

Asynchronous Telemedicine System for the Remote Diagnosis of ASD

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Published Date: February 26, 2016

ABSTRACT

This chapter summarizes the design, use, and field evaluation of NODA (Naturalistic Observation Diagnostic Assessment) [1,2]. NODA is a novel asynchronous telemedicine system for the remote diagnosis of autism spectrum disorder (ASD). The results from the field evaluation demonstrate that NODA enables 1) parents to *easily* collect *clinically valid* in-home video evidence of their child's behaviors and 2) diagnosticians to *complete* remote diagnostic assessment for ASD using in-home video evidence and child's brief developmental history.

TELEMEDICINE AND AUTISM

ASD is the fastest-growing developmental condition, and is diagnosed using three main criteria; a child's difficulties with social interactions, impairment in verbal or nonverbal communication, and restrictive interests and repetitive behaviors [3]. The prevalence of ASD in the United States has increased dramatically from 1 in 150 to 1 in 68 children between 2000 and 2010 [4,5]. However, there has been a growing recognition of the potential of telemedicine to improve access to care for individuals with ASD [6-23].

Telemedicine to Facilitate Services for ASD

A recent literature review concluded that seven of the eight studies reviewed have reported successful use of new telehealth technologies with positive outcomes of services delivered for individuals with ASD [10]. Telemedicine has been investigated as an effective means of supporting the successful delivery of a wide array of services for individuals with ASD and their caregivers [6-23]. These services are provided remotely and included assessment and treatment [9-13], coaching of parent-implemented early intervention programs [8,19,20], classroom behavioral support [17], remote behavioral assessments [21,22], and professional development [23].

Telemedicine to Facilitate Remote Diagnosis of ASD

Recently, attempts have been made to explore the potential of telemedicine in supporting diagnosis of ASD [7,14-16]. Reese et al. [14] explored the use of telemedicine in the diagnosis of ASD. The authors reported that the accuracy of diagnosis, the associated family satisfaction, and the reliability of diagnostic assessments did not differ between the in-person assessment and the telemedicine.

Asynchronous telemedicine for ‘timely’ remote diagnosis of ASD

Currently tele-practices for remote diagnosis of ASD are based on technologies that support synchronous (real time) video interaction between the diagnostician and the family. However, there is a real need and potential benefit of telehealth technologies that enable asynchronous store-and-forward mechanisms. One challenge with a synchronous telemedicine system employed for assessment and diagnosis is that it demands parents and diagnosticians to be available at the same time to conduct assessments, and due to the large number of children needing services and limited availability of clinical professionals, this may cause a delay in assessment and diagnosis. Delay in diagnosis can lead to delay in invaluable early interventions, which could impact a child’s future learning capabilities and developmental outcomes [24-27]. Research shows that there is a significant time lag (20-60 months) between the age at which parents first become concerned and the age at which the child finally gets diagnosis [28-30]. One of the major factors causing this delay is lack of timely access to diagnostic services especially in remote and rural communities [31-34]. Therefore telemedicine and in particular asynchronous telemedicine system can make it at large scale feasible to connect parents and diagnosticians for timely diagnosis.

Asynchronous telemedicine for ‘naturalistic evidence’ based remote diagnosis of ASD

In addition to temporal dependency, another challenge with current synchronous telemedicine systems employed for assessment and diagnosis is that families need to travel to a clinic or center where special technology equipment is installed and environment is staged with various probes (e.g., toys, books) for engaging the child based on the diagnostician’s instructions during the remote session. Whereas, a store-and-forward asynchronous solution may enable parents to

easily record and share their child's natural behavior in the natural environment home and in the course of day-to-day activities. This solution also avoids any possible reactivity due to the remote presence of the diagnostician or the artificial setup of clinic or center. This is imperative since observing behavior in the natural environment is crucial to obtain an accurate and comprehensive assessment of a child's behavior [24,25,35]. Even current in-person diagnostic practices are limited to in-clinic observation since due to limited resources it's not feasible to conduct observation in naturalistic environment [35-39]. Therefore an asynchronous in-home video based solution can make naturalistic evidence based diagnosis feasible.

