

ASD Advisory Committee
October 4, 2017 Meeting Notes

Notes compiled by Sharon Flanagan-Hyde, Facilitator—sharon@flanagan-hyde.com

Participants

1. Aaron Blocher-Rubin, PhD, BCBA/LBA, Chief Executive Officer, Arizona Autism United
2. Ann Monahan, Board President, Arizona Autism Coalition; Vice President, State and Governmental Affairs, H.O.P.E. Group, LLC
3. Blythe FitzHarris, PhD, LCSW, Chief Clinical Officer, Mercy Maricopa Integrated Care
4. Brian van Meerten, MEd, BCBA, LBA, Director of Behavioral Health Services, Behavioral Consultation Services of Northern, Arizona, LLC (BCSNA)
5. Bryan Davey, PhD, BCBA-D, CEO, Touchstone Health Services
6. Carrie Burgess, Clinical Director for Behavioral Consultation Services Arizona Autism United
7. Christopher Smith, PhD, Vice President and Research Director, Southwest Autism Research & Resource Center (SARRC)
8. Cynthia Macluskie, Vice President, Board of Directors, Autism Society of Greater Phoenix
9. Danny Kessler, MD, FAAP, Retired Developmental Pediatrician
10. Denise Resnik, Co-Founder and Emeritus Board Member, Southwest Autism Research & Resource Center (SARRC); and Founder, First Place
11. Dennis Friedman, DO, Psychiatrist, Banner University Medical Center - Phoenix, University of Arizona
12. Diana Davis-Wilson, DBH, BCBA, LBA, Director of Clinical & Business Development, Hope Group
13. Diedra Freedman, JD, Board Secretary/Treasurer, Arizona Autism Coalition
14. Don J. Fowls, MD, Medical Strategies (formerly Chief Medical Officer), Mercy Maricopa Integrated Care (MMIC), RBHA
15. Ginger Ward, MAEd, Chief Executive Officer, Southwest Human Development
16. Janna Murro, Director of Family Support and Education, Raising Special Kids
17. Jared Perkins, MPA, Director of Operations, Children's Clinics; Vice President, Autism Society of Southern Arizona
18. Joanna Kowalik, MD, Chief Medical Officer, Arizona Department of Economic Security/Division of Developmental Disabilities (DES/DDD)
19. Jon Meyers, Executive Director, The Arc of Arizona
20. Joyce Millard Hoie, MPA, Executive Director, Raising Special Kids
21. Karla Birkholz, MD, Arizona Academy of Family Physicians, HonorHealth Medical Group
22. Kelly Lalan, Health Choice Integrated Care (HCIC), RBHA
23. Lauren Prole, Clinical Project Manager, Arizona Health Care Cost Containment System (AHCCCS)
24. Leslie Paulus, MD, PhD, FACP, Medical Director, UnitedHealthcare Community Plan

25. Lindsey Martinell, Mercy Maricopa Integrated Care (MMIC), RBHA
26. Megan Woods, MEd, BCBA, LBA, Behavior Analyst, Arizona Department of Economic Security/Division of Developmental Disabilities (DES/DDD)
27. Monica Coury, Vice President of Legislative and Government Affairs, Centene
28. Ramiro Guillen, MD, Chief Medical Officer, Southwest Behavioral & Health
29. Rene Bartos, MD, MPH, FAAP, Medical Director, Mercy Care Plan
30. Robin K. Blitz, MD, FAAP, Chief, Developmental Pediatrics, Barrow Neurological Institute at Phoenix Children's Hospital
31. Ron Copeland, Senior Director of Program Development, Cenpatico Integrated Care (CIC), RBHA
32. Sandra Stein, MD, Child & Adolescent Psychiatry, Banner-University Medical Center
33. Sara Salek, MD, Chief Medical Officer, Arizona Health Care Cost Containment System (AHCCCS)
34. Sherri Wince, ALTCS Administrator, Arizona Department of Economic Security/Division of Developmental Disabilities (DES/DDD)
35. Sydney Rice, MD, MSd, Board-certified Developmental Pediatrician; Associate Professor, Pediatrics, The University of Arizona College of Medicine in Tucson
36. Terry Matteo, PhD, Clinical Child Psychologist

NODA™ Tool

Christopher Smith, PhD, Vice President and Research Director, Southwest Autism Research & Resource Center (SARRC)

NODA™ (Naturalistic Observation Diagnostic Assessment)—slides, peer-reviewed article, and supplemental materials provided via e-mail.

NODA was designed to expedite the behavioral assessment of a child (18 months to 6 years) by connecting a parent directly to qualified professionals through technology. As with any assessment for ASD, the process informs clinical judgment, which ultimately determines if there is evidence to support DSM-5 criteria. It was designed in response to the need for improved access to diagnosis, especially in rural areas.

NODA is not meant to replace the need for a thorough medical evaluation (in fact, that is the first recommendation in the report) or meant to be better or more accurate than any existing high quality diagnostic approach.

NODA may be yield an accurate diagnosis in 85% of children needing an evaluation.

15% of children may still require an in person assessment; characteristics of this group include higher cognitive functioning with age appropriate abilities; fewer observable behaviors that suggest autism; potentially difficult to diagnose even in an in-person assessment. Clinics using NODA may be able to serve 85% of their clients seeking diagnosis, and see only 15% in the clinic, which significantly reduces the burden on staff.

At this time, NODA is not a covered benefit under AHCCCS plans.

NODA takes one hour of a rater's time and one hour of a psychologist's time. Chris said that an in-person evaluation ranges from 12 to 20 hours, including preauthorization, scheduling, psychometrician, psychologists, and follow-up, and the average reimbursement is \$800 to \$900. NODA would be lower cost and could improved the efficiency of the diagnostic clinic.

It could be used to triage the waiting list of children coming in for an evaluation, and get children more quickly to intervention services.

At this time, results are sent to a parent via a letter and parents can call with questions. They are researching using a Skype call for delivering results.

In response to a question about bias or selectivity in the videos of behavior scenarios, Chris said that they don't think that parents are structuring the videos they submit, although this is a definite concern. Most parents don't know what the diagnostician is looking for.

A question was asked about any differences in inter-rater reliability for children of different ages. Anecdotally, no differences were apparent, but the sample size is not large enough to accurately reflect any differences. Sensitivity is strongest when a child has more observable behaviors; it's hard to reach conclusions in the absence of a behavior.

Crisis Services

Cynthia Macluskie, Vice President, Board of Directors, Autism Society of Greater Phoenix

Urgent needs include:

- A well-coordinated, multidisciplinary network of providers who treat individuals with ASD who have complex co-occurring medical issues.
- Crisis services for children with ASD and their families.
- Meeting the needs of children/adults with developmental delay/ASD in Emergency Department and inpatient settings.
- Access to respite and other support services for parents of children with ASD. Preventing parental burnout can help avoid the need for out-of-home placement.

Cynthia reported that she has received troubling feedback from multiple families that have required crisis services. Typically, the child is a nonverbal adolescent with ASD, complex medical conditions, and aggressive behavior. In some cases, the child's behavior has been labeled as domestic violence.

She reported that families believe there is no safe place in Arizona to bring a child in crisis. Providers have threatened to call the Arizona Department of Child Safety (DCS) as a way to manage families with whom there is a disagreement, and some have followed through on the threat. Some families are now afraid to access needed care or to complain about quality of care because they fear retribution.

Key points of the discussion included:

- The behaviors reported by families about some providers are inappropriate and unacceptable.
- Threats are not consistent with system of care principles and values; it is only appropriate to call DCS when there is legitimate concern about safety of a child.
- We need to understand the underlying causes of why families and providers feel defensive and adversarial. It benefits everyone to avoid adversarial situations.
- Families are afraid to complain about quality of care; they fear retribution; there is fear and anger on both sides.
- Levers are in place (clinical resolution team, quality of care team, performance evaluations) to investigate and make needed quality of care improvements. Mercy Maricopa Integrated Care (MMIC) will follow up regarding families' complaints

about providers and evaluate the need for process changes and additional provider training.

- The system and families must work together to find solutions for complex situations.
- To prevent problems, we must pay more attention to caregiver status and provide supportive services. When issues and needs are not being addressed, a situation is more likely to deteriorate into an adversarial crisis. Providers need to regularly assess the caregiver as well as the individual with ASD, and track caregiver status in the system.
- A competent workforce critical. People use the tools that they have, and no one works well under stress. We want to educate and support providers so that they have the necessary knowledge and competence level to address the needs of the ASD population and deliver high quality services. We need to give providers the resources they need to do a good job.
- We need to ensure that family-centered principles, which are included in current contracts, are embedded into the system of care at all levels. These principles need to be given greater weight in provider training and the delivery of services.
- Credentialing in hospitals and coordinated care is essential.
- We need an ASD-specific crisis intervention team—a “firehouse” model, a 24/7 rapid response model that addresses medical and behavioral problems. Services should be available to all children with ASD, not just AHCCCS members. The responder would coordinate care for the family, smooth the way, and begin to work on discharge plans from the onset of the crisis.
- Physicians need education; they often don't fully investigate the medical problems that may underlie aggressive behaviors of nonverbal individuals with ASD. Robin Blitz developed training for PCH to help physicians, nurses, and technicians understand that when a child with ASD is self-injurious, rages, and/or has sleep problems, the provider must look for physical illnesses, and not just address the problem with psychopharmacology.
- These issues are a national problem; we should look at solutions being generated in other locations.

