SUPPORTING IN-HOME COLLECTION AND SHARING OF BEHAVIOR SPECIMENS FOR DIAGNOSTIC ASSESSMENT OF CHILDREN WITH AUTISM

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Nazneen

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SUPPORTING IN-HOME COLLECTION AND SHARING OF BEHAVIOR SPECIMENS FOR DIAGNOSTIC ASSESSMENT OF CHILDREN WITH AUTISM

Approved by:

Dr. Gregory D. Abowd, Co-Advisor
School of Interactive Computing
Georgia Institute of Technology

Dr. Rosa I. Arriaga, Co-Advisor
School of Interactive Computing
Georgia Institute of Technology

Dr. Betsy DiSalvo
School of Interactive Computing
Georgia Institute of Technology

Dr. Ellen Yi-Luen Do
School of Industrial Design and School of Interactive Computing
Georgia Institute of Technology

Dr. Agata Rozga
School of Interactive Computing
Georgia Institute of Technology

Dr. Karrie G. Karahalios
Department of Computer Science
University of *Illinois at Urbana-Champaign*

Date Approved: April 7, 2014

I dedicate this thesis to my loving parents, Muhammad Anwar and Zubda Begum, and my beautiful daughter Nazafreen Zahoor.

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LIST OF SYMBOLS AND ABBREVIATIONS

Behavior Specimen	Video evidence of child behavior
CRAFT	Continuous Recording and Flagging Technology
NODA	Naturalistic Observation Diagnostic Assessment
NODA Smart Capture	Commercial capture system
NODA BI-Connect	Commercial Access system
DSM	Diagnostic and Statistical Manual of Mental Disorders
ADOS	Autism Diagnostic Observation Schedule

SUMMARY

Direct observation of the child remains an essential part of the gold standard clinical practice in diagnosis, assessment, and treatment planning for children with autism and related developmental conditions [1,2,3]. Clinical professionals acknowledge that observing behavior in the natural environment is crucial to obtain an accurate and comprehensive assessment of child behavior [1, 4]. However, direct observation in the natural environment is not feasible for wide-scale implementation into clinical practice. It is time consuming and resource intensive for clinicians to travel to families' homes in order to observe the child, and impractical to do so for remotely located families. Therefore, although direct observation in the naturalistic environment is the best-case scenario, in practice it is mostly limited to direct observation in a clinical setting. Another key challenge with respect to autism diagnosis is that there is 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 [5,6,7,8]. Delay in diagnosis can lead to delay in invaluable early interventions which could impact a child's future learning capabilities and developmental outcomes [1,9,10,11,12,13].

I posit that capture and access solutions can play a role to fill these gaps. This thesis presents the design, development, and evaluation of a *clinician-directed capture and access system* that can enable parents to easily collect clinician-prescribed behavior specimens in the home and clinicians to use this data to complete a diagnostic assessment for autism. Analogous to a traditional lab specimen collection and assessment procedure, this approach involves three steps: 1) the clinician's prescription of behavior specimens to be collected; 2) in-home collection and remote sharing of prescribed behavior specimens by parents; and 3) diagnostic assessment of behavior specimens by a remote and qualified clinician. The clinician-directed capture and access system consists of a

smartphone-based capture system for in-home behavior specimen collection by parents, and a web-based access system for prescription and assessment of behavior specimens by clinicians with diagnostic experience.

The contributions of this thesis are as follows: a) introduced and explored the notion of in-home behavior specimen collection for clinical assessment; b) investigated parents' and clinicians' current practices with respect to in-home recording and sharing of behaviors and derived concrete design guidelines based on key stakeholders' (parents and clinicians) reflection on potential design opportunities and adoption challenges towards a technology solution that facilitates in-home behavior specimen collection for diagnostic assessment of autism; c) identified key features and functionalities of a capture system that can enable parents to *easily* collect clinician-prescribed behavior specimens that have *clinical utility;* d) identified key features and functionalities of an access system that facilitates clinicians to guide behavior specimen collection procedure and to *complete* remote diagnostic assessment based on behavior specimens collected from a naturalistic home environment; e) demonstrated through an end-to-end field study with parents and clinicians that parents can easily collect diagnosis-ready behavior specimens through the capture system, and clinicians can complete remote autism diagnostic assessment based on in-home behavior specimens via the access system with high confidence in diagnostic outcome; and f) introduced the *prescription, collection and assessment model,* the model behind the clinician-directed capture and access system, which is generalizable and transferable to various other use cases in addition to the remote autism diagnostic assessment demonstrated in this thesis. This model augments the traditional ubiquitous computing capture and access models emphasizing the role of the user of the access system as the consumer of the collected specimens and one who directs or guides the capture process.

