



Diagnosis of ASD in Adulthood

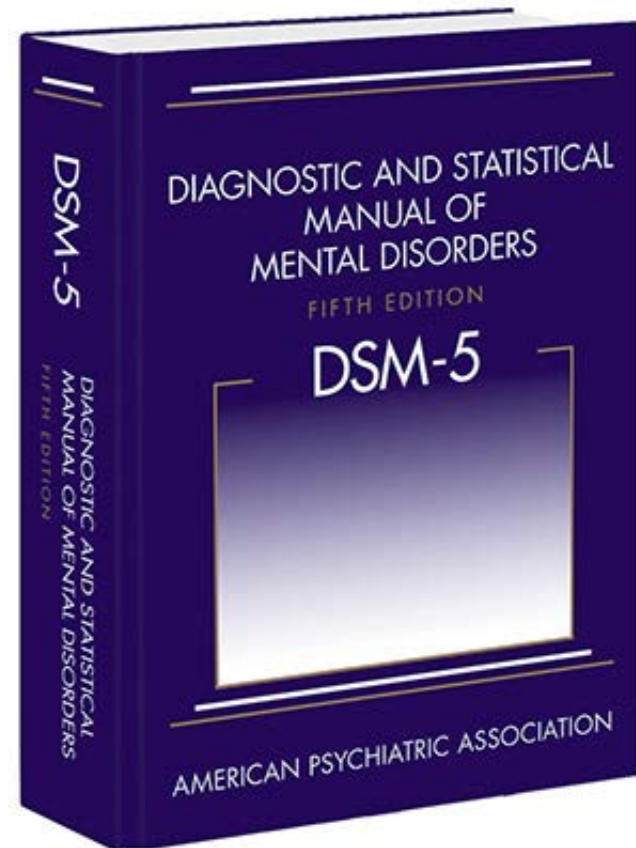
Vanessa Hus Bal, PhD

PWDF Conference

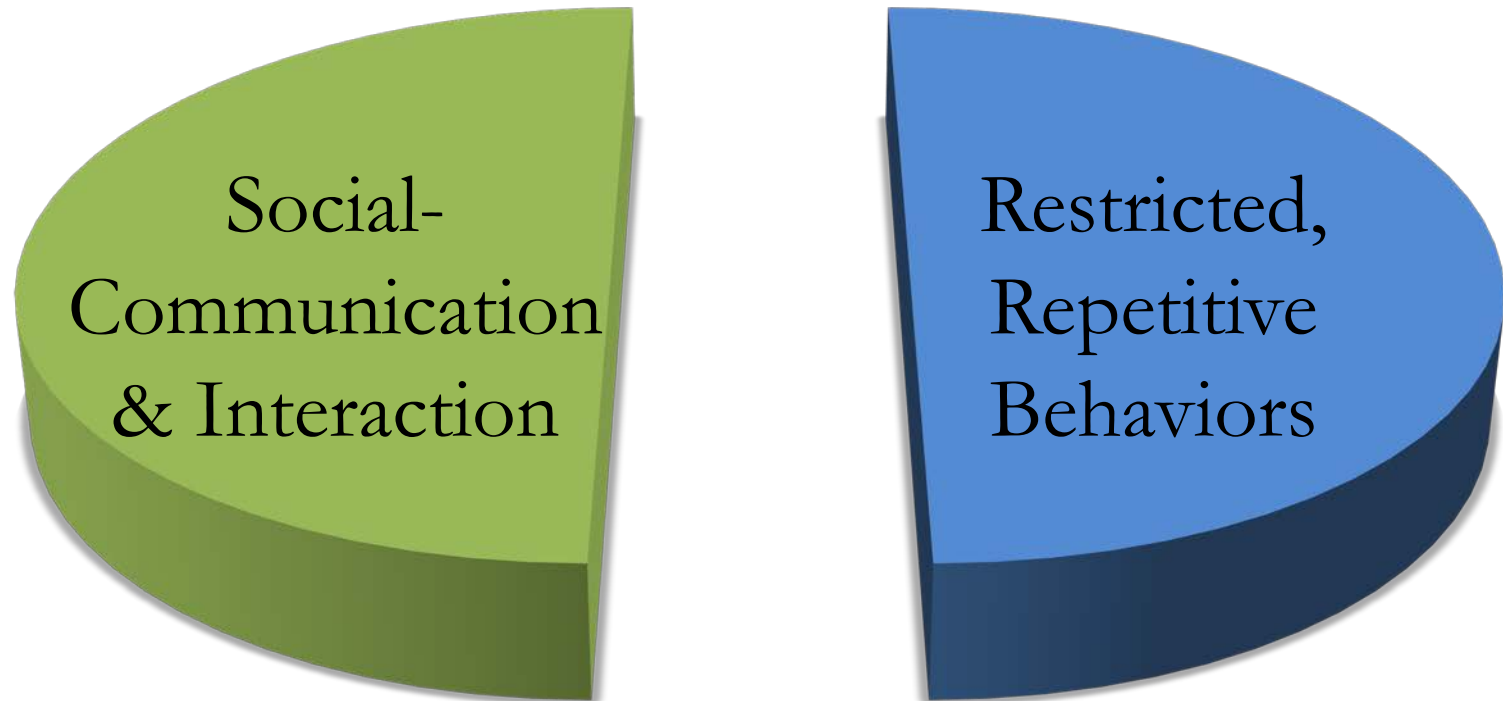
December 6, 2016

What is Autism Spectrum Disorder?