Recommendation: Convene a Crisis Work Group to identify problems and generate concrete recommendations for the improving system of care. The Work Group will be open, positive, respectful, constructive, collaborative, and solutions-focused.

Suggestion: Invite a representative of Aurora Behavioral Health System to participate in the ASD Advisory Committee.

Emergency Department Care

Dennis Friedman, DO, Psychiatrist, Banner University Medical Center - Phoenix, University of Arizona

Dennis is working on a quality improvement plan at Banner to improve the quality of care and quality of experience for individuals with ASD seeking care in the Emergency Department (ED). Although there is little evidence-based medical literature on this topic, one article noted in a retrospective study that about one-third of individuals with autism who seek care in the ED end up in restraints. Another study estimated that 50% of

individuals with autism and a comorbid psychiatric diagnosis end up in restraints when they seek care in the ED. This not only degrades the patient/provider relationship, it also degrades diagnosis, care, medical decision-making, outcome, and both patient and provider satisfaction.

Dennis provided a document from the University of South Florida that offers practical guidance to health care systems. Hospital systems that now utilize these recommendations anecdotally report better outcomes. He is undertaking a quality improvement project that focuses on recommendation #2 from this guide: “Let the Caregiver Be Your Guide to Success.” He developed a family questionnaire that Emergency Departments could give to families when they bring their loved ones with autism to the hospital. These questions were largely developed at Children’s Hospital of Philadelphia; similar questionnaires’ are utilized in a variety of settings nationally. There is also a “memory jogger” for nurses and care teams working with people with autism.

The cost to the hospital to implement this is minimal and the added value to the patients’ health care could potentially be great. Simple modifications can result in better outcomes.

Question: Is there an Emergency Department that could serve as a champion? Or multiple EDs that could form a learning collaborative?

Comments:

- St. Joseph’s ED has demonstrated expertise in treating patients with ASD.
- Mercy Maricopa Integrated Care has a work group addressing issues related to people with special needs in EDs. Phase 1 of a Behavioral Health 101 curriculum for ED providers has been developed. Perhaps this could be added to Phase 2.
- Robin Blitz has developed a training video for providers on working with a child with autism. There is also a training video for first responders on autism.
- The Department of Developmental Disability (DDD) expressed interest in working with Dennis.

Developmental Screenings & Early Identification—Moved to January 10, 2018 Agenda

Rene Bartos, MD, MPH, FAAP, Medical Director, Mercy Care Plan

Robin Blitz, MD, FAAP, Chief, Developmental Pediatrics, Barrow Neurological Institute at Phoenix Children’s Hospital

Developmental screenings, early identification (before age 3), and early comprehensive ABA services

Concern raised: Problems with the PAS Tool – identifying young children who are “at risk for institutionalization” (under-identifies those who need intervention the most)

Updates on ASD Centers of Excellence

Bryan Davey, PhD, BCBA-D, CEO, Touchstone Health Services

Ramiro Guillen, MD, Chief Medical Officer, Southwest Behavioral & Health

In partnership with Mercy Maricopa Integrated Care and Mercy Care Plan, two Autism Centers of Excellence in Phoenix held grand openings.

Touchstone Health Services Autism Center of Excellence—

<http://www.touchstonehs.org/behavior-analytic-services/autism-center-excellence/>

Southwest Autism Center of Excellence (Southwest Behavioral & Health Services and Southwest Human Development— <http://www.saceaz.org>)

Lack of providers who can provide ASD interventions—Moved to January 10, 2018

Agenda

- Lack of consistency with training, supervision, and payment for providers.
- Low reimbursement for Speech Therapists (communication problems are one of the primary deficits with ASD)
- Hab workers require different skills for different/specific disabilities (e.g., ASD vs. CP) – Require hab workers to have training and skills specific to the disability of the individual they are working with

DDD Age Limit

A concern was raised about the DDD age limit for autism-specific treatments (some Committee members want to extend eligibility beyond age 5). Conversation focused on misperceptions about accessing services. In addition to DDD, families can access services through the Regional Behavioral Health Authority (RBHA) or the acute care plan. Work remains to be done to educate families about how to navigate the full array of agencies and services available. This discussion will be added to the January 10, 2018 agenda.

Services for Adults with ASD

Concern raised: continued lack of services for adults who have autism and the difficulties getting into the system after childhood

Vitalyst Health Foundation has convened an Adults with ASD Innovation Group. At its first meeting in September, the group decided to focus on the Transition Years (14-30). Contact Sharon Flanagan-Hyde (sharon@flanagan-hyde.com) if you'd like to participate.

Announcements

Rene Bartos announced that **Best practices for early identification and management of Autism Spectrum Disorder (ASD) for Primary Care Providers** is scheduled for Tuesday, November 7th beginning at 5:30pm. The venue is centrally located and we are serving a very nice catered dinner. The presentation begins at 6pm and ends at 8:30pm and offers at no charge 2.5 Category 1 CMEs for physicians and mid-level providers. A flyer with all of the details is on the following page.

Future Agenda Topics

Please send agenda items for the January 10, 2018 quarterly ASD Advisory Committee meeting to Sharon Flanagan-Hyde (sharon@flanagan-hyde.com).

The Spring meeting will be April 11, 2018.



Integrated Care Training Institute, Fall 2017

Best practices for early identification and management of Autism Spectrum Disorder (ASD) for Primary Care Providers

Earn 2.5 AMA PRA Category 1 Credits™ at no cost to you



Tuesday, November 7, 2017

5:30 – 8:30 p.m.

Schedule of events

5:30 p.m.: Check in and dinner

6:00–8:00 p.m.: Best practices for early identification and management of Autism Spectrum Disorder (ASD)

8:00–8:30 p.m.: Care Coordination



Foundation for Senior Living Caregiver House

1201 E. Thomas Rd.
Phoenix, AZ 85014



Register by
October 27, 2017

To register, visit

www.mercymaricopa.org/providers/training

and click on the 'register here' link.

Participants will learn to:

- List best practices for early identification of ASD
- Discuss how to use screening procedures to identify patients with possible ASD
- Explain referral processes and on-going management of ASD
- Identify considerations for transition of youth with ASD to adulthood

Best practices for early identification and management of Autism Spectrum Disorder (ASD) presented by:

Rene Bartos, MD, MPH, FAAP

VP, Systems of Care, Medical Director
Mercy Care Plan/Mercy Care Advantage

Sala S. Webb, M.D., F.A.P.A.

Children's Medical Administrator
Mercy Maricopa Integrated Care

Care Coordination presented by:

Janet Holtz, BAS

Division of Developmental Disability Liaison
Mercy Care Plan

This activity has been planned and implemented in accordance with the accreditation requirements and policies of the Accreditation Council for Continuing Medical Education (ACCME) through the joint providership of St. Joseph's Hospital and Medical Center, and Mercy Care Plan. St. Joseph's Hospital and Medical Center is accredited by the Accreditation Council for Continuing Medical Education (ACCME) to provide continuing medical education for physicians.

St. Joseph's Hospital and Medical Center designates this live activity for a maximum of 2.5 AMA PRA Category 1 Credits™. Physicians should claim only the credit commensurate with the extent of their participation in the activity.



Integrated Care Training

Behavioral health conditions such as addiction, anxiety and depression are often thought of as secondary, even though they have an impact on health outcomes. That's why it's important to treat behavioral and physical health together. The Integrated Care Training Institute offers a variety of office-based training and education focused on this integrated care model. For more information, visit www.mercymaricopa.org/providers/training.