CHAPTER I

INTRODUCTION

In this chapter, I discuss a few key challenges with respect to diagnostic assessment of autism and propose the *clinician-directed capture and access system* as a potential technology solution. This chapter also covers the thesis statement, research questions and contributions.

1.1 Background and Motivation

1.1.1 Supporting diagnostic assessment of autism with evidence of naturalistic behaviors

Direct observation of the child remains an essential part of the gold standard clinical practice in diagnosis, assessment, and treatment planning for children with autism and related developmental conditions [1,2,3]. Clinical professionals acknowledge that observing behavior in the natural environment is crucial to obtain an accurate and comprehensive assessment of a child's behavior [1, 4]. The best-practice guidelines for diagnosing conditions like autism suggest that some observation of the child in the natural environment, such as the home or school, is optimal [1, 4]. Moreover, parents often report that their child acts differently at home than he or she does when brought to a clinical setting.

However, direct observation at home introduces a number of challenges. Based on a literature review and my discussions with clinicians and parents of children with autism, I have categorized key challenges as resourcing, validity, and behavior accessibility [14, 15,16,17,18,19,20,21].

- Resourcing: It is time consuming and resource intensive for clinicians to travel to families' homes and spend a few hours observing the children, and impractical to do so for remotely located families. Therefore, at present, direct observation in the natural environment is not widely implemented into clinical practice on a large scale.
- Validity: The presence of an unfamiliar observer may cause children to alter their behavior due to their awareness of being observed. Such reactivity poses a threat to the validity of any collected data.
- Behavior accessibility: Key child behaviors may not occur during the short span of a home visit.

Therefore, direct observation in the naturalistic environment is optimal, but in practice it is mostly limited to direct observation in a clinical setting. There is a gap between what is optimal and what is practiced, and my research is focused on how a capture and access solution can bridge this gap.

1.1.2 Connecting caregivers to enable remote diagnostic assessment for autism

Another key challenge with respect to autism diagnosis is that there is significant time lag (20-60 months) between the age at which parents first become concerned about their child's development and the age at which the child finally gets a diagnosis [5,6,7,8]. In many poor and rural communities, care for children with autism is marked by lack of access to autism-specific expertise among professionals [22,23,24,25,26]. Even in urban communities where services are more widely available, timely access to diagnostic and interventional services is often hampered by long waiting lists at centers and clinics [21,22,24,25,26]. Delay in diagnosis can lead to delay in invaluable early interventions which could impact a child's future learning capabilities and developmental outcomes [9,10,12,12,13]. I posit that technology can play a role in connecting parents and clinicians to enable timely diagnosis of autism.

1.2 Focus of research

I posit that a capture and access solution can enable clinicians to incorporate naturalistic observations of a child's behavior into their clinical practice for assessments. Further, it can connect parents and clinicians to enable timely remote diagnostic assessment of autism.

In this thesis, I present the concept, design, development and evaluation of the clinician-directed capture and access system that enables parents to collect and share clinician-prescribed behavior specimens in their homes, and clinicians to perform diagnostic assessment of autism on these behavior specimens [70, 71]. Analogous to traditional lab specimen collections and assessment procedures (see Figure 1), this approach involves three steps: 1) the clinician's prescription of behavior specimens to be collected; 2) in-home collection and remote sharing of prescribed behavior specimens by parents; and 3) the assessment of behavior specimens by a remote and qualified clinician. The implementation of the clinician-directed capture and access system consists of a smartphone-based capture system for in-home behavior specimen collection by parents and a web-based access system that interfaces with the smartphone application for prescription and assessment of behavior specimens by clinicians with diagnostic experience.