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

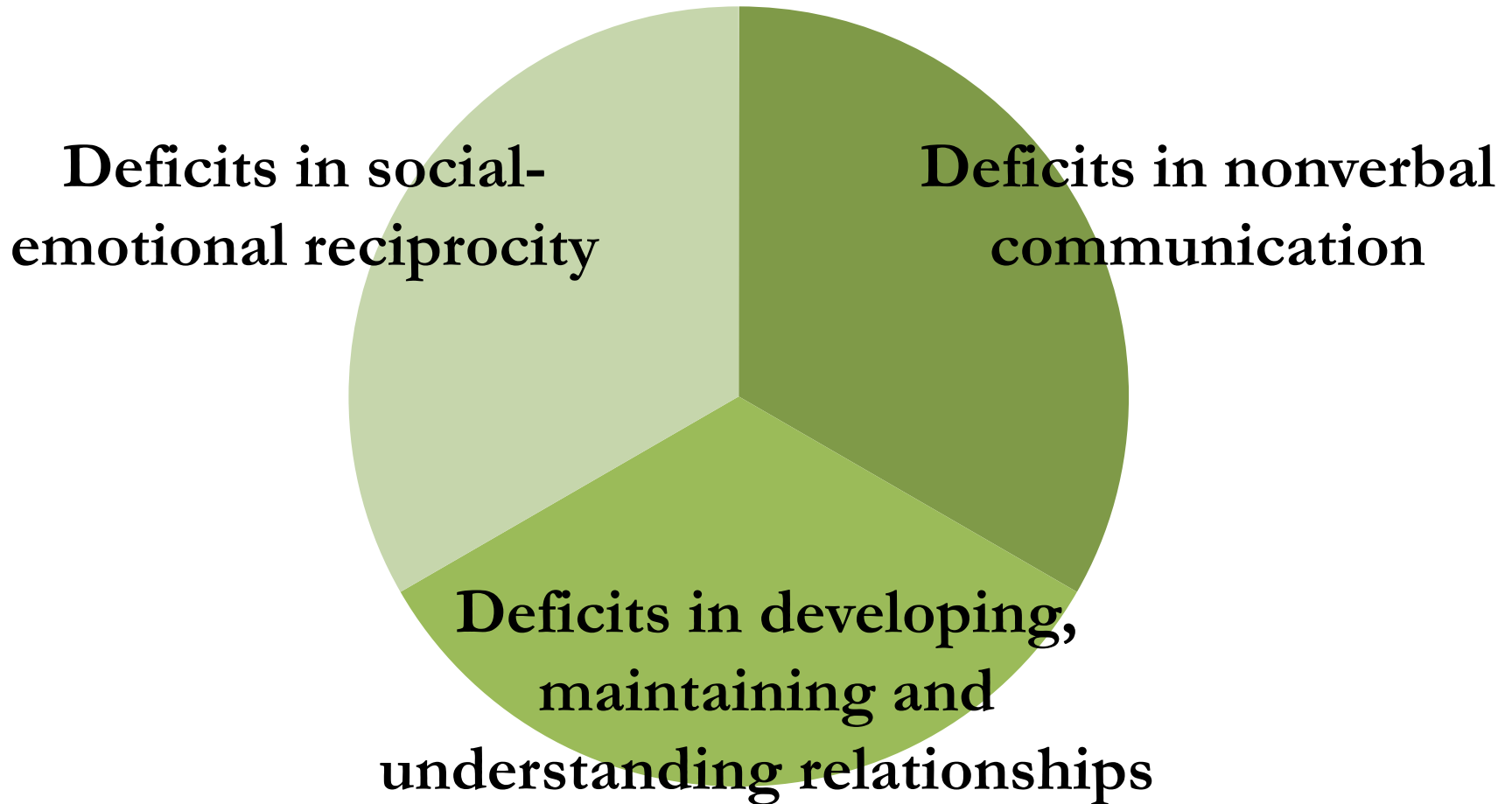


ASD in DSM-5

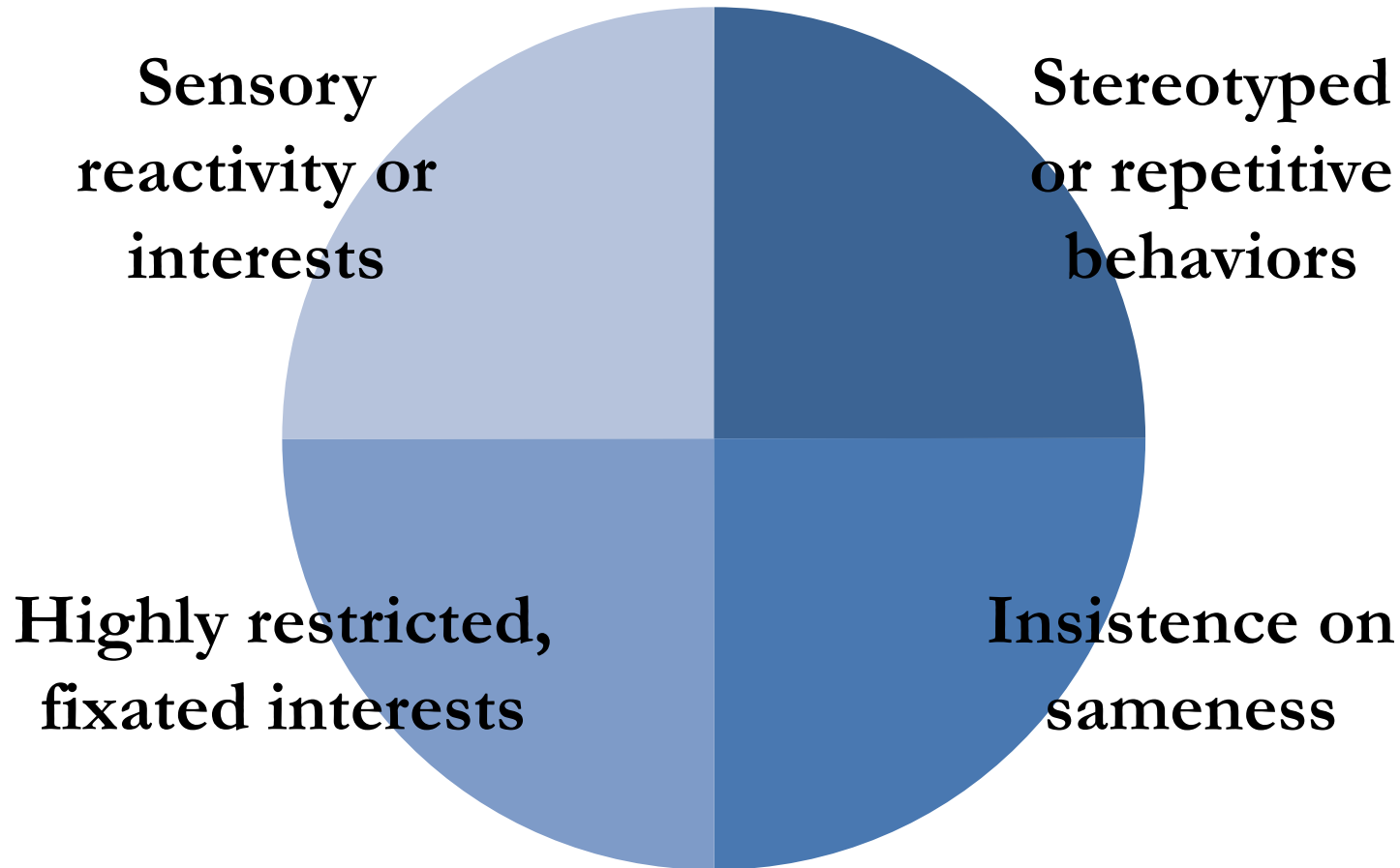


- Present in early developmental period
 - Clinically significant impairment
- Not accounted for by ID or global DD

