

# **New thoughts about assessment and diagnosis of autism (from our time of social distancing)**

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# R. Bob Smith PhD. Excellence in Psychological Assessment Webinar

The Bob Smith Award was created to recognize Bob Smith, Ph.D. for his many years of service to the psychological profession by upholding the highest standards when creating and publishing evidence based psychological assessments. Bob began his career as a psychologist and later went on to found [Psychological Assessment Resources \(PAR\)](#).

- The individual or organization selected must be committed to an evidence-based approach to assessment.
- SCCAP members will receive a **free CE credit** from the proceeds from this endowed award. Certificates will be emailed to all attendees within 2 weeks.

# 2020 Webinar Series

Previous webinar recordings are available on [sccap53.org/resources/education-resources/webinars/](https://sccap53.org/resources/education-resources/webinars/)

## Remaining SCCAP webinars:

- Nov. 19 4pm ET, ***A Conversation About Social Justice: A Child Psychologist's Role in Policy and Advocacy*** Cosponsored by SCCAP, Div 37, and Div 54

# Audience Questions and Answers

- To submit your questions after this webinar:
- Post your questions for the Q&A segment! On right side of screen, click on the Questions tab on the Go-To-Webinar control panel, and submit your questions

# Questions?

Still have questions? Please post them on the  
SCCAP Listserv to continue the community  
discussion

[div53@lists.apa.org](mailto:div53@lists.apa.org)

# Conflicts of Interest

- I receive royalties from Western Psychological Services for diagnostic and screening instruments. I am on scientific advisory boards of the Autism Science Foundation, Autism Speaks, Child Mind Institute, Tilray and Gateway Learning Group. I am working with Roche and GW Pharmaceuticals/Greenwich Biosciences on particular projects. I have research funding from NICHD, NIMH, NIDCD, DoD and the Simons Foundation.

# Plan for this talk

- General issues in assessing children and adults with a possible autism diagnosis
- Importance of the time we're in
- Quick run through of major issues
- Researchers
- What we can do clinically
- Parents' perspectives
- Conclusions
- General point: Let's use this time to think creatively and seriously about priorities and what are we accomplishing.

# Lots of quandaries

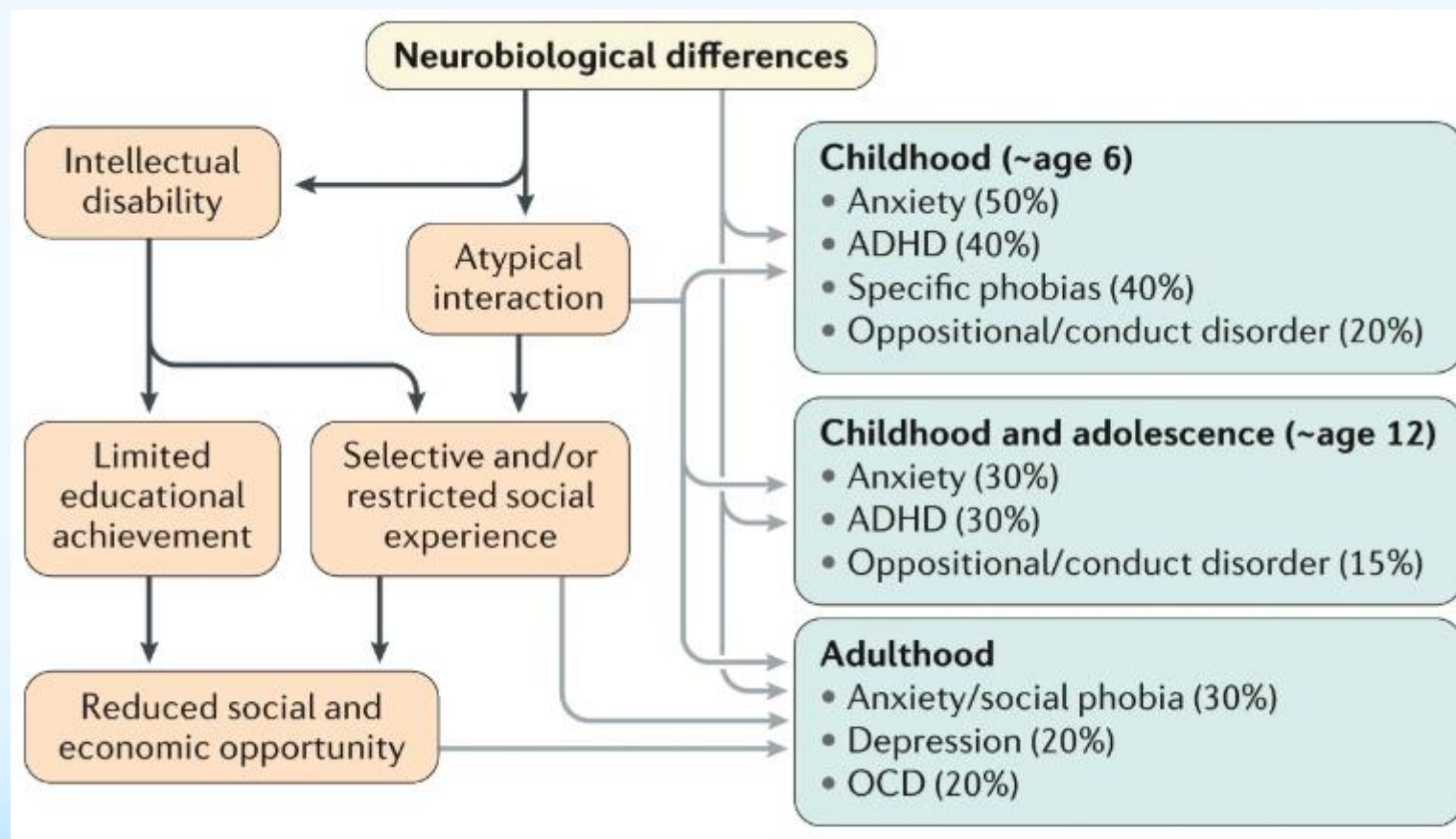
- Autism is very different in different children and different adults. It is a spectrum that is very heterogeneous.
- Different families and autistic people themselves, as they grow older, work out what they will do in different ways.
- We know how to diagnose autism. Sometimes it is very straightforward and could be done from a brief observation, but often initial impressions are wrong or insufficient.
- Evidence suggests that an adequate diagnosis almost always requires both an observation by an experienced clinician and information from parents or caregivers.
- In addition, co-occurring disorders including intellectual disability, language delays and disorders and mental health problems are the rule more than the exception. An adequate evaluation needs to at least screen for these issues and deal with them responsibly.
- Treatments for autism can make a big difference, both in changing specific skills or behaviors and ideally, in creating a cascade of events that leads to a better life.
- But there is no treatment that works for all children or adults at all times.
- The "mediator", the "in between" factor, is families (and then community resources).