Contract services are funded in part by the state of Arizona.

www.mercycareplan.com

www.mercymaricopa.org

AZ-17-08-04



ASD ADVISORY COMMITTEE MEETING

Wednesday, October 4, 2017 3:00 pm - 5:00 pm

Vitalyst Health Foundation, 2929 N. Central Ave., Phoenix, AZ 85012

Teleconference: 1-602-385-6524 Participant Passcode: 9999#

Go-To-Meeting: <https://global.gotomeeting.com/join/934000149>

AGENDA

Time	Topic	Presenter
3:00 pm	Welcome and introductions	Sharon Flanagan-Hyde, Facilitator
3:15 pm	NODA™ (Naturalistic Observation Diagnostic Assessment) — Presentation and Q&A	Christopher Smith, PhD, Vice President and Research Director, Southwest Autism Research & Resource Center (SARRC)
3:35 pm	Discussion: <ul style="list-style-type: none"> • Respite and other support services for parents with children with ASD: the importance of preventing parental burn-out and avoiding out-of-home placement • Network of providers who treat ASD members with complex co-occurring medical issues • Crisis services • Meeting the needs of children/adults with developmental delay/ASD in Emergency Department and inpatient settings 	Cynthia Macluskie, Vice President, Board of Directors, Autism Society of Greater Phoenix Dennis Friedman, DO, Psychiatrist, Banner University Medical Center - Phoenix, University of Arizona
3:50 pm	Developmental screenings, early identification (before age 3), and early comprehensive ABA services <ul style="list-style-type: none"> • Concern raised: Problems with the PAS Tool – identifying young children who are “at risk for institutionalization” (under-identifies those who need intervention the most) 	Rene Bartos, MD, MPH, FAAP, Medical Director, Mercy Care Plan Robin Blitz, MD, FAAP, Chief, Developmental Pediatrics, Barrow Neurological Institute at Phoenix Children’s Hospital
4:05 pm	Updates on ASD Centers of Excellence	Bryan Davey, PhD, BCBA-D, CEO, Touchstone Health Services Ramiro Guillen, MD, Chief Medical Officer, Southwest Behavioral & Health

Continued on next page

Time	Topic	Presenter
4:15 pm	Lack of providers who can provide ASD interventions (ABA/Floortime/PRT, etc.) <ul style="list-style-type: none"> • Lack of consistency with training, supervision, and payment for providers. • Low reimbursement for Speech Therapists (communication problems are one of the primary deficits with ASD) • Hab workers require different skills for different/specific disabilities (e.g., ASD vs. CP) – Require hab workers to have training and skills specific to the disability of the individual they are working with 	Sharon Flanagan-Hyde facilitates discussion
4:30 pm	Discussion: DDD age limit for autism-specific treatments (some Committee members want to extend eligibility beyond age 5)	Sharon Flanagan-Hyde facilitates discussion
4:40 pm	Services for Adults with ASD <ul style="list-style-type: none"> • Concern raised: continued lack of services for adults who have autism and the difficulties getting into the system after childhood • Innovation Group focus: Transition Years (14-30) 	Sharon Flanagan-Hyde facilitates discussion
4:50 pm	Announcements and Future Agenda Topics	Sharon Flanagan-Hyde
5:00 pm	Adjourn	

Upcoming Meetings: January 10, 2018 and April 11, 2018



EMERGENCY

HOSPITAL



Main Entrance

AUTISM &

The Hospital Emergency Room

*A practical guide for health professionals
to meet the needs of individuals with
Autism Spectrum Disorders*

Understanding Autism

Autism is a lifelong neurological disability that affects a person's ability to communicate, understand language, play, and socially interact with others. The first signs of autism usually appear as developmental delays before age three.

Every person with autism is different. However, there are some common characteristics of individuals with autism that may occur.

- Difficulty in using and understanding **language**
- Difficulty in using **social skills** and navigating social situations
- **Over or under sensitivity** to sound, sight, taste, touch, or smell
- **Repetitive behaviors** such as spinning or lining up objects
- **Difficulty with changes** to surroundings or routines
- **Challenging behaviors** such as aggression or self-injury





What Healthcare Providers Need to Know About Patients with Autism

Families of children with autism learn early how to anticipate and manage a crisis. But when the crisis involves emergency medical services or a trip to a hospital emergency room, it often takes a well-informed treatment team and caregivers to keep the situation under control. The sights, sounds, smells, and accelerated pace of hospital emergency services can overwhelm the senses of an individual with autism. The following suggestions are prepared for emergency treatment teams, hospital clinicians, and the families of individuals with autism.



Decrease Wait Time, Whenever Possible

- **Recognize** that simply entering a noisy, crowded waiting room may trigger acute anxiety and challenging behaviors in children with autism; accompany the primary caregiver and child to a quiet room for initial assessment and registration.
- If the triage nurse determines the child will need to wait to see a physician, **provide a quiet place**, whenever possible.
- Assess a child and **perform procedures as soon as possible**, to reduce or eliminate wait time.
- If transporting a child to another area in the hospital, **allow a primary caregiver to accompany child**.
- **Utilize hospital resources**; some ER departments employ a play therapist whose job it is to help put young patients at ease to reduce anxiety or distract child's attention during a procedure.

Treatment Team: Let the Caregiver Be Your Guide to Success

- Always ask about the **child's primary form of communication**
- If unable to speak, **make sure the child has a method of communication** familiar to them, such as a paper and pencil, pictures, gestures, or a communication device
- **Ask caregiver** what has worked in the past when at medical visits
- **Ask about sensory sensitivities** to light, sound, touch, and smell
- **Assess response to pain**; many children may either have a low or high tolerance to pain and may not feel typical sensations to heat or cold
- Be aware that **some children will be attracted to shiny objects** and may reach for or grab medical instruments
- **Inquire about previous emergency situations** and what worked to minimize anxiety and calm the individual



- Remember, parents of children with autism are under tremendous stress in daily life; **monitor the parents' stress levels** and respect individual methods of coping

Modify the Physical Environment

- Move child and caregiver to a **private exam and treatment area**, if possible
- **Dim overhead lighting** if necessary
- **Replace paper** gowns and paper covering on exam table with cloth
- **Anticipate resistance** if the child needs to be in a reclined position
- Be aware that there may be a fight-or-flight response to any emergency situation; **arrange the exam room and treatment area** to help motivate the child to stay in the room
- **Monitor the patient** continuously for signs of overstimulation





Model a Caring Attitude for the Treatment Team

- Move slowly to the patient's level to communicate
- Give praise and encouragement
- Use calming body language and give the patient extra personal space
- Whenever possible, prepare the team to work from the floor, the caregiver's lap, or wherever the individual feels comfortable
- Use a quiet, calm voice and minimize words and touch
- Speak slowly in simple, non-medical phrases and pause between requests
- Using a neutral tone of voice, tell the caregiver and child everything the medical team is going to do right before they do it
- Allow extra time for response
- Expect minimal eye contact
- Allow individual to touch and hold equipment whenever possible
- If the patient is a child, use a toy doll, stuffed animal, or pictures to demonstrate a medical procedure, whenever possible
- If the patient is an adult, remember the individual may not be able to understand direct questions or give informed consent for treatment

Reinforce Cooperative Behavior

- Provide rewards through praise and encouragement for all cooperative behavior
- Ignore behaviors that appear different (unusual body movements, unexpected vocalizations, inappropriate words or comments)
- Use pictures to redirect attention and to show what will happen and what is expected

Be Prepared, Be Proactive

- When senses are overloaded and anxiety escalates, an individual with autism may respond with aggressive behaviors toward others, hospital equipment, or themselves
- Behavior can include prolonged screaming, biting, scratching, dropping to the floor, and kicking, etc.
- Encourage caregivers to help redirect, reassure and restore calm to an escalating situation
- Notify the treatment team to be prepared, and to gently and quietly assist as needed





Florida's First Choice for Autism Support

The Center for Autism & Related Disabilities (CARD) provides support and assistance with the goal of optimizing the potential of people with autism and related disabilities.

Center for Autism and Related Disabilities
Department of Child and Family Studies
Louis de la Parte Florida Mental Health Institute
College of Behavioral and Community Sciences
University of South Florida MHC 2113A
13301 Bruce B. Downs Blvd.
Tampa, FL 33612

In Florida: 1-800-333-4530 or 813-974-2532
<http://card-usf.fmhi.usf.edu>





Behavior Imaging®

Investigating the accuracy of novel telehealth diagnostic approach for ASD:

The Naturalistic Observation Diagnostic Assessment (NODA)



Southwest
Autism
Research &
Resource
Center



Christopher J. Smith, Ph.D.
Vice President & Director of Research



The need for improved access to diagnosis

Substantial delays between first concerns and diagnosis:

- ineffective screening
- “wait and see” approach
- long waitlists for diagnosticians

Particularly long for rural families:

- live in areas with fewer professionals
- need to travel long distances to see professionals
- greater family hardship

Elements of high quality ASD diagnosis

Practice parameters (AACAP, 2015) indicate:

- two methods of assessment should be used
 1. developmental history interview, and
 2. observation

Structured assessments:

