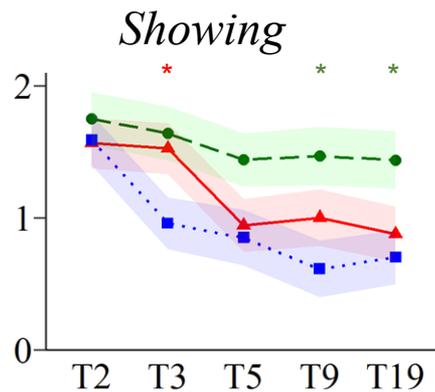
Symptoms vary by context



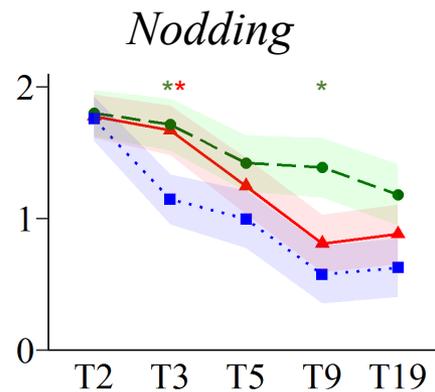
Symptoms vary by age and language

LANGUAGE: Verbal (phrases+) at 3 & 19, Delayed at 3, Verbal at 19, Delayed at 3, Minimally Verbal at 19

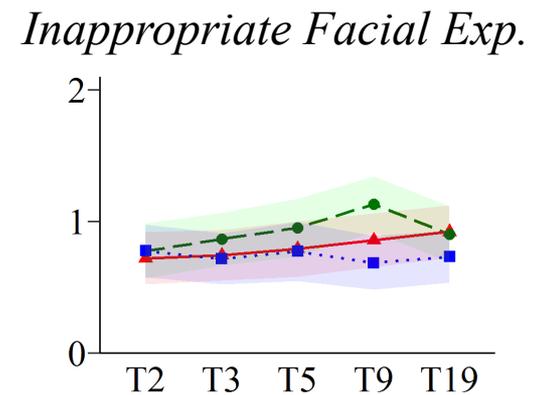
Change associated with language



Change associated with general development



Limited change over time



*p<.005 relative to Verbal group

Graphs are *representative examples* of different trajectories of symptoms reported by parents on the Autism Diagnostic Interview-Revised at 5 different time points
- On each item, higher scores indicate impairment

Bal et al., 2019, *Aut Res*

Why do symptoms change?

- Some changes reflect cognitive development/general maturation
 - Many ASD red flags are basic social communication skills so it may not be surprising that they develop over time)
- Others symptoms seem to be tied closely to language development
- Many adults report learning compensatory strategies and/or “camouflaging” to mask their difficulties (e.g., Hull et al., 2017; Livingston & Happé, 2017)

Why are these changes important?

Absence of childhood red-flags (e.g., limited eye contact) is often mistaken as evidence that an adult does not have ASD

- “Classic” childhood symptoms may not be best markers for ASD in young adults
- Instruments designed with children may not capture the full range of adult symptoms or impairments
 - Skills = strengths (not just an absence of abnormality)
- Adulthood should be viewed as a period of ongoing development (not just an “outcome”)
 - Revisiting previous strategies
 - (Re)Assessing goals

Neurodiversity

- Everyone has strengths and difficulties
 - Symptom → impairment → diagnosis
 - What is “impairing” differs across individual people
 - Environment (with or without accommodations) can affect how impairing a behavior is (Kapp, 2018)
- Intervention/Treatment/Accommodation
 - Not about CHANGING who someone is
 - About **increasing adaptability**
 - Individual/Environmental/Institutional change
 - “Symptoms” can become strengths in the right contexts and/or with the right supports
 - Also about identifying and mitigating risks