# Providers doing assessments are pulled in two very different directions

- Efficiency
  - Getting families into services
  - Reducing waiting lists
  - Expanding accessibility to lower resource communities
  - Generating income through greater volume
  - But the question is what is lost; do some families just move on until they find another provider or someone else who helps? Or just make their own resources?
- Providing individualized information
  - Supporting families
  - Addressing the complexities of individual children and adolescents
  - Accurately predicting short-term and long-term prognosis
  - Helping families make decisions
  - But we need so much more information and better information to do this well

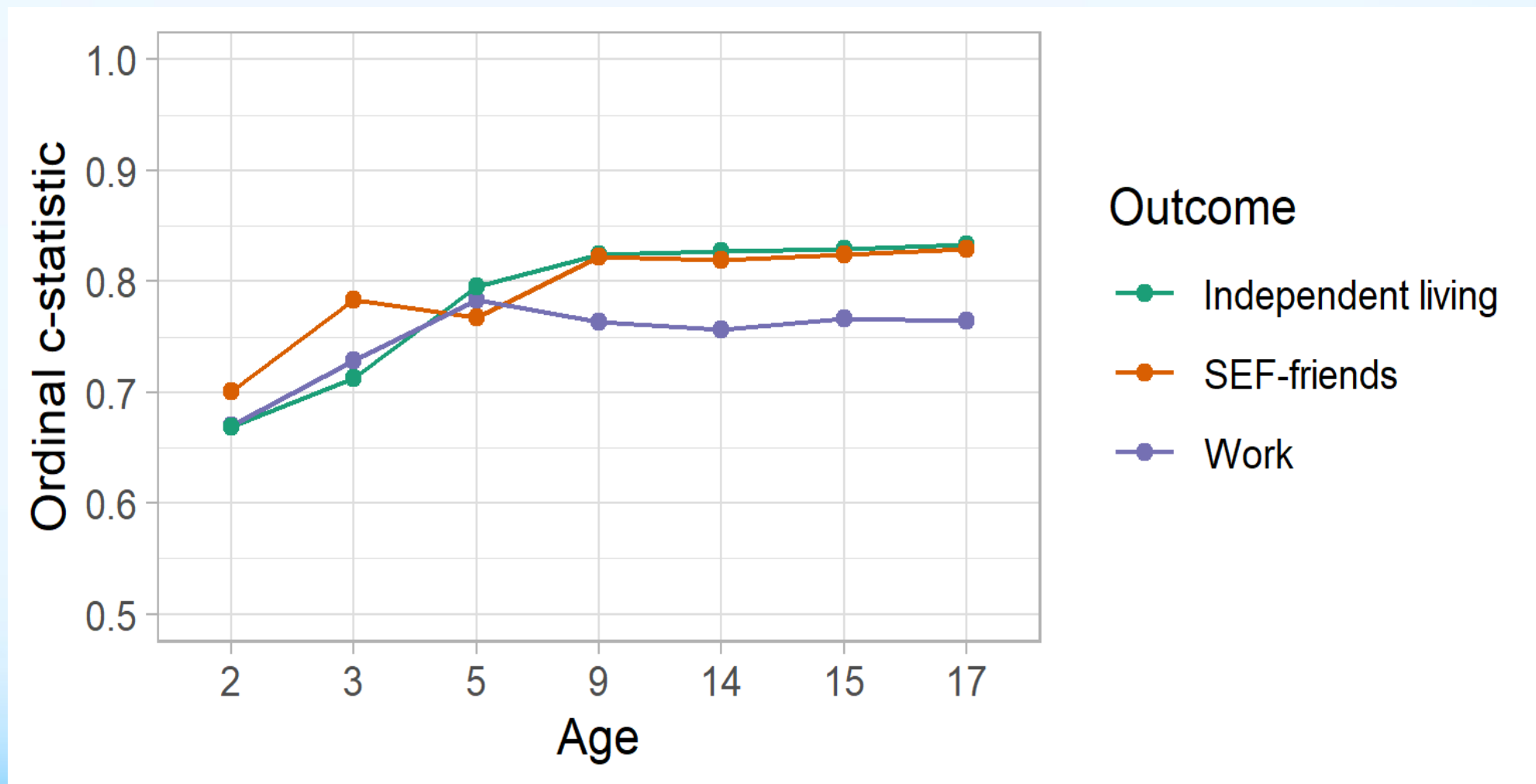
## Autism and co-occurring disorders



# What factors make a difference in lifetime outcomes for children with autism

- Expressive language (and receptive) and communication
- Nonverbal problem-solving and fine motor skills
- Adaptive skills
- Severity of autistic features
- Co-occurring problems (ADHD, irritability, aggression, depression)
- Behaviors specifically related to autism features (ADOS CSS or ADI RRB domain scores or ever ASD diagnosis)
  - Adaptive skills
  - Friendships and relationships
  - Family stress
  - Family involvement in treatment