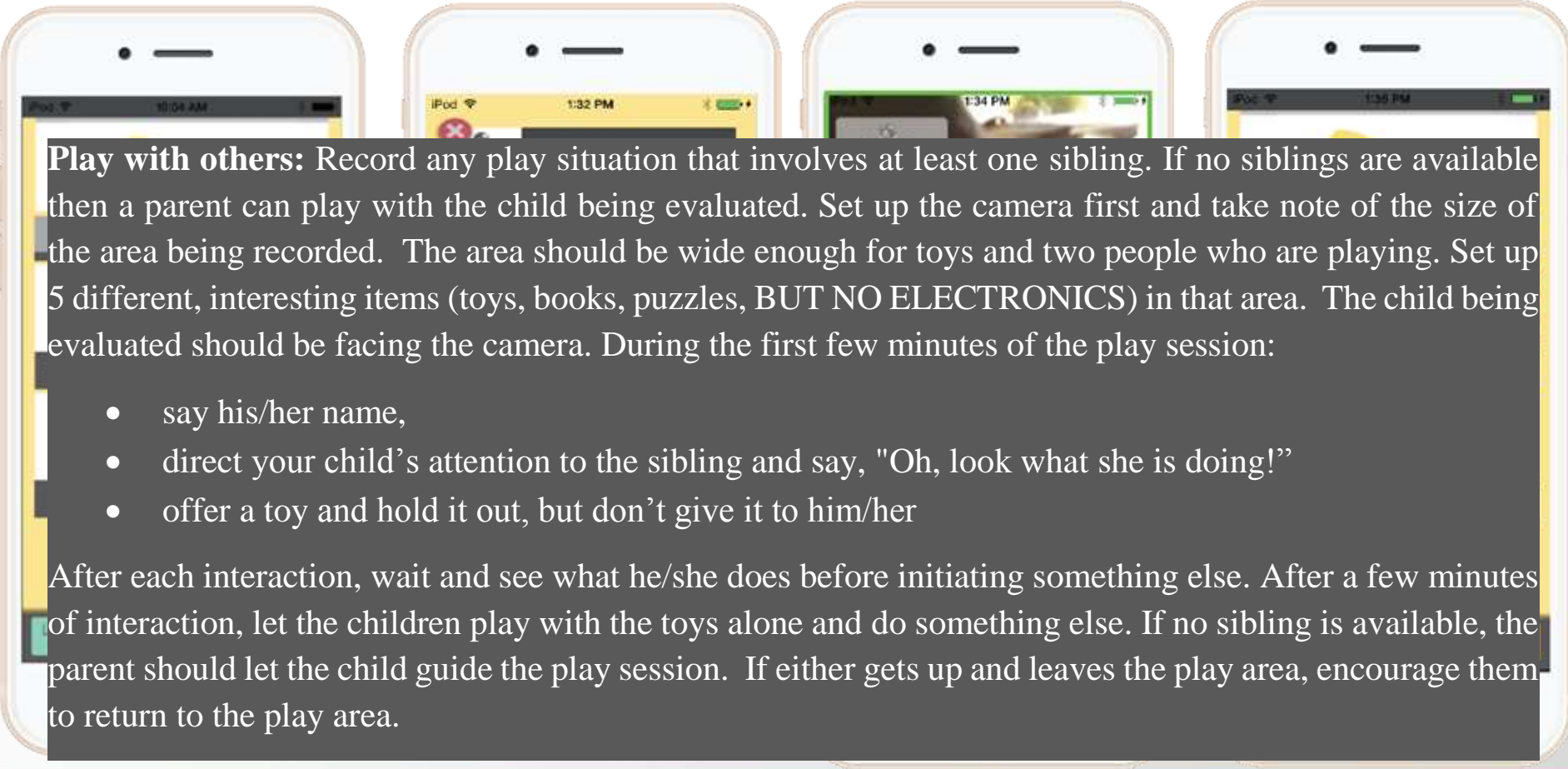
- add uniformity to the process
- Gold Standard: ADI-R and ADOS
- require training and time to administer correctly

Clinical judgement:

- assessments should inform clinical judgment
- expert clinical judgment is the most important component



Naturalistic Observation Diagnostic Assessment



Play with others: Record any play situation that involves at least one sibling. If no siblings are available then a parent can play with the child being evaluated. Set up the camera first and take note of the size of the area being recorded. The area should be wide enough for toys and two people who are playing. Set up 5 different, interesting items (toys, books, puzzles, BUT NO ELECTRONICS) in that area. The child being evaluated should be facing the camera. During the first few minutes of the play session:

- say his/her name,
- direct your child's attention to the sibling and say, "Oh, look what she is doing!"
- offer a toy and hold it out, but don't give it to him/her

After each interaction, wait and see what he/she does before initiating something else. After a few minutes of interaction, let the children play with the toys alone and do something else. If no sibling is available, the parent should let the child guide the play session. If either gets up and leaves the play area, encourage them to return to the play area.

Naturalistic Observation Diagnostic Assessment

NODA Assessment
? X

DSM5: Autism Spectrum Disorder
[View DSM 5 Checklist](#)
Client: 9017
Age: 6 years / 3 months

Data Viewer - 2014-02-26 at 09:53
? X

<u>SOCIAL</u>	<u>Behavior</u>	<u>Communication</u>	<u>Typical</u>
Ignores others	Play: Rep/Nonfunctional	Verbal: Echolalia	Eye contact
No response	Play: No play with toys	Verbal: Stereotyped Language	Eye contact with Facial Expression
No seeking comfort	Behavior: Hand/Finger Mann	Verbal: Odd intonation	Facial expression
No seeking to share	Behavior: Odd body Mann	Verbal: Limited language	Social response (i.e., laugh)
No/Limited interaction	Behavior: Compulsive Routine	Verbal: Articulation Issues	Verbal response
No/Limited joint attention	Sensory: Hyper focus	Verbal: Odd statements	Point
No/Limited engagement	Sensory seeking: Visual	Verbal: Repetitive sounds	Head shake/nod
No sharing (toys or emotions)	Sensory seeking: Auditory	Non Verbal: No point	Play with others
	Sensory seeking: Mouthing	Non Verbal: Odd/No gesture	Play with toys
	Sensory seeking: Tactile	Non Verbal: No eye contact	
		Non Verbal: No facial express	

Parent Concerns

Capture at max 10 minutes of problematic behavior

Request Evidence

[more info](#)

Naturalistic Observation Diagnostic Assessment

DSM 5 Checklist

Select a Clinician:

Ingr

1) Please describe current concerns you have with your child's development: She is not speaking.

She doesn't use language on a regular basis.

A. Persistent deficits in social communication

2) Does your child regularly seek attention or interaction with you and others in a positive, enjoyable way? Yes

Child exhibits some typical social behaviors, but communication is delayed. During video tapes there were

3) How old was your child when he/she used single words on a daily basis? How old was your child when he/she used phrases? She was 14 months when she started using single words. She is not using phrases.

1. Deficits in social-emotional reciprocity, such as sharing of interests, emotions, or affect, or failure to initiate or respond to social interactions with appropriate nonverbal behaviors.
Criterion is met Yes No

4) Give an example of something you heard your child say this morning when he/she requested something of you: She did not speak this morning.

5) Does your child have any medical conditions? No.

6) Have you ever had your child's hearing checked? Yes.

7) Please describe your child's physical development (crawling or walking). Has anything appeared unusual to you? Nothing unusual. She walks, runs, crawls, climbs.

8) Does your child understand the function of common objects like a fork, spoon or telephone? Yes.

2. Deficits in nonverbal communication, such as abnormalities in eye contact and body language, or atypical or absent facial expressions.
Criterion is met Yes No

9) Do you ever see your child pretend to use these objects during play? Yes.

10) When you hide a toy or an object in front of your child (for example, under a blanket), does he or she attempt to find it? Yes

11) Does your child look for a favorite toy or book if it's not nearby? Yes

12) Does your child point at items he/she is interested in? Yes

13) How about other gestures? She waves goodbye.

14) Briefly describe your child's interest in other children of the same age group: She plays with kids her age but it is more side by side play than interacting with the children

15) Briefly describe your child's interests in toys or activities: She loves to play with her toys. She pretends to put her babies to sleep, and she builds with blocks. She loves being outside, and loves her swing set.



Social: Ignoring

Social: Ignoring



Comm: Verbal:
Odd/repetitive sounds

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Naturalistic Observation Diagnostic Assessment

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Verbal: No phrases
Does not use phrase speech to communicate.

Verbal: No verbal response
Does not respond verbally to questions or comments

Verbal: No words
The child is nonverbal.

Non Verbal: No point
Does not point to request.

Non Verbal: Odd/No gesture
May display a lack of common gestures (e.g., reaching and waving). May also use gestures in a way that is unusual (i.e., exaggerated, or limited in range of flexibility).

Non Verbal: No eye contact
Displays a lack of eye contact, or uses eye contact in an unusual way. This may include avoiding eye contact, or using only fleeting eye contact, in social situations.

Non Verbal: No facial express:
Does not use facial expressions to display emotions. The child's expression may be neutral or flat, or the child may have a perpetual smile.

Non Verbal: Does not point at objects of interest
Child does not indicate curiosity or interest by pointing

Non Verbal: Limited gestures
May display a lack of common gestures (e.g., reaching and waving). May also use gestures in a way that is unusual (i.e., exaggerated, or limited in range of flexibility).

Non Verbal: Odd eye contact
Displays a lack of eye contact, or uses eye contact in an unusual way. This may include avoiding eye contact, or using only fleeting eye contact, in social situations.

Non Verbal: Odd facial expression
Uses odd facial expressions or expressions that do not seem to match the situation (e.g.; smiling when injured, scowling when someone says something nice to him/her).

Questions?

Questions about the assessment? Interested in a follow up telephone consultation?
Email: NODA@autismcenter.org

Questions about the technology?
Email: NODA@behaviorimaging.com



Example Client 12/17/2016

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Validation Study: Sample Collection

- 51 children between 18 months and 6
- 40 Families seeking an evaluation for their child
 - recruited through advertisements for the study
 - or if they called the center seeking an evaluation
- 11 Families with a typically developing child
 - recruited from a program at the center that includes typically developing children

Every family completed both NODA and the in-person assessment. Each assessment was completed by blinded clinicians.

Validation Study: Results, Full Sample (TD and EV)

Agreement between NODA and IPA: 88.2%

Kappa = .75 95% CI [.56, .94]

Sensitivity = .85 95% CI [.67, .94]

Specificity = .94 95% CI [.71, 1.00]

DSM-5 symptom criteria ICC = .86, 95% CI [.73, .92].