Adaptability can make a difference

Symptom	Job	Impairment (no adaptability)	Strength (with adaptability)
Insistence on item arrangement	Sous Chef	Takes too much time; serving delayed	Ensures plating and presentation is perfect
Intense interest in computer programming	App/Web Developer	Insistence that only “best” method be used	Present pros/cons of multiple approaches to obtain desired product
Difficulty making small talk; strict adherence to routines	File clerk	Upset when co-workers interrupt, especially spontaneous requests	Enjoys working alone; accurate filing



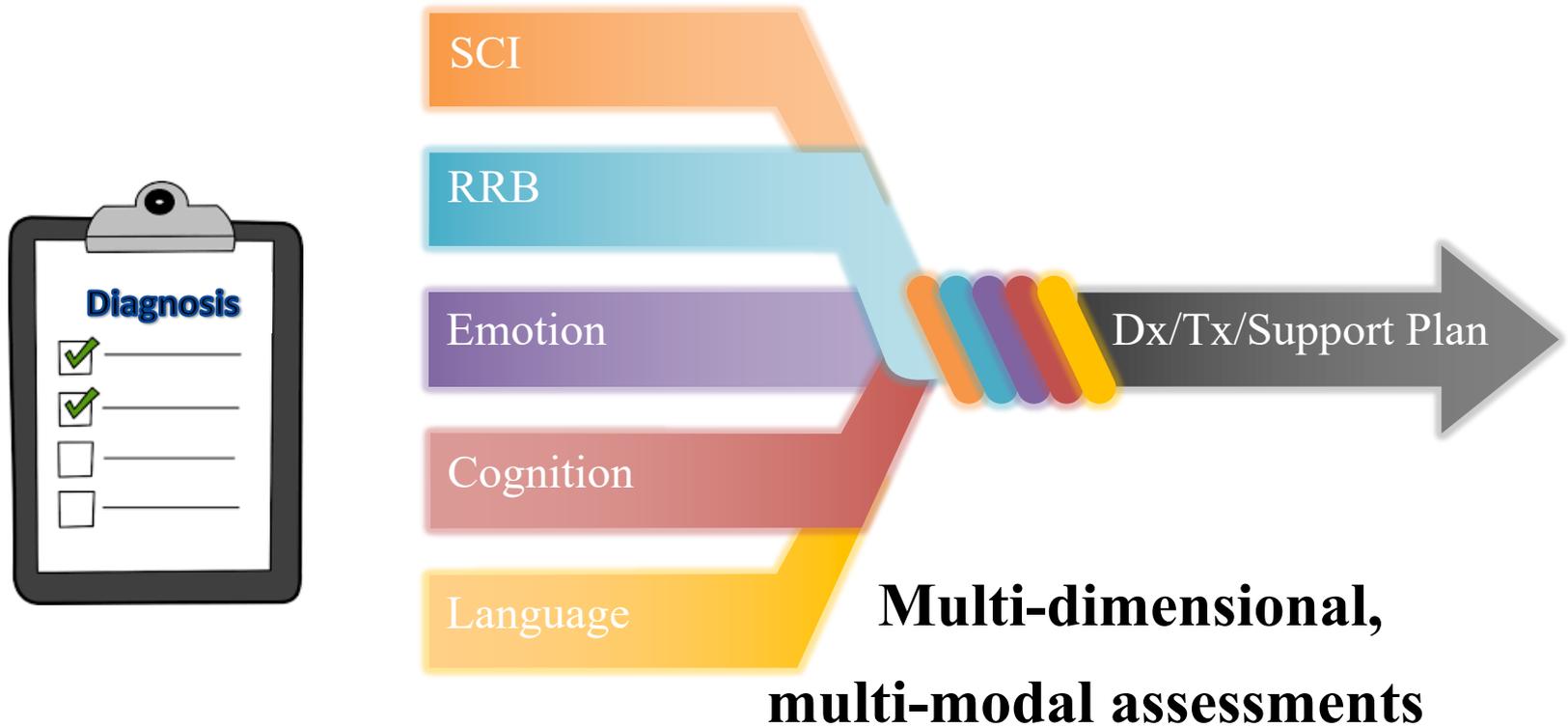
Assessment of adults

What should an adult assessment include?