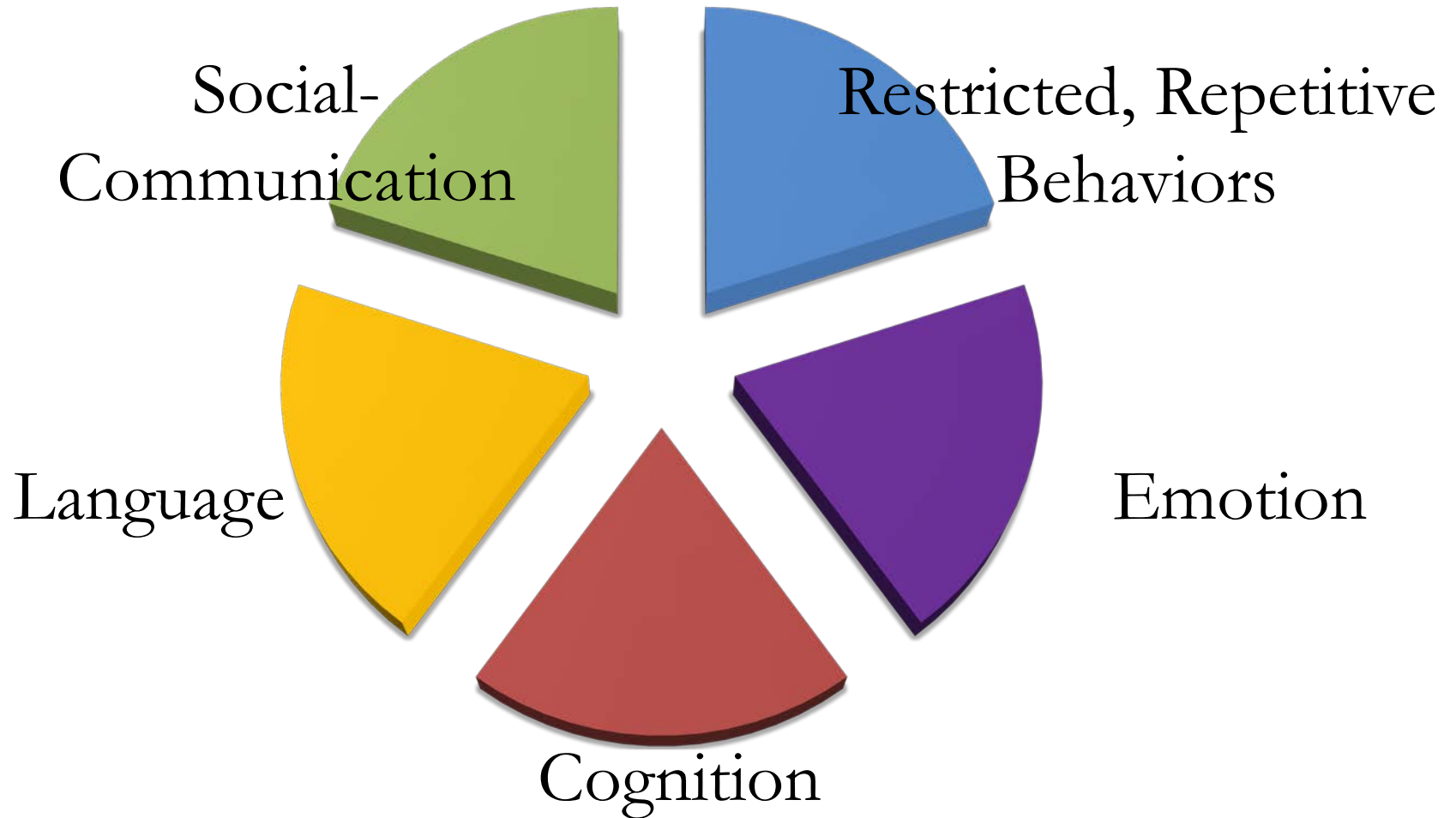
Social-Communication Interaction



Restricted, Repetitive Behaviors



ASD+...



Heterogeneity & diversity within ASD



ASD is a **developmental** disorder

- Core features vary by age and developmental level
 - Continued development
 - Stability and change in symptoms and areas of strength and impairment



(e.g., McGovern & Sigman, 2005; Shattuck et al., 2007; Gillespie-Lynch et al., 2012; Howlin et al., 2013)

Associated conditions and challenges

- Adults with ASD have high rates of:
 - Psychiatric conditions (e.g., anxiety, depression)
 - Health problems (e.g., seizures, hypertension, Parkinson's)
- Adults with ASD may need support with:
 - Adaptive skills (e.g., self-care)
 - 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