Interrater reliability: 78%

Kappa = .56 95% CI [.53, .59]

DSM-5 symptom criteria ICC = .85 95% CI [.73, .91]

* Seven of the ten secondary NODA raters agreed with the primary rater on four of the five cases that were assigned to them; of the remaining raters, two agreed on three of their five cases and one agreed on all five cases.

Validation Study: Sub Sample (EV only)

Agreement between NODA and IPA: 85%

Kappa = .58 95% CI [.27, .89]

Sensitivity = .85 95% CI [.67, .94]

Specificity = .86 95% CI [.42, .99]

DSM-5 symptom criteria ICC = .60, 95% CI [.25, .79]

Interrater reliability: 72%

Kappa = .35 95% CI [.15, .58]

DSM-5 symptom criteria ICC = .72 95% CI [.47, .85]

- * To evaluate kappa, the number of codes to be assigned in the comparison must be considered when determining the represented level of accuracy (Bakeman & Quera, 2011). As there were only two codes in this study (ASD, not ASD), the kappa coefficients indicate 85% to 90% accuracy in all analyses.

Summary

- NODA may be yield an accurate diagnosis in 85% of children needing an evaluation
- 15% of children may still require an in person assessment:
 - higher cognitive functioning with age appropriate abilities
 - fewer observable behaviors that suggest autism
 - may be difficult to diagnose even in an in person assessment
- Clinics using NODA may be able to serve 85% of their clients seeking diagnosis, and see only 15% in the clinic.
- Significantly reduced burden on staff

Thank you for your
interest in NODA



Psychological Assessment

Investigating the Accuracy of a Novel Telehealth Diagnostic Approach for Autism Spectrum Disorder

Christopher J. Smith, Agata Rozga, Nicole Matthews, Ron Oberleitner, Nazneen Nazneen, and Gregory Abowd

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Investigating the Accuracy of a Novel Telehealth Diagnostic Approach for Autism Spectrum Disorder

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Georgia Institute of Technology

Research indicates that a substantial amount of time elapses between parents' first concerns about their child's development and a formal diagnosis of autism spectrum disorder (ASD). Telehealth presents an opportunity to expedite the diagnostic process. This project compared a novel telehealth diagnostic approach that utilizes clinically guided in-home video recordings to the gold standard in-person diagnostic assessment. Participants included 40 families seeking an ASD evaluation for their child and 11 families of typically developing children. Children were between the ages of 18 months and 6 years 11 months; mean adaptive behavior composite = 75.47 ($SD = 15.94$). All parent participants spoke English fluently. Families completed the Naturalistic Observation Diagnostic Assessment (NODA) for ASD, which was compared to an in-person assessment (IPA). Agreement between the 2 methods, as well as sensitivity, specificity, and interrater reliability, were calculated for the full sample and the subsample of families seeking an ASD evaluation. Diagnostic agreement between NODA and the IPA was 88.2% ($\kappa = 0.75$) in the full sample and 85% ($\kappa = 0.58$) in the subsample. Sensitivity was 84.9% in both, whereas specificity was 94.4% in the full sample and 85.7% in the subsample. Kappa coefficients for interrater reliability indicated 85% to 90% accuracy between raters. NODA utilizes telehealth technology for families to share information with professionals and provides a method to inform clinical judgment for a diagnosis of ASD. Due to the high level of agreement with the IPA in this sample, NODA has potential to improve the efficiency of the diagnostic process for ASD.

Keywords: autism, diagnosis, video, telehealth, remote assessment

Supplemental materials: <http://dx.doi.org/10.1037/pas0000317.supp>

There are substantial delays between parents' first concerns about their child's development and a diagnosis of autism spectrum disorder (ASD; Wiggins, Baio, & Rice, 2006). These delays

will likely worsen, given that prevalence rates for the disorder continue to climb and access to qualified health care professionals is limited in many communities (Autism and Developmental Dis-

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This study was presented as a poster at the American Academy of Child and Adolescent Psychiatry's 62nd Annual Meeting, San Antonio, TX, October 2015, and the International Meeting for Autism Research, Salt Lake City, UT, May 2015.

All phases of this study were supported by National Institute of Mental Health's Small Business Innovation Research Grant 9 R44 MH099035 awarded to BIS. Subcontracts with SARRC and Georgia Institute of Technology support Christopher J. Smith, Nicole Matthews, and Agata Rozga and their work on this study. Christopher J. Smith's and Nicole

Matthew's employer, Southwest Autism Research and Resource Center (SARRC), will be paid in the future by Behavior Imaging Solutions (BIS) to conduct the reviews of cases for people who pay them for the commercial version of the Naturalistic Observation Diagnostic Assessment (NODA). Ron Oberleitner is the chief executive officer of BIS, the company that will commercialize NODA. Gregory Abowd was co-advisor for Nazneen Nazneen during her graduate studies, which may present a conflict of interest that is registered with and managed by Georgia Institute of Technology. The remaining authors have no conflicts of interest to disclose.

The authors express gratitude to the families who participated in this research and to Raun Melmed of the Melmed Center and SARRC for providing valuable insight during this project.

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abilities Monitoring Network Surveillance Year 2000 Principal Investigators, 2007, 2014; Liptak et al., 2008; Mandell, Novak, & Zubritsky, 2005; Thomas, Ellis, McLaurin, Daniels, & Morrissey, 2007). Lengthy wait lists for diagnostic evaluations delay early intensive intervention, which is critical for optimal outcomes (Howlin, Magiati, & Charman, 2009). Telehealth approaches have been investigated as a means of treatment delivery in ASD, but few have explored the potential for such technologies to support diagnostic assessments (Baharav & Reiser, 2010; Parmanto, Pulantara, Schutte, Saptono, & McCue, 2013; Vismara, Young, & Rogers, 2012; Wainer & Ingersoll, 2015). The current project examined a method that guides families to collect clinically relevant videos in the home and share them with diagnostic professionals using telehealth technology. If validated, this approach may present one avenue for reducing the time between parent concerns and diagnosis.

Practice parameters from the American Academy of Child and Adolescent Psychiatry have recommended that professionals first determine a diagnosis and then conduct a multidisciplinary evaluation to identify factors that may have contributed to developmental delay (Volkmar et al., 2014). The recommended diagnostic process includes a parent interview to assess developmental history and direct observation of the child (Huerta & Lord, 2012; Volkmar & Klin, 2005), though these procedures should inform, not replace, clinical judgment. The use of recommended semistructured assessments to collect this information may be hampered by required training, cost and lengthy administration time. Ultimately, skilled professionals evaluate development through some method, but ultimately rely on clinical judgment to diagnose (Charman & Gotham, 2013). Despite consistent recommendations for two methods of assessment (interview and observation), most practitioners rely on only one method to diagnose ASD (Rice et al., 2014) which may affect the validity of the diagnostic outcome lengthy administration time.

Store-and-forward telehealth approaches to diagnosis may facilitate sharing of both current behavior examples and developmental history with diagnostic professionals. These systems support video recordings of live events, which are subsequently shared with a clinical expert for review and assessment. This approach may offer several key advantages particularly relevant to remote diagnosis of ASD (Oberleitner, Laxminarayan, Suri, Harrington, & Bradstreet, 2014). It enables families to record videos in their home, in the course of their day-to-day activities, which ensures the capture of natural expressions of child behavior that are widely acknowledged as crucial to an accurate and comprehensive assessment. Moreover, because home recordings can be carried out over the course of several days, they may mitigate some of the shortcomings associated with a single clinic-based or live telehealth assessment, such as the child's reactivity, their current mood or level of fatigue, or the likelihood that low-frequency behaviors may not be observed. Developmental history can also be shared through a parent survey within the telehealth system. From a practical standpoint, such an approach minimizes the need to coordinate schedules with a clinician and reduces the need for remotely located families to travel long distances to a clinic. Finally, beyond the opportunity to provide a timely diagnosis directly to the family, it may also enable clinical centers to more efficiently make use of their limited resources by triaging families on waiting lists for diagnostic assessments.

Pilot studies have demonstrated parents' ability to collect videos of child behavior in the home and share them with diagnosticians who, in turn, determined their relevance for ASD diagnosis (Nazneen et al., 2015; Smith, Oberleitner, Treulich, McIntosh, & Melmed, 2009). Still, comparison of the resulting diagnostic outcomes to a gold-standard, in-person assessment (IPA) has not yet been reported. The current report presents a comparison of the Naturalistic Observation Diagnostic Assessment (NODA), a store-and-forward telehealth approach to ASD diagnosis that relies on parent-collected videos, to an independently conducted IPA.

Method

Participants

Participants included 51 children in the southwestern United States and at least one parent of each child. The full sample included 11 children who were typically developing (TD) and 40 children whose parents were seeking an evaluation for ASD in response to advertisements for the study (EV subgroup). TD children were recruited from a database of children who were previously evaluated for a clinical program that included typically developing peers as part of the treatment model. Children were between the ages of 18 months and 6 years 11 months and had no known genetic condition. All parent participants spoke English fluently and were evaluated by English-speaking raters. See Table 1 for additional participant demographics. Study procedures were approved by the Western Institutional Review Board, and informed consent was obtained from at least one parent or guardian of each child. Evaluations were conducted after participants were provided informed consent, and there were no exclusions on the basis of results of the IPA.