Figure 3: Optimism corrected predictive performance for ordinal outcomes



# Incremental Prediction of Adult Outcome classes:

Class 1 Best  
Outcome

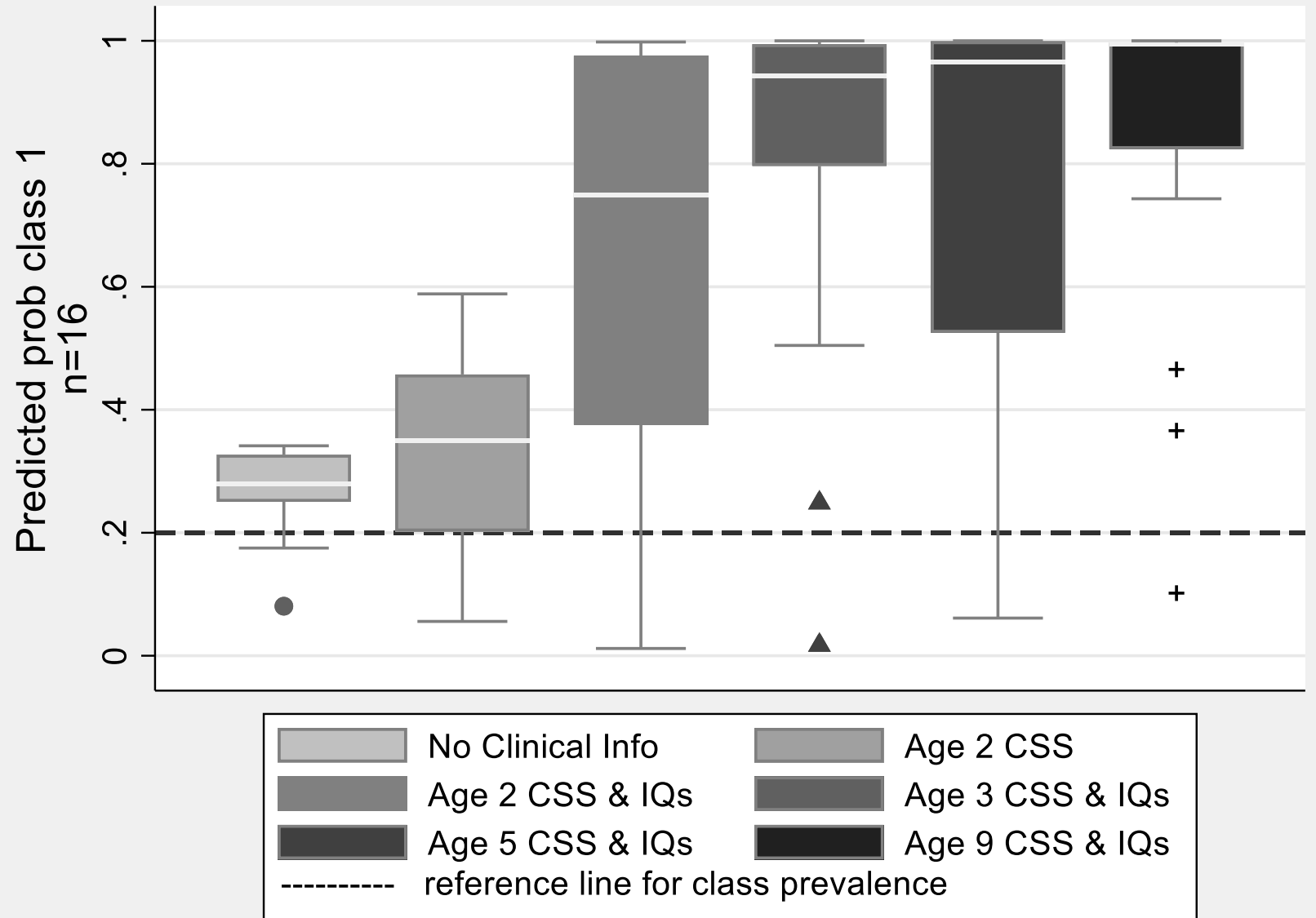
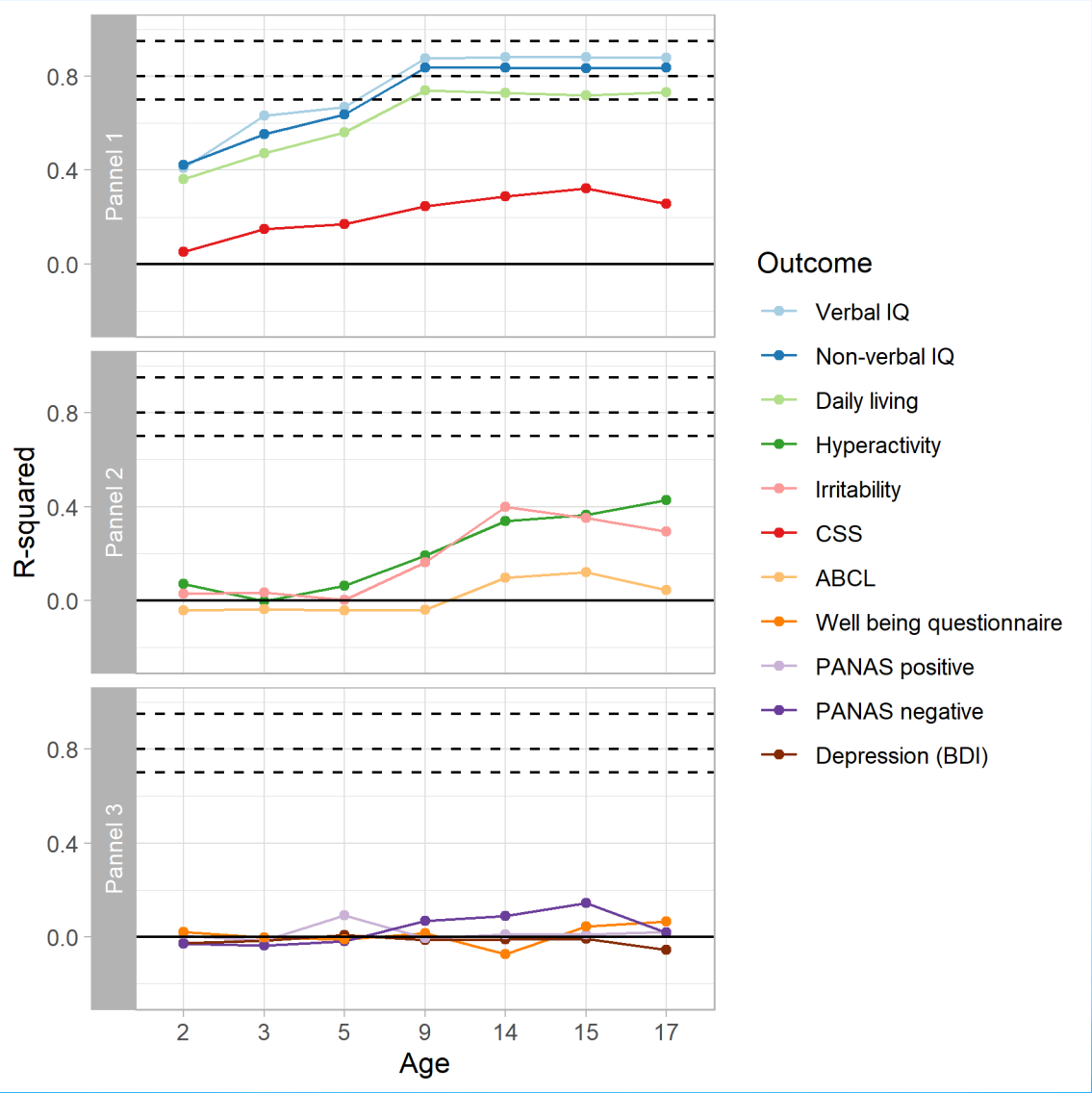