Moreover, the child may not exhibit the target behaviors in the presence of a diagnostician during a live telehealth session, but a store-and-forward technology will enable parents to capture the best evidence of their child's behavior as it naturally occurs and share it with the diagnostician asynchronously. However, a clear advantage of synchronous communication is that diagnostician can directly engage the child, in addition to viewing and guiding the parents' interaction with the child for assessment. Hence, in order to make video evidence clinically meaningful, the NODA has embedded recording instructions that guide parents through the desired interactions with the child while recording. These recording instructions were finalized in collaboration with experts in autism domain based on analysis of families recording their child's behaviors in a home like controlled experimental setup. In addition, NODA also allows diagnosticians and parents to asynchronously communicate and hence once parents uploaded video, the diagnostician can view it and guide parents regarding desired interactions with the child while recording.

NODA: Asynchronous Telemedicine Remote Autism Diagnostic System

NODA consists of NODA SmartCapture and NODA connect for parents to collect in-home video evidence and diagnostician to complete remote diagnosis of ASD based on naturalistic video evidence.

NODA SmartCapture

NODA SmartCapture is a smartphone app that enables parents to collection and share in-home video evidence of their child's behavior (Figures 1-4). It allows parents to record and upload four 10-minute NODA scenarios. NODA scenarios include the child playing alone, the child playing with others, a family mealtime, and a behavior of parent's concern. Each scenario has embedded instructions that include a sample video and recording instructions to guide parents about the environment setup (e.g. desired field of view) and required interactions (social presses like calling child's name) with the child while recording [40-43]. These instructions were intended to maximize the likelihood that the parent records clinically valid and right kind of video evidence of child behavior from the diagnostician's perspective. See Vidoe 1 for sample video and recording instruction for 'family meal time scenarios.



Video 1:

Video 1: Play with other: sample video and recording instructions.

“Record your child playing with a sibling (or with you if no siblings). Set up 5 fun items (toys/ books/NO ELECTRONICS). Mount camera so both play partners and the toys are in view and the child is facing camera. Briefly interact with the child (say his name; direct his attention to sibling; offer a toy- hold it out but don’t give it to him) and then wait for his reaction. After a few minutes, let the children play. If no sibling is available, play with the child but let him guide the play.”



Figure 1: NODA SmartCapture: Home screen showing 4 NODA scenarios, as well as status of ones recorded.

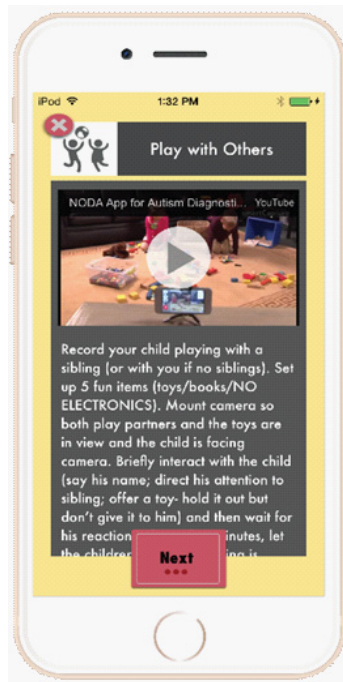


Figure 2: NODA SmartCapture: Each scenario has explicit embedded instructions that include a ‘sample video’ and recording instructions for parents regarding desired interactions with the child while recording.

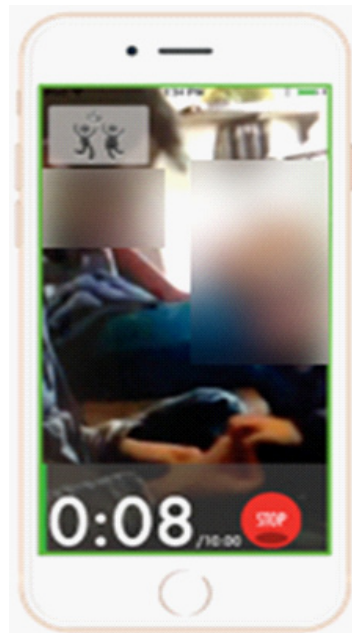


Figure 3: NODA SmartCapture: After going through embedded instructions parents can start video recording. Video can be stopped any time or it auto stops after 10 minutes.

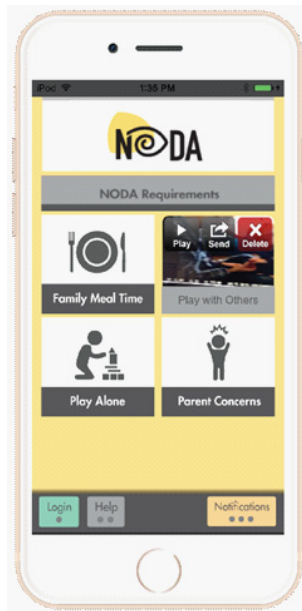


Figure 4: NODA SmartCapture: Home screen shows status of the recorded scenario with options to view, delete or sent it video to diagnostician. Once video is sent it uploads to NODA Connect. Home screen also shows pending notification from diagnosticians.