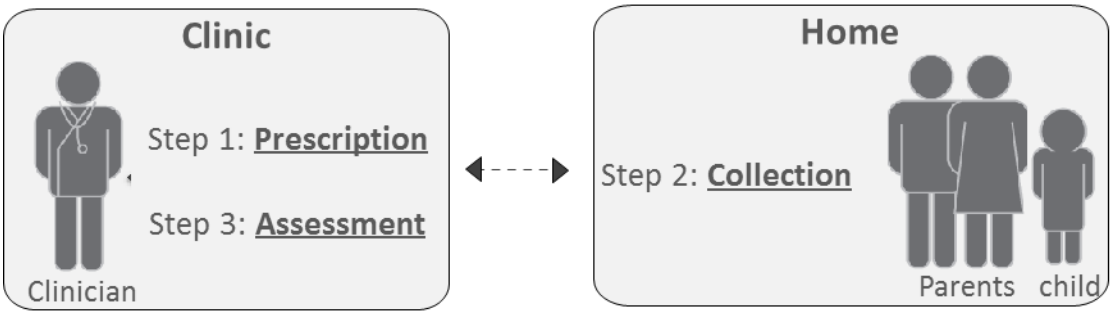

Figure 1: Clinician-directed capture and access system concept

The *prescription, collection and assessment model* behind the clinician-directed capture and access system is generalizable. This model is transferable to various use cases in addition to the remote autism diagnostic assessment demonstrated in this thesis. Chapter 8 discusses details of the transferability of this model across various use cases related to health outcomes such as treatment monitoring, treatment follow up and evidence-based intervention planning. In addition, this model is transferable to other services such as evidence-based training of caregivers, facilitating communication among caregivers; inter-rater reliability and participant recruitment. These use cases were identified by clinicians who participated in various studies conducted for this thesis. This model augments the traditional ubiquitous computing capture and access models emphasizing the role of the user of the access system as the consumer of the collected specimens and one who directs or guides the capture process. This enables users of the capture and access systems to be partners in data collection.

1.3 Thesis statement, research questions and contributions

Thesis statement: An appropriately designed capture and access technology can enable: 1) parents to ***easily*** collect in-home behavior specimens that have ***clinical utility*** and 2) clinical experts to ***complete*** a diagnostic assessment for autism based on parent-collected in-home behavior specimens.

In particular, I address the following research questions:

RQ1: What are the potential opportunities and challenges specific to the design and adoption of a technology solution that enables in-home behavior specimen collection and diagnostic assessment for autism based on these specimens?

For this question, I designed and developed an initial prototype of the clinician-directed capture and access system and used it as a technology probe in a Needs Analysis study with clinicians (n=11) and parents (n=7) of children with autism and related conditions (described in detail in Chapter 3).

Contributions:

This study helped me investigate parents' and clinicians' current practices with respect to in-home recording and sharing of behaviors, and formulate concrete design guidelines based on key stakeholders' (parents and clinicians) reflection on potential design opportunities and adoption challenges towards a technology solution that facilitates in-home behavior specimen collection for diagnostic assessment of autism. The clinician-directed capture and access system design is informed by findings from the Needs Analysis study described in Chapter 3.

RQ2: What are key features and functionalities of a smartphone-based capture system that allow parents to easily collect behavior specimens that have clinical utility?

To address this question, the capture system was iteratively designed through a usability study in a home-like controlled setting, and the improved design was evaluated in the field (actual homes).

In this study parents were asked to use the capture system in a home-like laboratory setting. This study was conducted in two phases. In phase-I an initial design of the capture system was tested, whereas in phase-II the revised design of the capture system informed by phase-I was tested. The goal was to identify functionalities and factors that contribute to the ease of use of the system as well as the clinical utility of collected behavior specimens rated by a clinician experienced in autism diagnosis. Based on a detailed analysis of behavior specimens along with clinician rating and feedback, factors that affect behavior specimens' clinical utility were identified. Analysis of the factors that affect the clinical utility of a video specimen facilitated the formulation of recording instructions for parents that were later embedded in the capture system as a prescription.