Figure 2: Optimism corrected predictive performance for continuous outcomes modelled using Lasso regression

Dashed lines show limits of predictive performance for test retest ICCs of 0.95, 0.8, and 0.7



# In this time

- We have learned that testing is important but complicated and one step in many steps to resolve issues
- We have learned that not everyone can do testing that is meaningful
- We have learned that we need science and systematic information about what is happening, and we don't have enough of this (for example, what are the risks if children go back to school in some way?)
- We have learned that access to testing in the U.S. is not fair
- All of these things are true for testing in autism as well
- We do not want to make this worse

# Initial access to services

Nots: Shouldn't be dependent on a particular diagnosis

Shouldn't be dependent on a particular tool for entry to services

Shouldn't be dependent on particular professions

Realistically: Having some standards for tool use is not unreasonable

There is a wealth of evidence that use of some kind of standard tool results in more careful and reliable diagnosis of just about anything.

For accuracy

For monitoring

For communication among professionals and families

But we need to work with systems to make sure these standards do not limit care.



# Social justice and responsibility

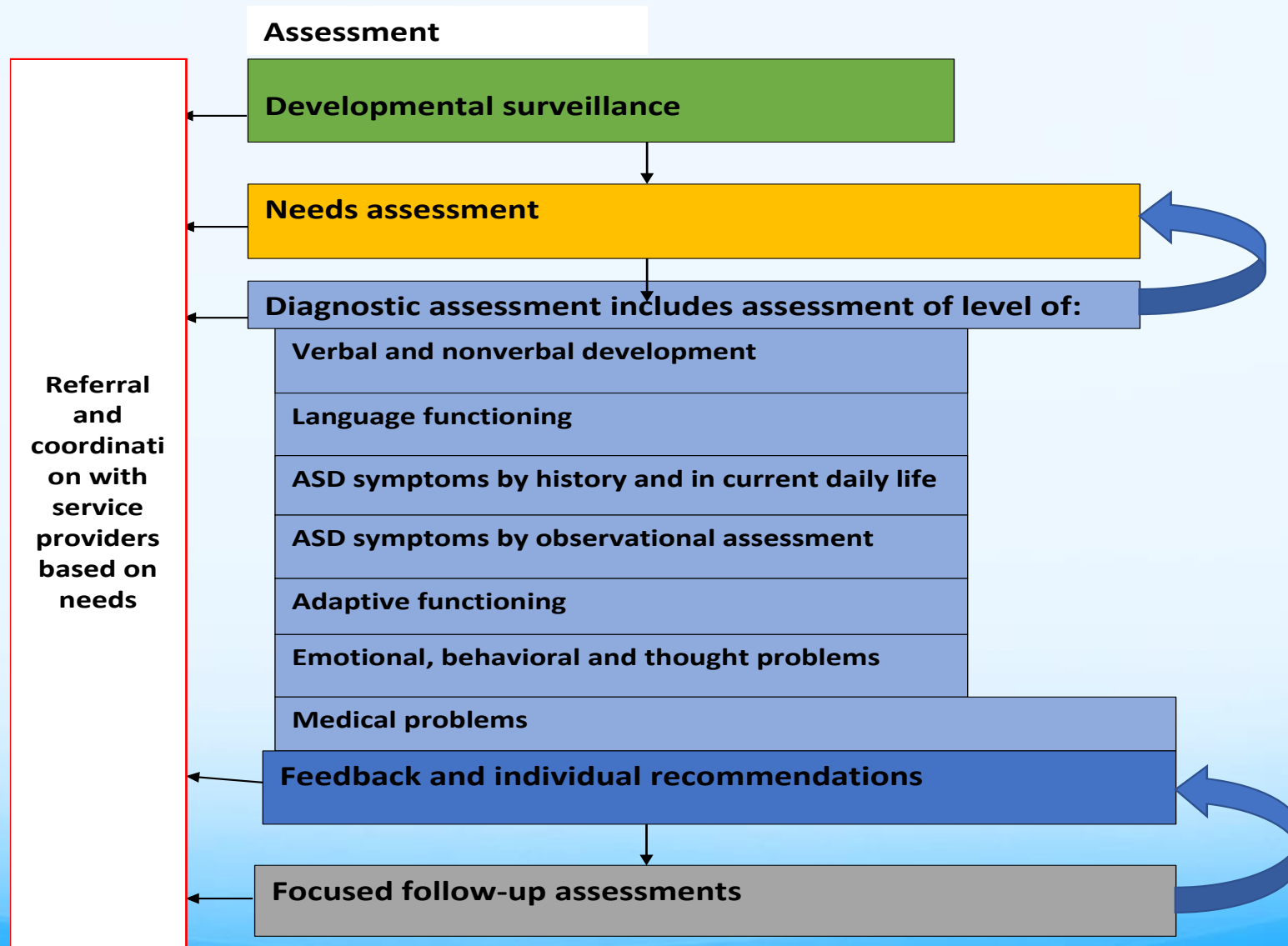
Anyone who says they can diagnose your child in a parking lot and that is sufficient for what you need is irresponsible.