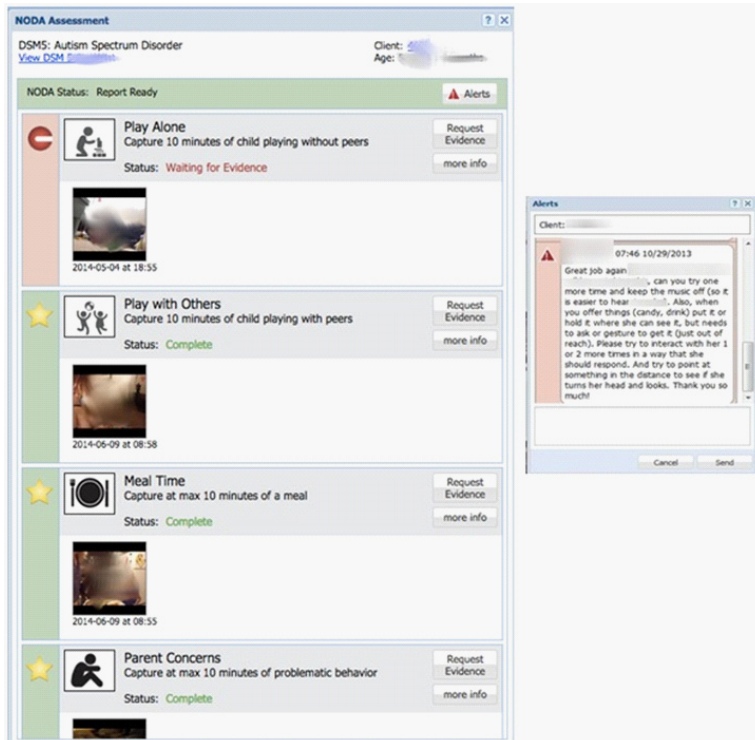


Figure 5: NODA Connect: Video access and notification features.

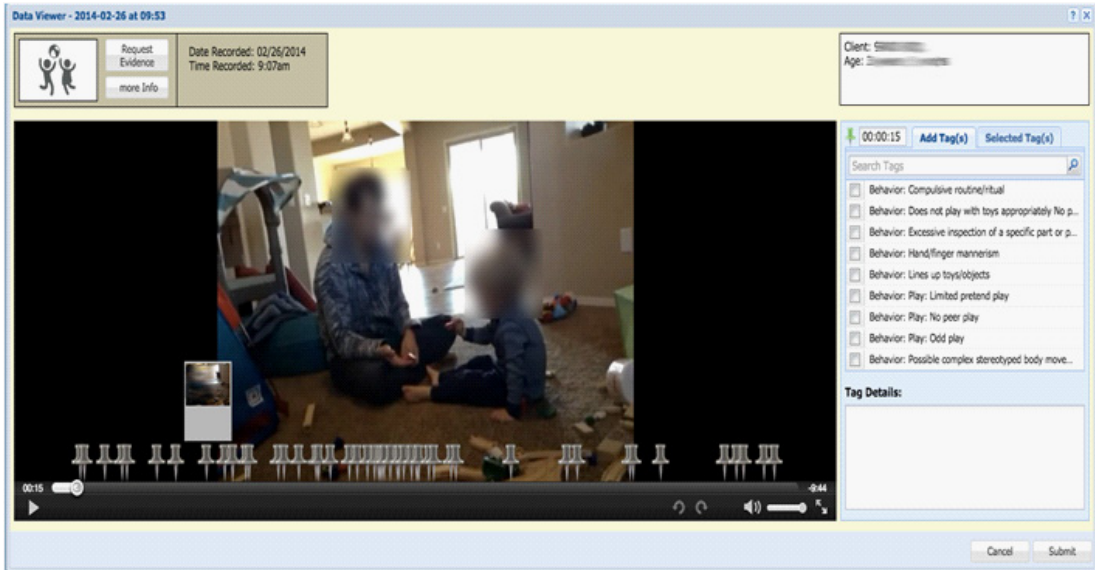


Figure 6: NODA Connect: Vide tagging.