The primary NODA rater had a master's degree in psychology and 10 years of experience conducting ASD assessments. To demonstrate usability of the NODA system and determine inter-rater reliability, 10 secondary raters (clinical or research professionals with a minimum of 10 years of experience conducting observational assessments for ASD) were recruited from different regions of North America, and each was assigned five cases. Informed consent was obtained from each secondary rater. The primary rater and secondary raters were blind to the child's group membership (EV or TD), the results of the IPA, and results from the other raters. Although the primary rater was employed by the research center, she worked remotely (i.e., off-site) and did not have direct contact with the staff members who conducted the IPAs. The principal investigator conducted a 30-min training on the web-based assessment portal and NODA procedures (described in the Method section) with each rater.

Procedure

In-person assessment (IPA). All participants completed the IPA during their first visit to the center. The IPA included the Autism Diagnostic Interview—Revised (ADI-R; Rutter, Le Couteur, & Lord, 2003); the Autism Diagnostic Observation Schedule—Second Edition (ADOS-2; Lord et al., 2012); either the Mullen Scales of Early Learning (MSEL; Mullen, 1995) for participants up to 68 months or the Kaufman Brief Intelligence Test—Second Edition (KBIT-2; Kaufman & Kaufman, 2004) for

Table 1
Sample Characteristics for Participants Who Were Either Seeking an Evaluation for ASD or Were Typically Developing

Variable	ASD evaluation ^a			Typically developing			Full sample		
	<i>n</i>	<i>M</i>	<i>SD</i>	<i>n</i>	<i>M</i>	<i>SD</i>	<i>n</i>	<i>M</i>	<i>SD</i>
Age in months	40	52.78	17.58	11	42.55	11.07	51	50.60	16.84
Males	30			6			36		
Ethnicity									
Caucasian	15			6			21		
Hispanic	19			3			22		
Black	3			1			4		
Other	3			1			4		
MSEL ^b	26	74.38	16.18	9	111.78	15.87	35	84.00	22.95
FSIQ ^c	6	91.17	16.65	0			6	91.17	16.65
ABC ^d	40	69.98	11.80	11	95.45	12.95	51	75.47	15.94
ADOS Comp ^e	34	6.53	2.45	2 ^f	2.00	1.41	36	6.28	2.61

Note. ASD = autism spectrum disorder; MSEL = Mullen Scales of Early Learning Composite Score; FSIQ = Full Scale IQ; ABC = adaptive behavior composite; ADOS Comp = Autism Diagnostic Observation Schedule Comparison score.

^a Referred for ASD evaluation. ^b For participants ≤ 68 months of age; there were eight incomplete assessments in the *referred* group and two incomplete assessments in the *typically developing* group. ^c For participants older than 68 months from the Kaufmann Brief Intelligence Test. ^d From the Vineland Adaptive Behavior Scales. ^e Comparison score for Modules 1–3 ($n = 36$); toddler module ($n = 8$) does not have a comparison score. ^f Only two comparison scores are reported for the typically developing group because six participants were previously assessed with the first edition of the ADOS, which did not include a comparison score, and three participants were assessed with the second edition of the ADOS toddler module.

participants 69 months and older; and the Vineland Adaptive Behavior Scales—Second Edition (VABS–2; Sparrow, Cicchetti, & Balla, 2005). Six of the 11 TD children were previously evaluated with the first edition of the ADOS (ADOS; Lord, Rutter, Dilavore, & Risi, 1999), which did not include a comparison score. The rest of the IPA was completed during their participation in this study. Assessments were completed by experienced raters who were blind to the subject group (EV or TD) and to the information collected in NODA.

The principal investigator, a psychologist with 20 years of experience evaluating individuals with ASD for research purposes, completed a *Diagnostic and Statistical Manual of Mental Disorders* (5th ed.; *DSM–5*; American Psychiatric Association, 2013) diagnosis for each participant on the basis of the assessment results and clinical judgment. Results of the IPA were not provided to the family until after they completed the NODA procedures. Thus, families were not informed about the significance of their child's behavior before collecting videos for NODA.

Naturalistic Observation Diagnostic Assessment (NODA). NODA included collection of both developmental history and video data. First, caregivers completed a brief developmental history interview, and responses were stored in the family's online account. The NODA application, installed on a mobile device, guided parents to record their child in four 10-min scenarios: (1) family meal time, (2) playtime with others, (3) playtime alone, and (4) parent concerns. The first three scenarios provided opportunities for the child to demonstrate typical social-communication skills and play-based behaviors. Instructions to the parent to introduce specific social presses were included in the app (e.g., interact with your child playfully, say your child's name to get his attention, ask your child where something is in the room, give your child time to initiate or respond, point at something and direct your child's attention to it). Pilot studies demonstrated that these instructions improved the clinical utility of the videos (Nazneen et al., 2015). To avoid predisposing parents toward collecting examples of behaviors that indicate ASD (e.g., hand mannerisms, poor

eye contact, odd behavior), NODA included instructions that created opportunities for demonstrating typical social communicative behavior. The fourth scenario was less structured and simply asked parents to record any behavior that caused them concern. Additional instructions for each scenario suggested that parents use a mounting device (i.e., tripod) to set up and frame the recording ahead of time and to ensure relevant people and objects (i.e., the child's face, any toys the child was playing with, the child's social partner if relevant) were clearly in view. Each recording stopped automatically after 10 min, at which time parents had the option to either upload or delete the video. Parents had the capability to view the video before uploading if desired. More details about the content of the app can be found in the online supplemental materials and were previously published (see Nazneen et al., 2015).

Raters logged in to a web-based assessment system that enabled them to review children's developmental histories and the videos uploaded by families, to complete a *DSM–5* checklist for ASD, and to render a diagnosis (ASD or not ASD). While reviewing videos, the raters "tagged" examples of atypical behavior by pausing the video and selecting a term from a predefined list of descriptors, or "tags" (e.g., no social response) that were built into the interface. Each tag was automatically mapped by the NODA system to a specific *DSM–5* criterion. The behaviors represented by tags and their mappings to *DSM* criteria were informed by the *DSM–5* and determined by a team of experienced diagnosticians involved in this project. After tagging the videos, the raters reviewed the developmental history and then completed a *DSM–5* checklist within NODA. To assist the raters in making the determination as to whether each *DSM–5* criterion was satisfied, tags that had been inserted in the videos during the review process were listed below each criterion. Each tag linked to a relevant moment in the video for the raters to review if needed. On the basis of clinical judgment, the raters determined whether there was enough evidence from the developmental history and the tagged behaviors to satisfy each *DSM–5* criterion for ASD and ultimately whether to assign a diagnosis. After determining the final diagnostic category

(ASD or not ASD), the raters scored their confidence in the diagnosis on a scale from 1 (*extremely low*) to 5 (*extremely high*). More details about the content of the assessment portal can be found in the online supplemental materials and were previously published (see Nazneen et al., 2015).

Analyses

NODA was compared to the IPA by calculating percentage of agreement, kappa, sensitivity, and specificity, first for the full sample ($N = 51$) and then for the EV group ($n = 40$). Additionally, agreement at the *DSM-5* symptom level (A1 to A3 and B1 to B4) was measured by summing the values (1 = present, 0 = absent) on the subcriteria and calculating a two-way random effects model intraclass correlation coefficient (ICC; Type II; Shrout & Fleiss, 1979). Variables derived from each assessment method were used to investigate differences between participants for whom NODA and IPA were discordant. Kappa and ICC were also used to determine interrater reliability between the primary NODA rater and the secondary raters.

Results

Within the full sample, the diagnostic procedures (NODA and IPA) agreed in 88.2% of cases ($\kappa = .75$, 95% confidence interval [CI: .56, .94]). The sensitivity of NODA for a diagnosis of ASD was .85 (95% CI [.67, .94]) and the specificity was .94 (95% CI [.71, 1.00]). As a measure of agreement among the *DSM-5* symptom criteria, ICC was .86 (95% CI [.73, .92]). For interrater reliability, the secondary raters agreed with the primary rater in 78% of cases, and kappa was 0.56 (95% CI [.53, .59]) and ICC was .85 (95% CI [.73, .91]). Seven of the 10 secondary NODA raters agreed with the primary rater on four of the five cases that were assigned to them; of the remaining raters, two agreed on three of their five cases and one agreed on all five cases.

In the EV subgroup, the two diagnostic procedures agreed in 85% of cases ($\kappa = 0.58$, 95% CI [.27, .89]), with a sensitivity of .85 (95% CI [.67, .94]) and a specificity of .86 (95% CI [.42, .99]). As a measure of agreement at the *DSM-5* symptom level, ICC was .60 (95% CI [.25, .79]). For interrater reliability, the secondary raters agreed with the primary rater in 72% of cases, kappa was .37 (95% CI [.15, .58]) and ICC was .72 (95% CI [.47, .85]). Of the 40 children in this group, 33 met criteria for ASD on the basis of the IPA, and 29 met criteria on the basis of NODA. Of the seven participants who did not meet criteria for ASD on the basis of the IPA, six also did not meet criteria on the basis of NODA (see Table 2).