It is radically unfair to say that some children and families should get a 10 minute diagnosis or a one hour one time evaluation and others should get an appropriate multi-dimensional assessment and sufficient feedback to families every year or when there are transitions.

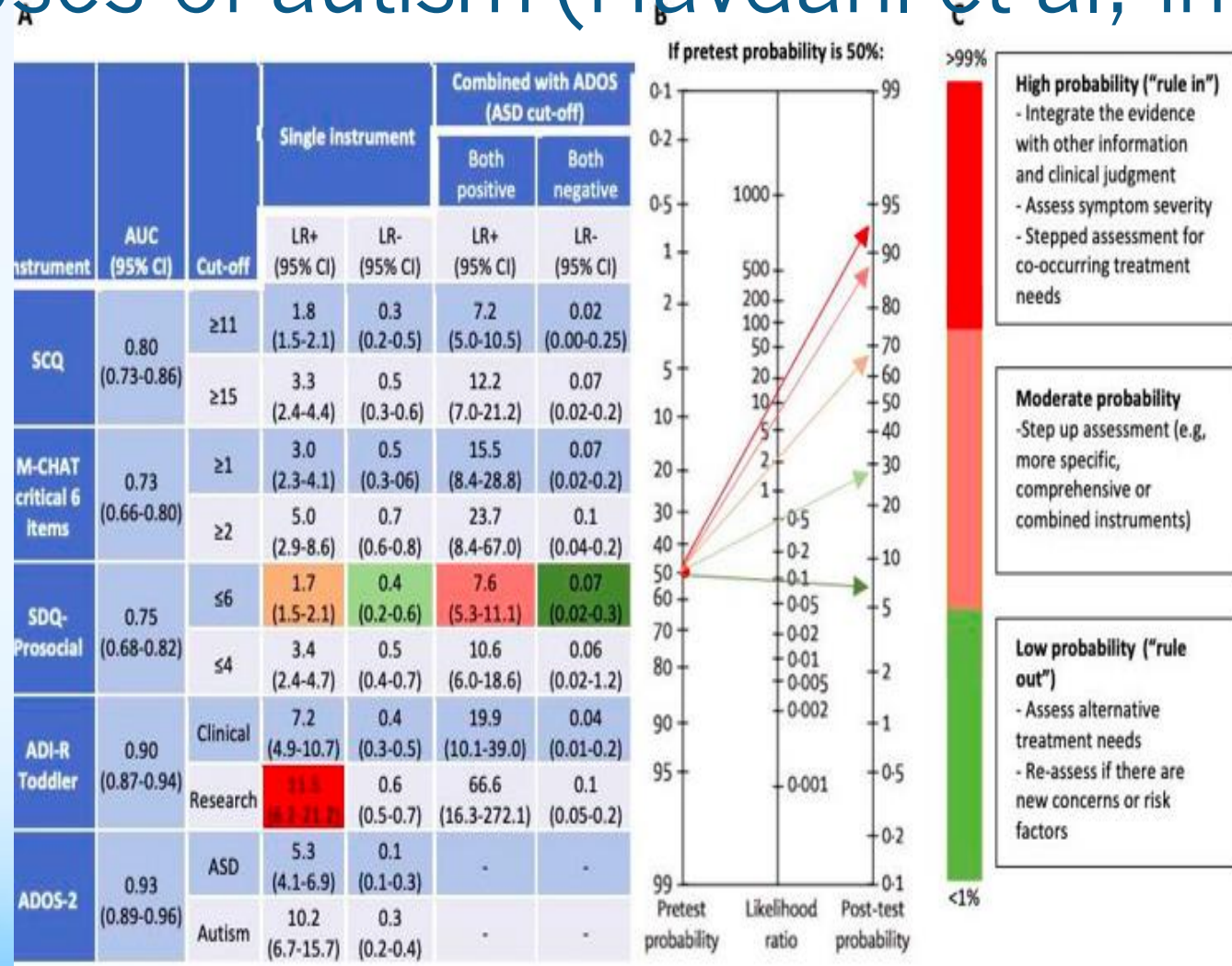
We need to work together to insist that autism and other neurodevelopmental disorders receive parity with other health issues (see Kanne & Bishop, JCPP, 2020). This is a mostly lifelong, complicated condition that affects everyone in the family.

But does require that our priorities match families and self-advocates: What makes a difference in short-term outcomes for whom when and how?