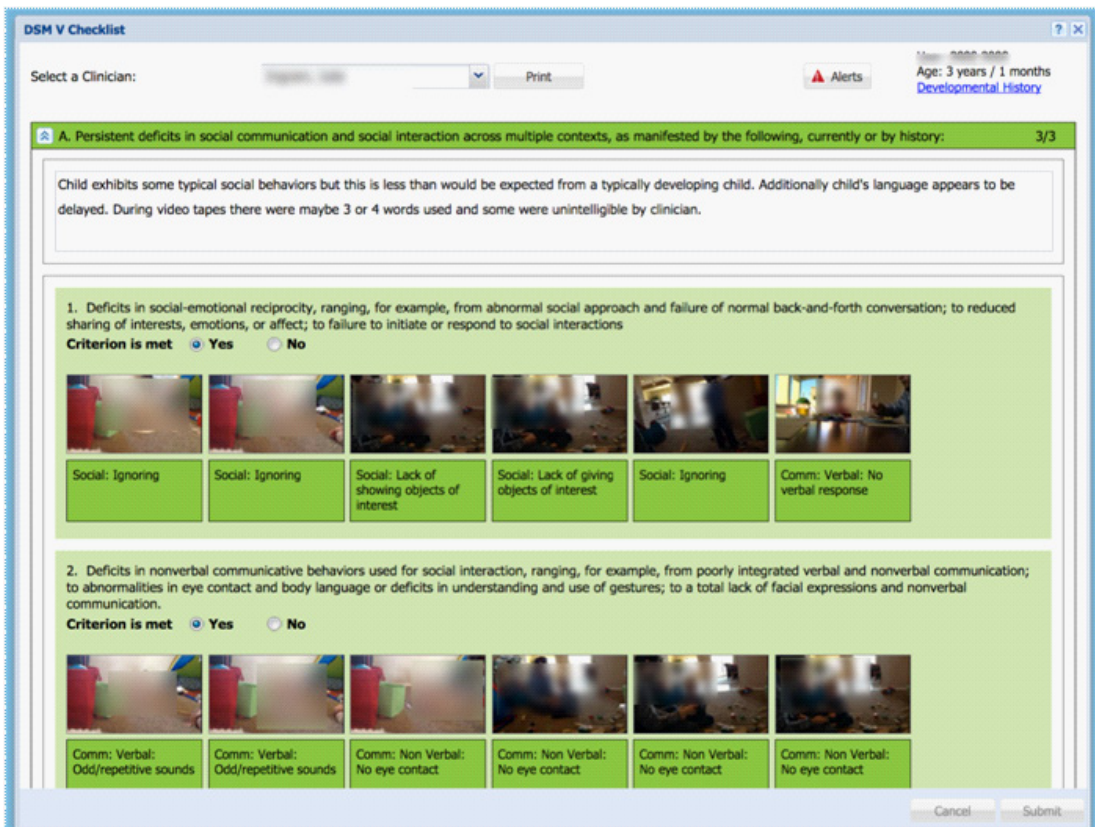


Figure 7: NODA Connect: DSM Check list.

Diagnostic Criteria

✓

C. Symptoms must be present in the early developmental period (but may not become fully manifest until social demands exceed limited capacities, or may be masked by learned strategies in later life).

Comment

Child is almost 4 so still in early developmental period.

✓

D. Symptoms cause clinically significant impairment in social, occupational, or other important areas of current functioning.

Comment

Yes, child is unable to request appropriately, play with toys, peers or adults as observed in videos and reported by parents.

✓

E. These disturbances are not better explained by intellectual disability (intellectual developmental disorder) or global developmental delay. Intellectual disability and autism spectrum disorder frequently co-occur; to make co-morbid diagnoses of autism spectrum disorder and intellectual disability, social communication should be below that expected for general developmental level.

Comment

It appears this child has an autism spectrum disorder.

Diagnostic Conclusion

Final Diagnosis

DSM-5 Autism Spectrum Disorder
299.00 (F84.0)

✓

ALL CRITERIA SATISFIED

This child obviously has an autism spectrum disorder.

Clinician Signature

Name: Erica Skegnek Psy.D
License #: 123598

Jane Jones, 02/02/2015

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Figure 9: NODA Connect: Diagnostic report.

NODA Connect

NODA Connect is a HIPPA-conforming online portal that interfaces with the NODA SmartCapture app. NODA Connect is a custom module of the commercially available BIS telemedicine platform Behavior Connect™, which has been commercially available since 2007 for sharing behavior data between caregivers and clinicians [13].