- Reason for referral
 - First time diagnosis
 - Second opinion
 - Re-evaluation (inform tx and/or transition plans)
 - Other referral questions (e.g., mental health)
- Who is available for assessment
 - Current caregivers vs. lifetime caregivers
 - Self only; no parent/caregiver
 - Other family (e.g., siblings, partners)
- **Regardless: understand the person's strengths and challenges**



Assessment is not just about diagnosis



1. Inform understanding of strengths and challenges
2. Identify comorbid medical or psychiatric disorders
3. Inform treatment plan

Components of a diagnostic assessment

- Reason for referral
- Direct testing
- Questions about current functioning and history
- (Other people's perspectives)

Reason for referral

- What is the goal/purpose of pursuing diagnosis/assessment process?
- If calling for diagnostic clarification...
 - What prompted the question of ASD?
 - Why pursue a diagnosis NOW?
 - Who wants to know? Adult? Parent? Spouse?
- Are there other concerns?
 - Mental health (depression, anxiety)
 - Current relationships (e.g., couples counseling)

Direct testing

- Adult's perspectives of strengths/challenges
 - May include what he or she has been told by others!
- Direct interaction to observe social and communication skills
 - We do not know the influence of camouflaging/compensation
 - Assumes honesty; encourage disclosure of discomfort or questions
- Other Testing
 - cognitive, language, adaptive
 - psychiatric interview (rule in/out other diagnoses)

Current functioning & history

- Education/Vocation
 - Grades, supports, 504/IEP
 - Number/type of jobs; reason for leaving; satisfaction
- Mental health
 - Previous diagnoses, evaluations
 - Treatment (e.g., speech/language, counseling)
- Adaptive functioning
 - Interests (how is free time spent)
 - Self care (financial, hygiene)
 - Relationships (family, peers, professional)
- Early development
 - Mother's pregnancy
 - Delays or concerns

Other people's perspectives

- Note that many ASD evaluations have a heavy focus on informant report (consistent with child assessment procedures)
- Multiple viewpoints provide a better understanding
 - We don't always realize our strengths/difficulties
 - Perceptions may vary in different settings
 - We may not be aware of early development
- Parents/caregivers
 - Especially re: early developmental history & concerns
- May include close friends, siblings, extended family

Is this all really necessary?

- Place difficulties in context of strengths
 - ASD diagnosis in isolation does not do much to inform individualized treatment
 - Specific patterns of skills and difficulties → areas for support, types of supports
- Provide a profile to communicate to others what ASD is for YOU
 - Counter stereotypes and assumptions
 - Underscore strengths
 - Highlight difficulties (may be unique to adulthood, adult settings)

May help to identify/understand risk

- How might difficulties put individual “at risk” for being:
 - Misunderstood
 - Underestimated
 - Physically harmed
- What can be done to proactively reduce risk?
 - Disclosure/education
 - Documentation of strengths
 - Teaching skills



Considerations for adults thinking about pursuing diagnosis

Why NOW?

- Is a professional diagnosis needed for your referral question?
 - Eligibility for services
 - Identity/self-understanding
 - Finding a community
 - Facilitating others' understanding
 - Conflict with partner
 - Treatment recommendations
 - Understanding previous tx difficulties
- A professional diagnosis may not always be warranted
- Important to understand diagnosis \neq eligibility
 - No matter how comprehensive the assessment, you may have difficulty accessing services

Pros and Cons of ASD diagnosis

Pros	Cons
Validation of experiences	Frustration/anger/worry about implications
Putting difficulties in context (self and others)	Stigma and discrimination
Social network	Your experiences may not match those of others with ASD
Inform treatment/supports/services	Lack of services

e.g., Stagg et al., 2019

What a diagnosis does NOT do

- Provide a panacea
 - It will not provide an answer to all of life's challenges
 - It does not magically improve relationships or make people more understanding
- Define you
 - You decide
 - How to integrate diagnosis into your sense of self
 - Who to disclose to
 - You are the same person before *and* after you are diagnosed
- Come with a clear list of referral sources for supports
 - (Hopefully this will change soon!)