# Stepped Care Approach to Assessment in Autism



# Using MoBa data to estimate likelihoods of clinical diagnoses of autism (Havdahl et al, in prep)



# So how do we do these with social distancing?

- We need to stick together with what is sufficient and appropriate.
- There are lots of ways to do this and lots of different professions and people can help.
- Can't do an ADOS but we need some standards
  - Whether services have to be or should be specific to autism is a whole other question (our field has made enormous gains by working together)
  - Need to be aware of limitations of non-expert assessments (e.g., no delays)
- But we have to be flexible (though we want to hold onto what will be possible eventually).

# Start with parent/caregiver reports via telehealth

- Interviews:
  - Vineland Adaptive Behavior Scales
  - Autism Diagnostic Interview – Revised
  - Others
- Questionnaires (more information, less clinical time though less valid and more work for parents):
  - Social Responsiveness Scale (SRS)
  - ABAS (adaptive scale)
  - CBCL
  - Early screeners: ITSEA, ITC, M-CHAT (with follow-up)
  - Others

# Observations:

- Via video or zoom:
  - NODA (preschool to schoolage)
  - SORF (for kids under 2, developing clinical version from research)
  - ASD-PEDS (for kids under 3, in development, but available)
  - CARS-2 (not tested but seems feasible; psychometrics are problematic)
- In person:
  - STAT (24- 36 months)
  - ADOS-2 (from toddler through adulthood)
  - CARS-2 (ST- under age 6 or delayed and HF-over age 6 and fluent)



# ADOS during social distancing

- One Telehealth publication with Module 4 (Schutte et al 2015) with good psychometrics showing good agreement between face to face and remote for adults with autism, no controls (using complex video system, 2 cameras, video-prompting for the examiner etc.).
- Many reasons to believe that ADOS with face masks or shields will not yield the same information at least on some dimensions (e.g., google glasses, accents).
- It is possible to use the questions and some ADOS tasks, which WPS has said is appropriate if working from copyrighted protocols. The use of ADOS tasks and the limitation of not using ADOS codes as intended should be recognized.
- ADOSes with masks or shields are not recommended. This could be tested but it needs to be tested with non-autistic participants too.

# Brief Observation of Symptoms of Autism (BOSA): Procedure

- Can be done "live" with a parent and a child with an examiner in the next room watching via video or one-way mirror, the examiner in a corner with a mask or at home (via zoom or video). Takes 12 – 16 minutes.
- Materials are selected from an ADOS kit, with a few additional items that need to be purchased and a few that you might want to replace to be more sanitary.
- 12 – 14 minute observation. Coding is done live or from video on ADOS protocols.
- However, codes are converted from 0-3 to binary: yes evidence in this area or no evidence in this area (which doesn't mean that you might not get evidence from some other source).



# What do you get?

- ADOS items are sorted according to DSM5 criteria.
- You can mark off subdomains where a child or adult meets criteria and also those where you do not have enough information to judge.
- This could be followed up by additional parent interview, home videos (e.g., ADI-R, NODA, SORF, ASD-PEDS) or other sources of information.
- THIS IS NOT AN ADOS – it doesn't feel like an ADOS where a competent examiner would be making the patient comfortable and then deliberately integrating specific presses.
- BUT it gives us a chance to see a child or adult with a parent.

# Brief Observation of Symptoms of Autism (BOSA)

- Four versions based on age and language level of the child
- Scored onto ADOS module that is most appropriate for the age and language level of the child
- Minimally verbal for children: 4 minutes play, then clean up; 2 minutes bubbles; repeat
- Phrase speech/young fluent: 4 minutes play; 2 minutes conversation with a shared toy; repeat, then with 2 minutes of bubbles
- Fluent 1 and 2 (different materials): 2 minutes warm-up with simple motor game; 4 minutes shared game with questions, 2 minutes conversation, repeat last two.
- Working on a minimally verbal version for adolescents and adults (different materials)





# Home observation with an adult



# Availability

- Instructions are available for free through our website, with a 90 minute video training. Google BOSA; UCLA.
- Coders need to be familiar with the ADOS, which is a limitation.
- No masks, so in most places will be done by parents or caregivers.
- We do have a therapist version (it's the same), but can't use it now because of masks.
- It is possible for families to do this at home, but does involve sending materials and instructing the parents on the video as well as the administration.
- We have instructions for families in English, Spanish and Polish but instructions for the coders are in English and coding needs to be on a properly translated ADOS.

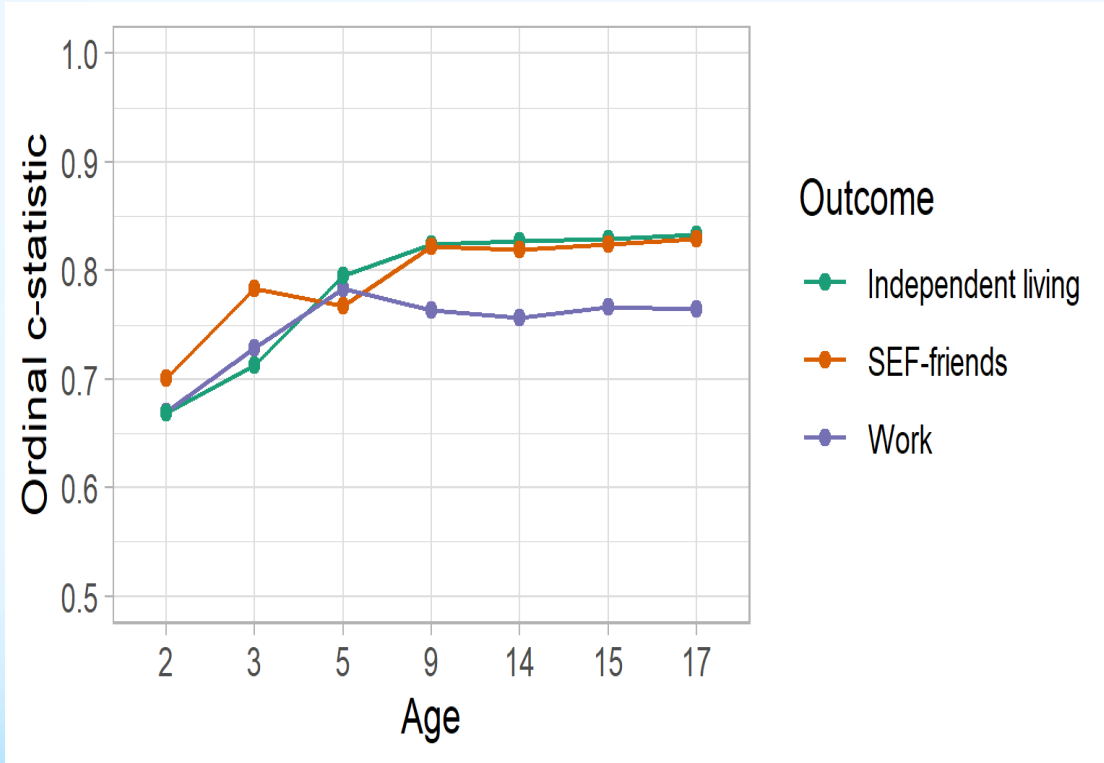
# For research:

- We can't promise anything but:
- If coders are reliable on the ADOS, they should be reliable on this (easy to check).
- If people can work together, we can accumulate enough data, and potentially make subdomain totals and domain scores that can be compared across samples and across time because this measure is more standardized than other measures.
- In the meantime, it's certainly worth using another measure for convergent validity (CARS is probably closest but could do others).

# Limitations

- Will dependent on behavior of parents (need to help them feel as relaxed as possible and make goal clear)
- Will probably be less specific than an ADOS
- May also be less sensitive than an ADOS with children or adults with more subtle difficulties
- May be more variable
- Likely to be affected even more than an ADOS by other factors: cognitive deficits, behaviors
- This isn't a BOSCC (not a way to monitor short-term changes) or an ADOS

Figure 3: Optimism corrected predictive performance for ordinal outcomes



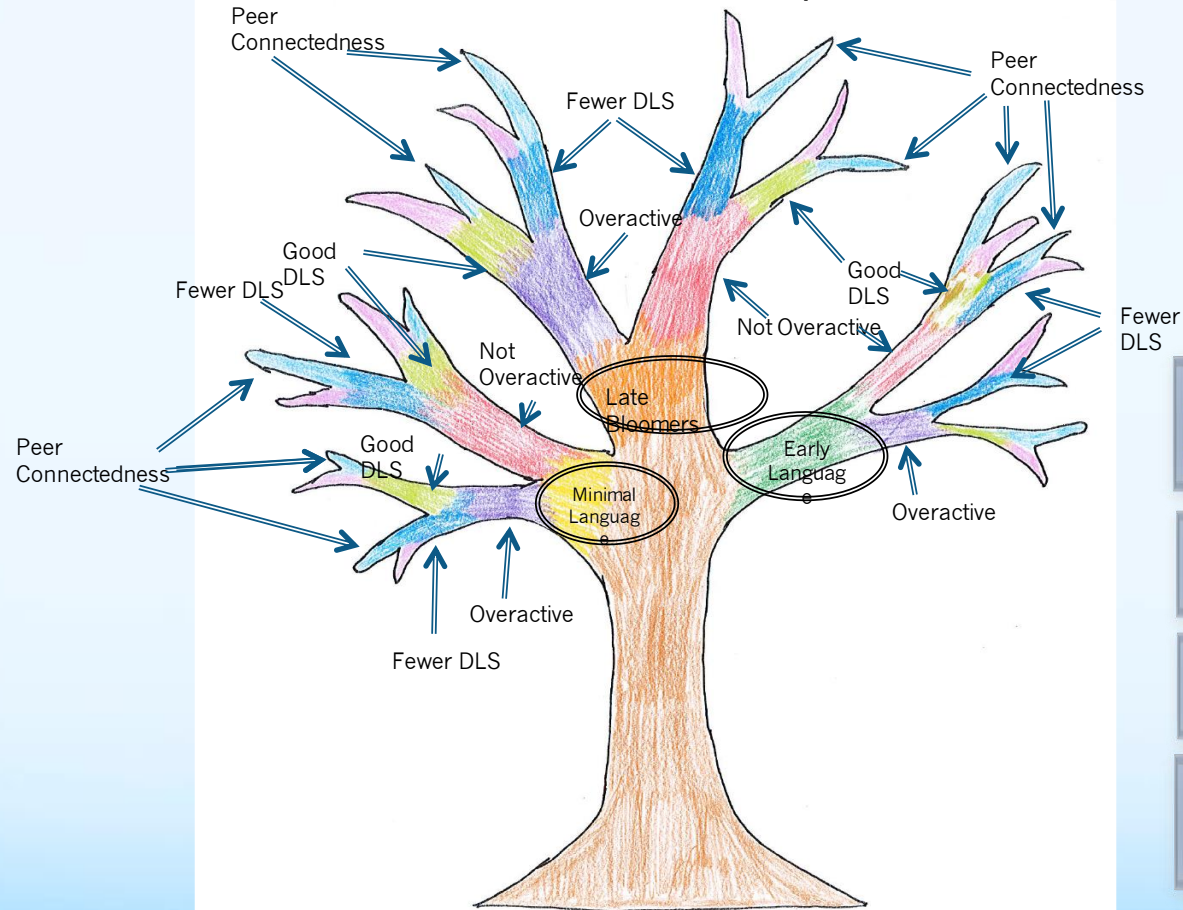
- Once we've acknowledged we can make gross predictions about these aspects of outcome from the standard variables, then what do we do?
- Can we do a better job of monitoring change?
- Do we know which treatments work best for whom when?
- We don't know about predictors of emotional status, mental health and well-being, but we do know these are related to family and community functioning. How do we address these issues?