NODA Connect enables diagnosticians to review and analyze parents' collected in-home videos shared via NODA SmartCapture, and assists the diagnosticians to guide parents during the video collection process when its necessary to send notification containing additional recording instructions (Figure 5). NODA Connect facilitates diagnosticians in completion of diagnostic

assessment of Autism. NODA Connect has a predefined list of tags for marking absence or presence of behaviors associated with autism (e.g. no eye contact, no facial expression, response to name call, no response to name call). These tags are extracted from standard autism diagnostic criteria from the Diagnostic Statistical Manual of Mental Disorders (DSM) [1]. Through NODA Connect diagnostician tag in-videos collected and shared by parents (Figure 6). NODA Connect has DSM Checklist that gets auto-populated with tags assigned by diagnosticians and their video snippet. The diagnostician can complete the DSM checklist by indicating whether each individual criterion has been met or not (Figure 7). Based on this in-home videos assessment as well as brief child's developmental history provided by parents through an online form and their clinical judgment, diagnostician concludes diagnostic outcome. An assessment report is generated through NODA once the DSM checklist is submitted (Figure 8). The resulting report can be shared with the parent and the referring pediatrician.

NODA EVALUATION

Initial Concept Validation

In order to validate the concept of “in-home video based remote assessment’ from key stakeholders, interviews were conducted with 11 clinicians and six parents of children with autism. Findings from this exploratory study helped in identifying potential design challenges and opportunities that informed the design of initial prototype of NODA.

Usability Studies in Control Environment

The initial NODA prototype was iteratively improved through two usability studies. In each study four families of children with autism experienced NODA SmartCapture in a home-like living laboratory facility. Outcomes from the first usability study helped us improve the design of the NODA SmartCapture with the goal of “simplifying parents’ capture experience”. In the second usability study the improved design of the NODA SmartCapture was evaluated and in addition to analyzing parents’ experience of capture, the videos collected during this study were analyzed for their clinical utility by a collaborating diagnostician with a 20 years of experience in autism diagnosis. Results indicated that 80% of the parent-recorded videos were appropriate and clinically valid for conducting diagnostic assessment for ASD. A systematic analysis (conducted in collaborating with diagnostician), of how parents record as well as content of recorded evidence, identified a number of parameters that affect the clinical utility of parents’ collected video evidence. These parameters can broadly be categorized under staging (e.g. camera and environment setup) and social presses (e.g. frequency and type of interactions with the target child). In collaboration with the collaborating diagnostician and another expert in autism domain these parameters were analyzed and a set of recording instructions for NODA scenarios were finalized. These instructions were embedded within NODA SmartCapture for parents to follow them while recording.

Initial in-field evaluation

NODA SmartCapture resulted from the usability studies and NODA Connect resulted through a participatory design process (involving a collaborating diagnostician and another expert in autism domain), was subjected to a formative in-field study. Participants included five families of children (four with previous autism diagnosis, one typically developing) and diagnosticians (n=3) of children with autism. During the study parents collected videos evidence of their child behaviors through NODA SmartCapture in their homes. For each family two diagnosticians, blind to the child's previous diagnostic status established through current in-person diagnostic practices, independently completed an autism diagnosis via NODA Connect. Results shows that without any prior training, parents found NODA SmartCapture easy to use and were able to successfully record videos in their homes. In addition, 96% of the videos recorded by parents were clinically valid. The outcome of the assessment between the two diagnosticians, and between each diagnostician and the child's previous diagnostic status were compared. Results showed that for four of the five children (three children with a previous diagnosis of autism and one typically developing child), both remote diagnosticians independently arrived at the same diagnostic decision, and in agreement with the child's previously established diagnostic status. For the fifth child (with a previous autism diagnosis), one diagnostician matched the diagnosis in the child's record but the second did not, though the latter indicated with high confidence that the child was not typically developing. A third diagnostician independently reviewed this case via NODA Connect and also confirmed the diagnosis in the child's medical record. Hence, 91% cases (10 out of total 11 assessments) diagnosticians were able to confidently arrive at a diagnostic outcome via NODA Connect that matches the child's medical record.

