

Assessments in this time of social distancing

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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, DoD and the Simons Foundation.

When they think they know the answers,
people are difficult to guide.

When they know they don't know, they can
find their own way.

From Tao Te Ching (Mitchell Harper's
perennial)

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 figure out ways to work together on these issues.

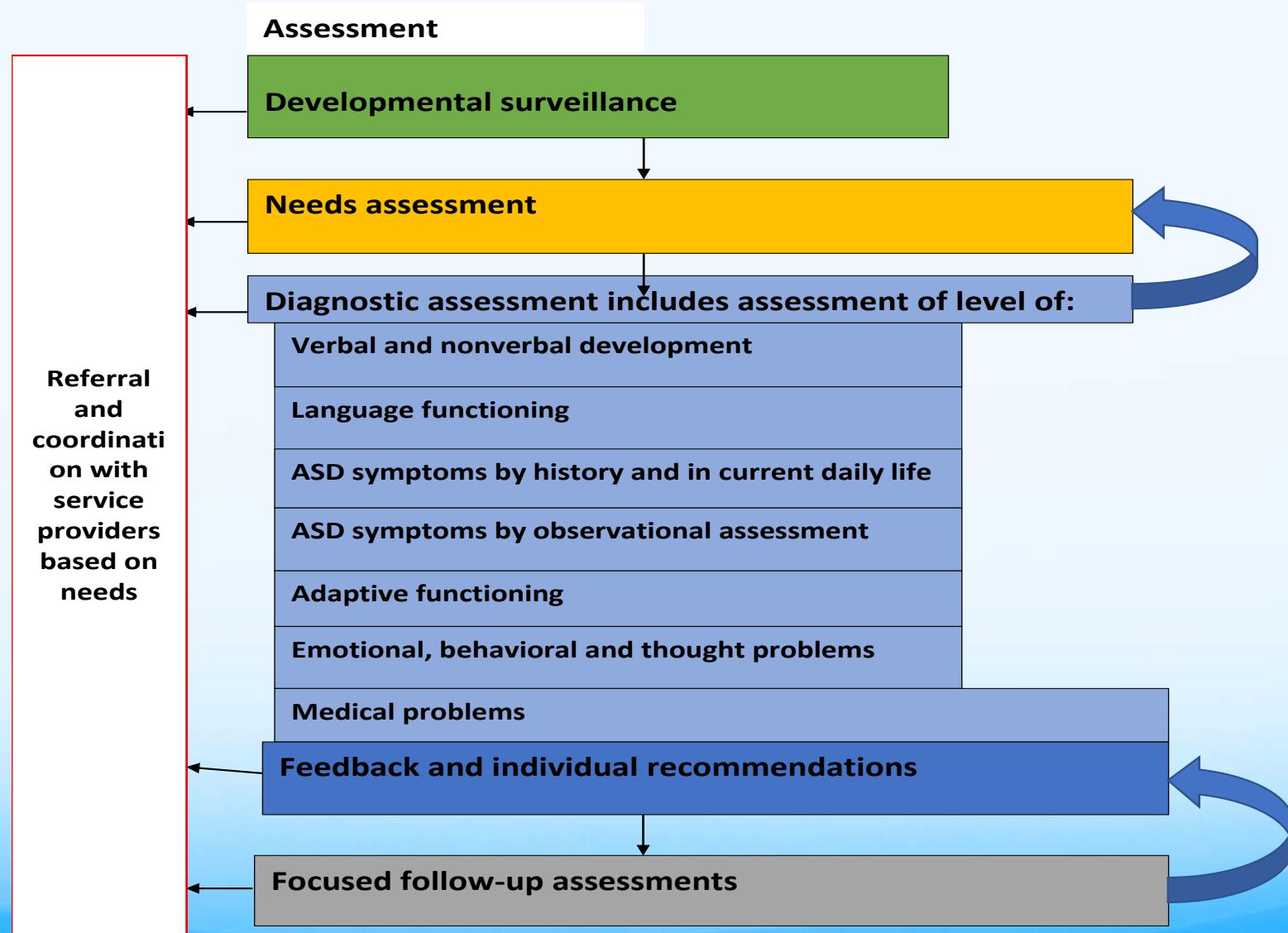
Lots of quandaries

- Autism is very different in different children and different adults and different families work out what they will do in different ways.
- We know how to diagnose autism, which can't be done in 10 minutes and requires information from parents and an observation by an experienced clinician.
- 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).