Participants for whom NODA and IPA were concordant ($n = 34$) were compared to participants who were discordant ($n = 6$) across variables derived from each assessment method (see Table 3). From the IPA, we created a *developmental estimate* variable, consisting of the MSEL composite score ($n = 26$) or the KBIT-2 ($n = 6$). For participants missing the MSEL composite score because one or more subscales was incomplete ($n = 8$), we used the VABS-2 adaptive behavior composite (ABC), which was strongly and positively correlated with MSEL in the full sample ($n = 35$; $r = .75$, $p < .001$; 95% CI [.57, .86]). The groups did not differ significantly in age, $t(38) = 0.38$, $p = .70$; $d = 0.16$, or the VABS-2 ABC, $t(38) = 1.53$, $p = .13$; $d = 0.78$, but the discordant

Table 2
Characteristics and Category Agreement Between Diagnostic Methods Among Participants Seeking an ASD Evaluation ($n = 40$)

Variable	IPA category	
	Non-ASD ($n = 7$)	ASD ($n = 33$)
Males: n (%)	5 (71.43)	25 (75.75)
Age in months: M (SD)	53.14 (22.24)	52.70 (16.85)
Cognitive functioning: M (SD)	83.14 (6.18)	75.18 (17.94)
Primary NODA rater (%)		
ASD (%)	1 (14.29)	28 (84.85)
non-ASD (%)	6 (85.71)	5 (15.15)
Confidence: M (SD)	3.43 (.51)	3.76 (.83)
Secondary NODA raters		
ASD (%)	3 (42.86)	26 (78.7)
Non-ASD (%)	4 (57.14)	7 (21.21)
Confidence: M (SD)	3.14 (1.07)	3.87 (1.08)

Note. IPA = in-person assessment; NODA = Naturalistic Observation Diagnostic Assessment.

group had a significantly higher developmental estimate, $t(38) = 2.36$, $p = .02$; $d = 1.87$. Among the six discordant cases, the ADI-R and ADOS-2 disagreed on ASD or non-ASD in 66.7% of cases, compared to 27.5% among the 36 concordant cases. Fisher's exact test determined that group differences in disagreement on these instruments approached significance ($p = .08$).

Five continuous variables were created to represent ASD global symptom categories by summing the number of tags assigned by a rater (see Table 3). The confidence scores from the raters and the repetitive behavior category were normally distributed and were analyzed with t tests. The distributions from the remaining categories were nonnormal and were analyzed with Mann-Whitney U tests. The concordant group had significantly higher confidence scores from the primary rater, $t(38) = -2.51$, $p = .02$, $d = 1.00$; more repetitive behavior tags, $t(38) = 2.52$, $p = .016$, $d = 1.35$; and significantly more tags overall ($Z = 2.54$, $p = .01$), compared to the discordant group; no other significant differences were observed.

Characteristics for the six discordant cases are presented in Table 3. One participant did not meet *DSM-5* criteria for ASD on the basis of the IPA, but the primary NODA rater endorsed ASD with high confidence. The second rater did not endorse ASD but with low confidence (rating of 1). The MSEL was completed even though the participant was older than the 68-month ceiling (rater error). He was 82 months old and had an MSEL composite score of 80. The ADI-R endorsed autism, but the ADOS-2 did not; appropriate social initiations were frequently noted throughout the ADOS-2 despite a prominent expressive language impairment (MSEL expressive language score of 22). The five remaining discordant cases met criteria for ASD only on the basis of the IPA; three did not meet criteria on the ADI-R but met ADOS-2 criteria for autism; the remaining two met criteria on both the ADI-R and the ADOS-2. Although the primary rater tagged behaviors across categories for these five cases, there was insufficient evidence to endorse *DSM-5* criteria. As indicated previously, the primary rater's confidence scores were significantly lower for the discordant cases compared to the concordant cases. For two of these five cases, the secondary rater was in agreement with the IPA results and endorsed full *DSM-5* criteria for ASD.

Table 3
 Demographics, IPA Assessment, and Total NODA Tags in Symptom Categories for IPA and NODA Concordant and Discordant Groups and Discordant Participants

Variable	Group comparison				<i>p</i>	Discordant participants					
	Concordant (<i>n</i> = 34)		Discordant (<i>n</i> = 6)			Sub1	Sub2	Sub3	Sub4	Sub5	Sub6
	%	<i>M</i> (<i>SD</i>)	%	<i>M</i> (<i>SD</i>)							
Gender	76 (M)		67 (M)		.63 ^a	M	M	F	M	F	M
Age in months		53.32 (17.52)		55.33 (19.39)	.78 ^b	38	47	65	82	68	32
IPA											
ASD	82		83			1	1	1	0	1	1
ADI-R/ADOS-2 agreement ^c	74		33		.08 ^a	0	1	0	0	0	1
Developmental estimate ^d		74.67 (16.93)		93.00 (10.37)	.03 ^e	79 ^f	91 ^g	92 ^g	80 ^g	109 ^h	93 ^g
VABS ABC		68.79 (12.09)		76.67 (7.69)	.09 ^e	79	76	76	64	88	77
NODA tag categories ⁱ											
Social impairment		6.09 (5.29)		2.50 (2.88)	.06 ^e	1	3	1	0	1	5
Verbal impairment		6.47 (4.80)		2.83 (2.48)	.06 ^e	7	4	3	0	1	2
Nonverbal impairment		3.68 (3.64)		1.67 (1.75)	.12 ^e	1	2	1	0	1	5
Repetitive behaviors		4.50 (2.83)		1.50 (1.38)	.02 ^f	0	3	0	1	3	2
Sensory component		1.50 (1.99)		.50 (.58)	.40 ^e	1	0	0	0	1	1
Stereotyped mannerisms		1.97 (3.05)		.67 (1.21)	.17 ^e	3	0	0	0	1	0
Total tags		24.21 (15.84)		9.67 (5.43)	.01 ^e	13	12	5	1	15	12
NODA DSM-5 criteria ^j											
ASD	82		17			0	0	0	1	0	0
A1 Social reciprocity	88		33			0	0	0	1	0	1
A2 Nonverbal communication	88		33			0	0	0	1	1	0
A3 Relationships	85		33			0	0	0	1	0	1
B1 Repetitive behavior	88		83			0	1	1	1	1	1
B2 Rituals and routines	71		17			0	0	0	0	0	1
B3 Preoccupations	44		0			0	0	0	0	0	0
B4 Sensory component	47		33			0	0	0	1	0	1
NODA rater confidence											
Primary		3.82 (.72)		3.00 (.89)	.02 ^b	4	2	3	4	3	2
Secondary		3.79 (.98)		3.40 (1.52)	.44 ^b	5	4	*	1	3	4

Note. IPA = in-person assessment; NODA = Naturalistic Observation Diagnostic Assessment; Concordant = agreement between IPA and NODA; Discordant = disagreement between IPA and NODA; sub = subject; M/F = male/female; ADI-R = Autism Diagnostic Interview—Revised; ADOS-2 = Autism Diagnostic Observation Schedule—Second Edition; VABS ABC = Vineland Adaptive Behavior Scales adaptive behavior composite; DSM-5 = *Diagnostic and Statistical Manual of Mental Disorders* (5th ed.); MSEL = Mullen Scales of Early Learning; KBIT-2 = Kaufman Brief Intelligence Test—Second Edition.

^a Fisher's exact. ^b *t* test. ^c ADI-R/ADOS agreement: 1 = scales agree on diagnostic category, 0 = scales disagree on diagnostic category. ^d Developmental estimate includes MSEL composite score (*n* = 26), KBIT-2 (*n* = 6), or VABS ABC (*n* = 8). ^e Mann Whitney U. ^f VABS ABC. ^g Mullen Scales of Early Learning developmental composite. ^h Kaufmann Brief Intelligence Test Full Scale IQ. ⁱ NODA tag categories = total number of tags from the primary NODA rater in each category. ^j DSM-5 criteria endorsed by the primary NODA rater: 1 = criterion endorsed, 0 = criterion not endorsed.

Discussion

This report focuses on an initial validation of NODA, a telehealth diagnostic system that guides parents to collect short videos of child behavior and remotely share them with a clinician who conducts a diagnostic assessment for ASD. Although all analyses were conducted on both the full sample (including TD children) and the subgroup of families seeking an ASD evaluation for their child (EV subgroup), the results from the subgroup present the most pertinent evidence regarding the accuracy of NODA. However, because NODA is a novel approach to diagnosis for ASD, it important to demonstrate that it does not yield false positives among typically developing children.