Large-scale in-field evaluation

A large-scale in-field evaluation with 44 parents, 51 target children (40 whose families were seeking evaluation for autism, 11 were typically developing) and their siblings and 10 diagnosticians. Parents recorded videos through NODA smart capture and diagnosticians conducted remote diagnosis through NODA Connect. One goal of this in-field evaluation was to validate the clinical significance of NODA based remote diagnosis in comparison with current best in-person autism diagnostic practices. Comparison of remote autism diagnosis via NODA with in-person diagnosis via best current diagnostic practices (ADR-I, ADOS-2, Vineland Adaptive Behavior Scales) confirmed the clinical significance of NODA [44]. The second goal of summative large-scale in-field evaluation was to analyze key stakeholders (parents and diagnosticians) response on using NODA in the field. For this purpose, post deployment follow-up interviews and questionnaires were conducted with stakeholders to solicit their feedback about their experience of using NODA.

Data shows that 95% of parents (42 out of 44) found NODA SmartCapture easy to use and indicated a desire to use NODA in future. Only 8 out of 44 parents had high privacy concerns

but they were willing to record and share if data capture, sharing and ownership policies are explicitly identified. Few parents (n=2) were conscious of their self-image or fear of being judged based on their interaction with the child and/or their lifestyle. 84% parents considered this method a valid approach for sharing clinical information. Analysis shows that 59% (26 out of 44) of parents reported that their child noticed NODA SmartCapture. However, 91% (40 out of 44) parents stated that they were able to capture naturalistic representation of their child's behavior for all four (reported by 31 parents) or three (reported by 9 parents) NODA scenarios. Overall parents indicated that NODA would facilitate effective communication with caregivers about the child's naturalistic behaviors and would enable timely assessment.

Like parent diagnosticians also anticipated that NODA has potential for enabling remote and timely autism diagnosis based on in-home naturalistic evidence. In particular, they considered NODA extremely useful for providing timely remote diagnosis to families located remotely as well as for children who have classic symptoms of autism. According to the diagnosticians, the most vital component of the NODA is the built-in instructions within NODA SmartCapture. Diagnosticians expressed that due to these explicit instructions, the parents were doing exactly what they would have done in the course of an in-person assessment, namely inserting social presses like calling the child's name, directing his attention to a toy or withholding an item to look for a reaction. However, diagnosticians anticipated that remote diagnosis could be complex for a) children with complex conditions, b) high functioning autism and c) children who are younger than two years.

COMMERCIAL EXPERIENCE

NODA is conceptualized, design and evaluated through a joint collaboration among Georgia Institute of Technology, Behavior Imaging Solution (BIS) and South West Autism Research and Resource Center (SARRC). Based on positive findings that compared NODA method favorably to in-person assessments for diagnosing autism, and because NODA was developed as a Class I exempt technology according to FDA regulations, BIS has made the NODA system available commercially in several US markets. With limited market exposure to date, one large Children Hospital's network has already adopted NODA to arm its referring pediatricians to educate their families about NODA as an option, while they're awaiting an in-person assessment. In several cases where parents insisted to use NODA directly to learn a professional's diagnostic opinion earlier, NODA gave families an answer of a diagnostic opinion in 3 to 5 days after their video was submitted, compared to in-person assessments which have still not occurred 6 months after.

This limited commercial availability has also spawned exceptional interest from international health organizations, especially in countries such as Singapore, Japan, and India – to consider NODA especially because there is a shortage of trained diagnostic clinicians that this form of telemedicine can fast-track access to.

CONCLUSION AND FUTURE WORK

The design, use, and field evaluation of a novel asynchronous telemedicine system, NODA, demonstrated that a remote diagnosis of ASD can now be accomplished successfully. The field evaluation of NODA confirmed that the system enables parents to easily collect clinically valid in-home video evidence of a child's behaviors and allows diagnosticians to complete a remote diagnostic assessment for ASD by using in-home video evidence in conjunction with the child's developmental history.

Our future research is focus on NODA's field adoption. A potential adoption workflow includes pediatricians requesting referrals for NODA remote diagnostic assessments for children who are at risk for ASD. Once a referral is in place, parents could then collect and share in-home videos with a qualified diagnostician by using the NODA SmartCapture technology. The diagnostician located at an affiliated diagnostic center would then complete the remote diagnostic assessment via NODA Connect and share the assessment report with the pediatrician, who subsequently would share the findings with the parents.

A series of research studies summarized in this chapter demonstrates that NODA can connect parents and diagnosticians to enable *timely* and *naturalistic evidence* based remote Autism diagnosis.

ACKNOWLEDGEMENTS

We would like to thank all our collaborators from Georgia Institute of Technology and SARRC. We would also like to thank our participants for their time and valuable feedback. We would like to acknowledge that all phases of this research were supported by NIH grant #9 R44 MH099035-04.

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