Be aware of...

- Websites that offer checklists that will tell you if you “have ASD”
- Professionals who
 - Are dismissive of your concerns
 - Do not have prior experience with individuals with ASD and give you an “answer” after a brief session
- Even if these results are consistent with a more comprehensive evaluation... an ASD diagnosis is more than just “yes” or “no”

Setting the bar high

- Professional view: advocate for the best, most comprehensive care possible
- BUT YOU have to decide what you need **for yourself** *right now*
 - You may only be comfortable completing a self-assessment online
 - A brief evaluation may be all that is financially feasible (or available)
 - Others might want to know more than you do



**I have a diagnosis ...
Now what?**

Finding (your own) meaning in ASD

- Consider
 - What you know and don't know about ASD
 - Ways that ASD fits with how you perceive yourself
 - Ways in which ASD doesn't make sense for you
- ASK QUESTIONS
 - People close to you
 - Professionals
- Give yourself time to process
 - Expect mixed positive and negative emotions!

Moving forward

- Treatment planning
 - Should receive guidance from assessment
 - Make sure adult priorities are part of the plan!
 - What is needed to make YOU happy?
 - How does that match with others' priorities for you?
 - Consider developmental life stage
- Accessing services
 - ASD specialists vs. experts in treatment type
 - Service eligibility

Examples of treatment targets

- ASD symptoms
 - social skill development; social rule awareness; flexibility/adaptability
- Mental health
 - emotion regulation, mood
- Adaptive functioning
 - daily living skills; community navigation
- General support
 - processing, disclosure, understanding ASD

Things to keep in mind about treatments

- There are no one-size-fits-all “fixes”
 - Often focus on skill development and increasing knowledge
 - Often address “other” concerns (e.g., mental health)
- Is a process
 - Requires a lot of effort (and support!) during and outside of sessions
 - Should have clear goals
 - Progress toward goals should be monitored regularly
 - Goals should be revisited and updated periodically

Disclosure

- A very **personal** choice
- Factors to consider when deciding to tell X:
 - WHY would you tell X?
 - Do you need support/accommodations?
 - Do you want to deepen understanding?
 - HOW do you think disclosure will affect your relationship with X?
 - Better understanding?
 - WHAT are the benefits/risks of telling X?
 - Do they have informed knowledge/understanding of ASD
- Some research suggests knowledge of diagnosis may result in more positive impressions of autistic adults (Sasson & Morrison, 2019)

Who would you tell?

- Family members
- Romantic partners
- Friends
- Teachers/Employers
- Professional contacts (e.g., doctors)
- Acquaintances

Pros & Cons of disclosure

	Pros	Cons
Family Members	Better understanding	Not understand benefits to you
Romantic Partners	Closer	May overwhelm a relationship
Friends	Support	Misguided assumptions
Professional Contacts	Improved care	Unsure how to help
Teachers/Employers	Accommodations	Discrimination
Acquaintances	Educate community	Too personal

Conclusions

- Autism may “look” different in adults
 - The general public may not recognize ASD in adulthood
 - Affects understanding and acceptance
- Assessments are important for more than diagnosis
 - Limited understanding of strengths/challenges = less personalized supports
- Deciding to pursue or disclose a diagnosis is a very personal decision