There was substantial agreement between NODA and IPA for diagnostic categories (ASD, non-ASD) on the basis of the DSM-5. Confidence intervals were quite large for the statistics measuring agreement, which may be due to the relatively small sample size in this initial validation study. Sensitivity was the

same in the analyses of the full sample and the EV subgroup, but specificity dropped from 94.4% to 85.7% because fewer true negative cases were included once TD children were removed. Kappa coefficients were 0.75 (full sample) and 0.58 (EV subgroup) for comparing diagnostic outcomes between NODA and IPA and 0.56 (full sample) and 0.37 (EV subgroup) for interrater reliability. To evaluate kappa, one must consider the number of codes to be assigned in the comparison when determining the level of accuracy represented by kappa (Bakeman & Quera, 2011). As the number of codes increases, so does the magnitude of kappa for an associated level of accuracy (e.g., a kappa of 0.30 represents 85% accuracy when there are two codes, but to achieve 85% with five codes, a kappa of 0.64 is required). Because there were only two codes in this study (ASD, not ASD), the kappa coefficients indicate 85% to 90% accuracy between IPA and the primary NODA rater, as well as between the primary and secondary NODA raters.

In the full sample, ICCs indicated moderate to high agreement between IPA and NODA, and between raters regarding specific *DSM-5* symptom criteria. These results were inflated due to the inclusion of typically developing children. In the EV subgroup, the ICC between IPA and NODA was .60. Inspection of the data revealed the greatest number of disagreements in three criteria pertaining to restricted, repetitive patterns of behaviors and interests (i.e., B2 to B4). The number of disagreements on each of these items was nearly double the number of disagreements on A1 to A3 and B1 (e.g., seven for A2, A3, and B1, and 14 for B2). The lower ICC may also be due to the fact that ratings were made on different information. That is, the IPA ratings were based on information collected with assessments during the IPA, and the NODA ratings were based on behaviors captured on video in the home setting. Agreement between the NODA raters was higher, and although ratings were based on the same information (behaviors captured on video at home), the greatest number of disagreements were observed on the same three criteria. These analyses suggest that behaviors related to rigidity (B2), fixated interested (B3), and hyper- or hyporeactivity to sensory input (B4) may be the most difficult symptoms to detect with NODA. More specific questions on the developmental history questionnaire may help to compensate for this difficulty.

Due to the heterogeneous presentation of ASD, any one assessment method and clinical judgment is likely associated with some level of outcome variability. In this project, NODA disagreed with the IPA in six cases. These participants had higher cognitive abilities according to the IPA, fewer tagged behaviors in NODA, and significantly lower confidence scores from the primary rater in comparison to the confidence scores from concordant cases. Although the sample of discordant cases was small and results must be interpreted with caution, they suggest that children with higher cognitive ability and fewer observable behaviors may require additional assessment to determine the appropriate diagnosis. Notably, of the six discordant cases, the ADI-R and ADOS-2 disagreed in four cases (66.7%) compared to only nine disagreements among the 34 concordant cases (27.5%). This lack of consensus on standardized, gold-standard assessments is illustrative of the diversity of clinical presentation and the likelihood that IPA results may also vary among different diagnosticians depending on which methods of assessment they employ. In practice, a lower confidence score by the NODA rater could serve as a decision point for bringing the child in for an IPA or perhaps sharing the information with a second or even third NODA rater.

The identification and recruitment procedure for secondary raters emphasized NODA's ability to connect families to clinical professionals regardless of location. Secondary raters were located in different regions of North America and were able to complete NODA assessments on their own schedule (e.g., evenings and weekends) with relative ease after just 30 min of training on using the system. Most reported completing a single diagnostic assessment in less than an hour. Thus, NODA has potential to improve efficiency of the diagnostic process by creating easy access to professionals regardless of location.

Clinical judgment is a vital component in the IPA, and it plays a prominent role in NODA as well. NODA informs clinical judgment with data collected by families in their home and provides the clinician with a systematic and structured way to annotate behavior examples to support diagnostic determinations. With NODA, di-

agnosis is not based solely on observed behaviors present in one or two short video segments, and methods that attempt to do so have been observed to be less reliable (Gabrielsen et al., 2015). Instead, parents are guided to record specific scenarios that occur naturally in most homes and are given simple instructions to create opportunities for the child to express typical social communication. Still, clinical judgment is often based on a two-way exchange of information between patients and clinicians rather than a single opportunity to share information. Although not utilized in this initial validation study, the NODA system also includes a feature to allow raters to request additional information from families (e.g., rerecording a scenario with additional social presses from the parent), which shows up in the form of an alert within the family's NODA application (see Nazneen et al., 2015, for more details). This feature provides an additional opportunity for the rater to solicit clinically relevant information to clarify the nature of the child's behavior and perhaps improve the accuracy and confidence of clinical judgment.

NODA conveys the information needed for an initial diagnosis of ASD for most children. It is not intended to eliminate the need for future evaluations but to accelerate the pathway to treatment. Practice parameters indicate the need for additional evaluations to identify potential factors responsible for the developmental delay and for treatment planning (Volkmar et al., 2014); neither is necessary for the initial diagnosis. Likewise, the *DSM-5* includes several terms to specify severity of the disorder that may vary by context and fluctuate over time (American Psychiatric Association, 2013). Thus, these features are to provide additional information to help further characterize the individual's presentation once the diagnostic criteria are satisfied and are not a necessary component of the initial diagnosis. NODA is intended only to accelerate the diagnostic process by improving access to professionals who can provide information to parents about their child's development. The sooner parents get this information the sooner they can pursue a behavioral intervention program, the recommended treatment for developmental delays (Howard, Sparkman, Cohen, Green, & Stanislaw, 2005).

Although there are many potential benefits of a store-and-forward telehealth approach to diagnosis, this study focused on only the initial validation of NODA in making a diagnostic determination of ASD. Results indicate this approach can yield diagnostic information comparable to that of an IPA for most children. Other benefits should be carefully investigated. One goal of telehealth is to decrease the time between parent concerns and diagnosis. Randomized controlled trials in active diagnostic centers can determine whether NODA can actually decrease time from parents' concerns to receiving a diagnosis of ASD and also decrease time until they access intervention. An additional potential use of this approach is to triage cases on waiting lists for diagnostic assessments to separate clear-cut cases from children who will require an IPA to make the initial diagnostic determination. Also, NODA may be used to supplement an IPA for more complex cases where the clinician wishes to observe how the child behaves at home. Finally, the social validity of the procedure should also be investigated to better understand parent impressions for collecting videos on their child and sharing them remotely with a clinician they never met who, in turn, is evaluating their child's behavior.

In practice, NODA is designed to generate a detailed report that describes the specific behavioral examples (tagged in the videos)

that support each *DSM-5* criterion, a clinician summary, and recommendations for next steps. Possible modes of delivery include electronic delivery of the report alone or along with an opportunity to consult remotely with the NODA clinician. Alternatively, the report can be released to the referring diagnostic professional, who can meet with the parent in person, explain the results, and offer their own clinical interpretation. The optimal delivery of the final report generated from NODA needs to be investigated.

Limitations and Future Directions

This study demonstrated accuracy of a novel telehealth approach that may improve the diagnostic process for ASD; however, some limitations exist that should be considered when interpreting the findings. For one, the IPA was conducted before families completed NODA. Thus, parents may have learned about their child's behavior and development during the process, which may have influenced the type of behavior they captured on video for NODA. To minimize the possible order effect, we did not discuss results of the IPA with parents until after NODA videos were collected. Parents were not given information about the diagnostic relevance of their child's specific behaviors until after the NODA videos were obtained. Additionally, video collection was semistructured (i.e., uniform duration of 10 continuous minutes across four specific scenarios, and instructions for parents to shape the interaction), which makes it unlikely that parents would be able to selectively capture behavior that supports or does not support a diagnosis of ASD. By design, NODA does not allow families to pause and restart videos, which should reduce the possibility of families' submitting biased video footage. Future research may examine whether NODA's accuracy differs as a function of the order of IPA and NODA. Further, sampling bias may have inflated the rate of ASD cases (33 of 40 = 82.5%) among families seeking an evaluation. Some participants may have been previously identified with developmental delays but were never evaluated for ASD and their parents may have participated in this study for the free evaluation. This possible bias should be considered when interpreting the effect of the high rate of ASD diagnosis.

This study included only two participant groups (TD and EV) and two outcome categories (ASD and non-ASD). The utility of NODA may be improved by including a third category to classify children as non-ASD but developmentally delayed. For some children the primary evidence for delays is the absence of typical behavior, and a comparison to the rates of typical behavior expressed by TD children may be helpful in determining a diagnostic category. Pilot data were collected from TD children in this project to quantify rates of typical behavior, but this topic needs to be explored in focused investigation in a much larger sample. The resulting normative standards from future efforts may help to support a diagnosis of ASD or developmental delays for some children. Differential diagnosis for developmental disorders is a key area for future inquiry with NODA.

Determining reliability and validity of a new diagnostic method for a disorder as complex as ASD requires a series of studies conducted over time. Although the results of this project provide strong preliminary evidence for NODA, data were collected in a relatively small sample of participants ages 18 to 71 months. The

broad age range may have limited the applicability of NODA to a more specific age group (i.e., early childhood). Further, NODA was designed to improve efficiency of the diagnostic process for ASD, but the present study addressed diagnostic accuracy in comparison to only the IPA and interrater reliability. Thus, reliability, validity, and efficiency of NODA need to be further investigated in future studies with larger samples.

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