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
- Co-occurring problems (ADHD, irritability, aggression, depression)
- Behaviors related to autism (ADOS CSS or ADI RRB domain scores or ever ASD diagnosis)
 - Adaptive skills
 - Friendships and relationships
 - Family stress
 - Family involvement in treatment

Stepped Care Approach to Assessment in Autism



General issues and controversies

- Need for standard diagnoses for access to services
 - Early intervention
 - Community resource centers (sometimes providing early intervention)
 - Insurance companies
- What constitutes an adequate evaluation
 - Diagnostic instruments are tools that should provide useful information
 - This partly depends on what you do with the information and to whom it's given
 - Assessment as more than a static “stamp of approval” in a neurodevelopmental disorder
- Relevance of assessment to services
- Needs for research (we'll come back to these)

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

Access to services

Notes: Shouldn't be dependent on a particular diagnosis

Shouldn't be dependent on a particular tool

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.

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.

What constitutes an adequate evaluation?

- A discussion of history with the family
- An observation of the child's (or adult's) behavior in a relevant context or contexts with family's feedback about typicality
- An estimate of language level
- An estimate of non-verbal cognitive level
- A measure of daily living and adaptive skills and current issues
- Screening for common co-occurring disorders
- An updated pediatric or medical exam and history with referrals for additional concerns (psychiatry, neurology, motor, speech, genetics, other)

---- What do you sacrifice? How fast can you do these things?

So how do we do these with social distancing?

- We need to stick together with what provides access
- 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 this has 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 (though not tested but seems feasible; psychometrics are problematic)

Q-Global (cognitive, will not discuss here but has potential though concerns about validity with autism)

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)

Cognitive testing

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 a non-autistic participants too.

Issues for parents

- As a parent, you have the right to insist that a person making a diagnosis has seen the child (or adult) whom you know
- They can't know everything, but you have a right to be listened to and heard and also to know on what basis they are making decisions
- You need to know all kind of things about your child. 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 your child in the long run as autism so you need to know about them at some point

For clinicians: suggestions for a valid and empirically supported observation for ADOS users:

BOSCC: A set of versions of materials and simple activities that provide contexts in which a child or adult can be observed interacting with a "BOSCC-naïve" adult (e.g., a parent, a therapist, a research assistant not from this project) for 12 – 14 minutes.

Minimally verbal: 4 minutes of play with toys from BOX 1 (clean up), 2 minutes of bubbles or rockets; 4 minutes of play with toys from BOX 2 (clean up), 2 minutes of bubbles or rockets

Phrase speech/young fluent children: 4 minutes of play with toys from BOX 1 (clean up), 2 minutes of conversation about shared toy; 2 minutes of bubbles; 4 minutes of play with toys from BOX 2 (clean up), 2 minutes of conversation with shared toy

Fluent12 (same codes; different materials for children 6 – 10, 11- adult): 2 minutes of SLAPJACK, 4 minute of JENGA or similar game with integrated socio-emotional questions; 2 minutes of conversation with no materials; 4 minutes of Marble drop or similar game with questions, 2 minutes of conversation with no materials.

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).
- 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.
- Coding is done 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.

Availability

- We are negotiating with WPS to make this available through their online services to try to keep the cost down.
- Another possibility would be through our center, but we'll see.
- This does assume that coders will be familiar with the ADOS, which is a limitation.
- It is possible to do this at home, but does involve sending materials and instructing the parents on the video as well as the administration but Dr. So Hyun (Sophy) Kim, at CADB at Weill Cornell, has been working on this for several years within a research context and families have been very positive.

Issues for researchers

- Diagnostic confirmation
 - Clinical diagnosis
 - With other measures, including an ADI-R, a CARS, other autism screens
 - But still need some kind of observation
 - Also often need some way to quantify severity (can use above or specific scales such as the RBS-R)

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).
- We need to do a better job of lobbying for studies that assess the value of different treatments for different people, not just supporting one.

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

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





Thank you



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