Gaps impeding societal change

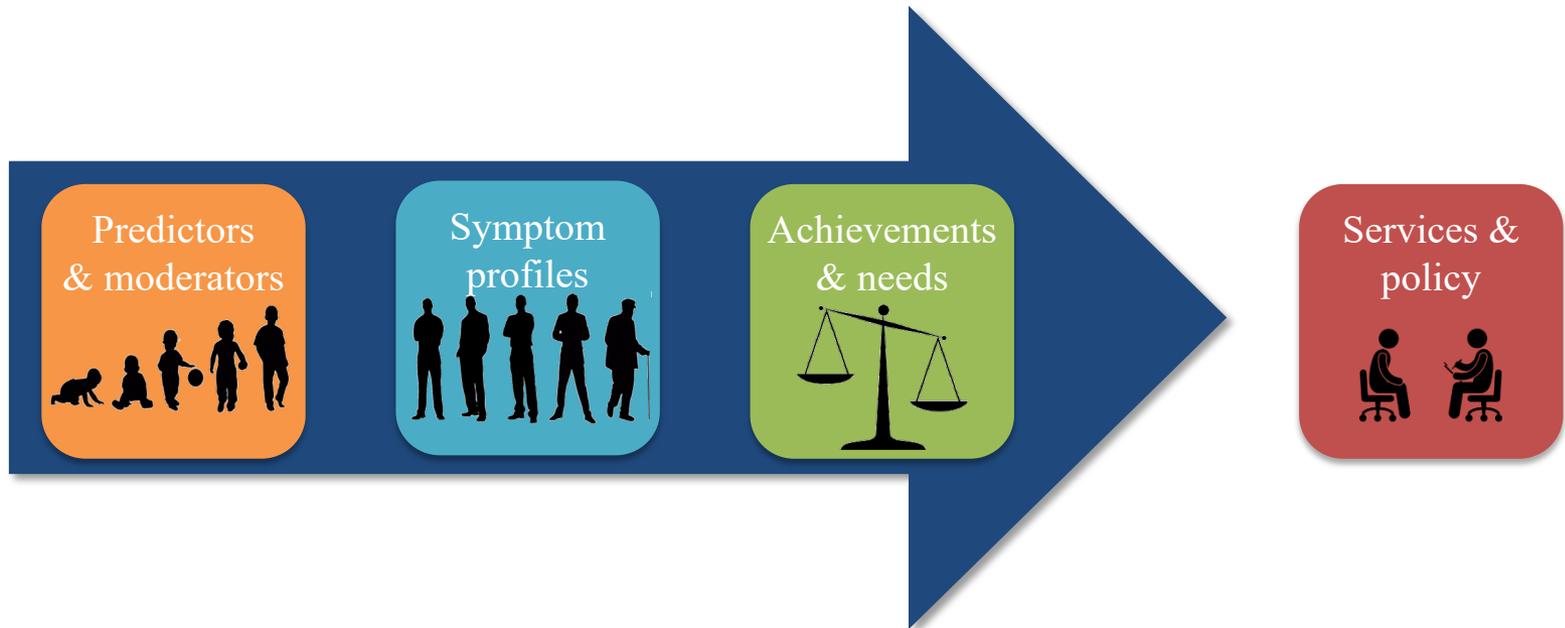
Dearth of research on adults with ASD limits our ability to develop large-scale supports and services

1. **WHO** needs what and what works for whom?
2. **WHAT** are the symptoms of ASD in adulthood and how do they affect daily function?
3. **WHEN** do we provide support? Are there childhood/adolescent factors that predict challenges or promote positive achievements? How do young adult supports predict later-adult outcomes?
4. **WHERE** do adults want/need supports and how do service needs vary across contexts?
5. **WHY** do they want supports? What goals do adults with ASD (and their families) have that they want to achieve?

LifeSPAN in ASD Lab

Lifespan Symptom Profiles, Achievements Needs

Aim: to advance understanding of the aging population of adults with ASD



LifeSPAN Lab Aims Summary

1. Inform the question of WHO needs what by:
2. Characterizing WHAT the strengths and challenges of individuals with ASD are across adult life
3. Increasing knowledge of WHEN to intervene or provide supports through studies of biological, behavioral and contextual factors affecting longer-term outcomes
4. Developing services to support challenges and needs WHERE they are identified
5. Moving the field beyond broad classifications of “poor” outcomes to consider goals and WHY adults want/need supports

Thank you!

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LifeSPAN lab

Lifespan Symptom Profiles Achievements & Needs

<https://gsapp.rutgers.edu/lifespanasdlab>