# Issues for parents

- Parents have the right to insist that a person making a diagnosis has seen the child (or adult) whom they know.
- Parents have the right to be listened to and heard and also to let them know on what basis you are making decisions
- Parents need to know all kind of things about their children. Not necessarily right away, but a valid diagnosis cannot be made without an estimate of cognitive and language skills
  - Autism is defined by social communication deficits beyond those accounted for by general delays
  - Other difficulties (such as cognitive delays, attention, motor) will make just as much difference to the child in the long run as autism so families need to be aware of them at some point.

# Patterns of Development



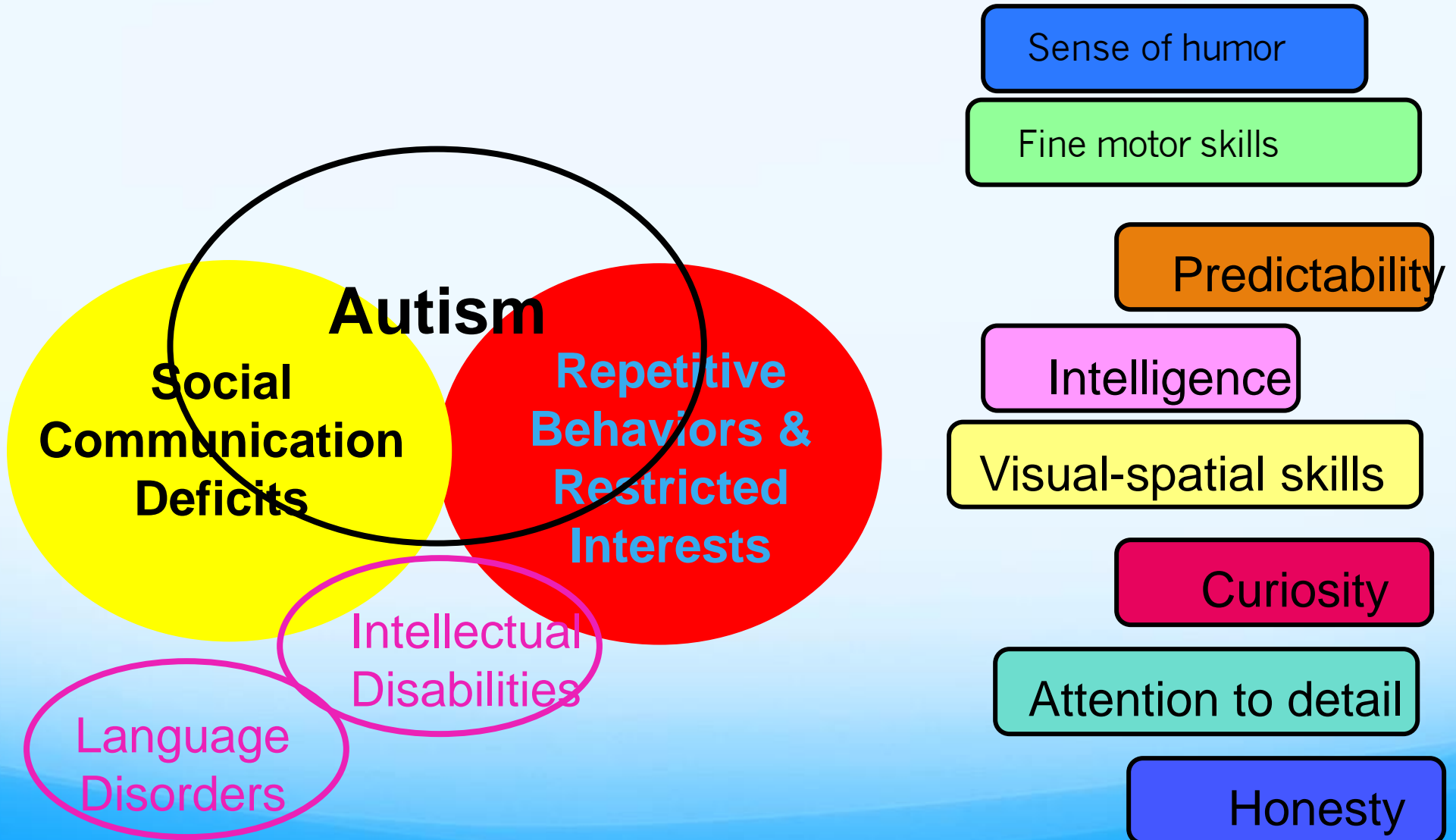
Language  
First words  
Late Bloomers  
Minimal Language

Activity  
Overactive  
Not Overactive

DLS  
Daily Living Skills  
Fewer DLS

Peer Connectedness  
Peer Connectedness  
Less Peer  
Connectedness

# Pervasive Developmental Disorders



# In conclusion:

- Focus on why we're doing assessments:
- If it's to establish a child's right to treatment (this shouldn't be dependent on a diagnosis but it's fair that it's requires some kind of standard tool, along with clinical impression). We don't want to move backward scientifically to diagnosis by prestige or self-defined experts. We also don't want to inflate the importance of one tool over another.
- We want to advocate for families' rights to an adequate assessment and then follow-up that monitors change. Stepped care means that you move up steps if you need it (are not just dismissed as referred to EI).
- And we want families to move forward and be safe.

Autism is more than the sum of its parts and the people with whom we work are more than autism





# Source Citation for this Presentation

Samples:

With website link

- Lord,C.. (2020). ***New Thoughts About Assessment and Diagnosis of Autism*** [PowerPoint slides]. Retrieved from <https://sccap53.org/resources/education-resources/webinars/recordedwebinars/>
- **Without website link**
- Lord,C.. (2020). ***New Thoughts About Assessment and Diagnosis of Autism*** [PowerPoint slides]. Webinar sponsored by the Society of Clinical Child and Adolescent Psychology, Division 53 of the American Psychological Association. New York, NY.



Thank you