The diagnostic assessment process



Assessment goes beyond ASD diagnosis

- Comprehensive assessments help to:
 1. Understand strengths and challenges
 2. Identify comorbid medical or psychiatric disorders
 3. Inform treatment plan
 - Set goals (needs/wants)
 - Develop strategies to achieve goals, taking into account profile of abilities and impairments
 - Baseline and markers for treatment-related change

Reason for referral

- What do you hope to gain from the diagnosis/assessment process?
 - Should guide the assessment!
- If calling for diagnostic clarification...
 - What prompted the question of ASD?
 - Why are you pursuing a diagnosis NOW?
 - Do **you** want to know? Does someone else?
- Are there other issues you need help with?
 - Mental health (depression, anxiety)
 - Current relationships (e.g., couples counseling)

Direct testing

- Your perspectives of own strengths/challenges
- Direct interaction to observe social and communication skills
 - e.g., Autism Diagnostic Observation Schedule
 - Try to be honest; disclose discomforts
- Other Testing
 - cognitive, language, adaptive
 - psychiatric interview (rule in/out other diagnoses)

Current functioning & history

- Early development
 - e.g., mother's pregnancy; delays or concerns
- Education/Vocation
- Mental health
- Adaptive functioning
 - interests (how is free time spent)
 - self care (financial, hygiene)
 - relationships (family, peers, professional)

Other people's perspectives

- 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
- Close friends, siblings, extended family

Things to consider if seeking a diagnosis...



What to look for

- Expertise
 - Experience working with (adults) with ASD or other developmental disorders
 - Training in assessment and diagnosis
- Multimodal assessment
 - Direct observation, self report, other report
 - Focus on your questions & needs – not just yes/no checklist
- Is there support beyond diagnosis?
 - Assessments of other areas of functioning
 - Multidisciplinary team (e.g., Psychology, BCBA, Speech/Language, Psychiatry, Social Work)

What to expect

- Pediatric settings and approaches
 - Department of Pediatrics or Child & Adolescent Psychiatry
 - Instruments extended from childhood measures
 - Include a parent/caregiver perspective
- WAITLISTS
 - ASD specialty clinics often have long waitlists
- Other barriers
 - Don't serve a certain age
 - Don't take your insurance
 - Need you to fill out a lot of forms

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

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

Setting the bar high

- Websites that offer checklists will claim to tell you if you “have ASD”
 - No checklist is perfect: **scores \neq diagnosis**
- 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
 - Others might want to know more than you do

Neurodiversity

- Everyone has strengths and difficulties
 - Symptom → impairment → diagnosis
 - What is “impairing” differs across individual people
 - Environment/support affect how impairing a behavior is
- Intervention/Treatment
 - Not about CHANGING who you are
 - About **increasing adaptability**
 - Individual
 - Environmental/institutional
 - Symptom + Adaptability = Strengths

Adaptability makes a difference

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

Pursuing a diagnosis

- Deciding to pursue a diagnosis is an individual decision
 - Ask someone you know/trust to help weigh pros and cons of pursuing a diagnosis.
- Resources
 - UCSF Service, Training, Advocacy & Research (STAR) Center for ASD & NDDs <http://star.ucsf.edu>
 - Autism Speaks Resource Guide
 - <https://www.autismspeaks.org/resource-guide/state/CA>
 - *Where to get an Autism Diagnosis* (bottom of list!)
 - *Adult - Ages 22 and Older* (top of list!)
 - Input zipcode; click links for provider info

Acknowledgements



Colleagues

- Katy Ankenman
- Somer Bishop
- Whitney Ence
- Tara Glavin-Javaid
- Robert Hendren
- Janet Miller
- Young Shin Kim
- Bennett Leventhal

Funders

- Bay Area Autism Consortium
- Tauber Research Scholars Program

LifeSPAN lab

Lifespan Symptom Profiles Achievements & Needs

- Megan Fok - Erin Rosenberg - Alexis Sullivan

lifespanlab.ucsf.edu

Questions?

- STAR services:
 - Website: <http://star.ucsf.edu>
 - Email: star@ucsf.edu

- Adult research opportunities:
 - Website: <http://lifespanlab.ucsf.edu>
 - Email: lifeSPANlab@ucsf.edu

General Resources

- Autism Society San Francisco Bay Area

<http://www.sfautismsociety.org/getting-started.html>

- Interactive Autism Network

<https://iancommunity.org/cs/adults>

- Autism Speaks Resource Library: Adults w/ Autism

<https://www.autismspeaks.org/family-services/resource-library/adults-autism>

- AASPIRE Healthcare Toolkit

<http://autismandhealth.org/?p=home&theme=dk&size=small>