For the in-home study the revised design of the capture system that was informed by the usability study in the controlled environment was evaluated in a real setting, with parents using the system in their homes (described in detail in Chapter 5). Behavior specimens collected through this study were assessed by clinicians during the access system evaluation (described in detail in Chapter 7) for conducting autism diagnostic assessments.

Contributions:

Usability studies in the controlled and home environment established and validated a set of design features and functionalities essential for a capture system which is easy to use and supports collection of behavior specimens that have clinical utility.

RQ3: What are the key features and functionalities of a web-based access system that enables clinicians to guide in-home behavior specimen collection and complete remote diagnostic assessment for autism based on in-home behavior specimens?

For this question, I designed and evaluated the web-based access system in which clinicians experienced in autism diagnosis completed a diagnostic assessment for autism with high confidence. Diagnostic assessments were based on in-home behavior specimens collected by parents during the capture system in-home evaluation. The results of the diagnostic assessment via access system were compared with the child's previous diagnosis conferred through the current best in-person diagnostic assessment.

Contributions

I established and validated a set of design features and functionalities that are needed within the access system to support a clinician in: 1) guiding in-home behavior specimen collection, and 2) completing a remote diagnostic assessment for autism, based on in-home behavior specimens with higher confidence.

1.4 Collaborators

The work for this thesis was done in collaboration with a commercial company, Behavior Imaging Solutions, Inc. (BIS), located in Boise, Idaho, and a clinical partner, the Southwest Autism Research and Resource Center (SARRC) located in Tempe, Arizona. The NODA (Naturalistic Observation Diagnostic Assessment) diagnostic protocol that is incorporated into the capture system was invented and piloted by Dr. Christopher Smith and colleagues at SARRC [27]. Behavior Imaging Solutions is working on the commercialization of the clinician-directed capture and access system and the commercial products are referred as NODA Smart Capture (capture system) and NODA BI-Connect (access system) [28].

1.5 Overview of thesis

In this thesis, I present the design, development, and evaluation of the clinician-directed capture and access system that enables parents to easily collect clinician-prescribed behavior specimens and clinicians to complete remote diagnostic assessment of autism based on in-home behavior specimens.

In Chapter 2, I present related work on capture and access technologies that are designed for collection and sharing of naturalistic evidence of behaviors of children with autism, and technologies that support a remote diagnostic assessment of autism. Chapter 2 also includes details on an exploratory study that inspired the concept of the clinician-directed capture and access system. Chapter 3 includes findings from the Needs Analysis study conducted with parents and clinicians of children with autism, and an initial design of the capture system that was used to solicit participants' feedback during the Needs Analysis study. This chapter also includes a summary of design guidelines based on parents' and clinicians' feedback. Chapter 4 describes how the iterative design of the capture system resulted through a usability study conducted in

home-like controlled settings. Chapter 5 describes the in-home evaluation of the capture system by parents. Chapter 6 presents the iterative design of the access system through a participatory design process. Chapter 7 describes details of the evaluation of the access system when used by clinicians to conduct diagnostic assessments of autism based on in-home specimens collected by parents during the capture system in-home evaluation. In Chapter 8, I discuss the high-level design specification and generalizability of the generic *prescription, collection and assessment* model behind the clinician-directed capture and access system and present various examples of its transferability to other use cases in addition to the case of autism remote diagnosis demonstrated in this thesis. Chapter 9 includes details about the future directions for the clinician-directed capture and access system with respect to: 1) a clinical trial to assess reliability of in-home video-based autism diagnosis; 2) technology advancements towards a smart clinician-directed capture and access system; and 3) vision on field adoption of the clinician-directed capture and access system. In Chapter 10, I summarize and reflect back on the thesis statement, the research questions and the resulting contribution from a series of research studies conducted to address these research questions. Table 1 below summarizes the research questions that I plan to answer with this thesis, and the studies that have addressed them.

Table 1: Summary of the research questions and related studies

#	Research Question	How it will be Addressed
RQ1	What are the potential opportunities and challenges specific to the design and adoption of a technology solution that enables in-home behavior specimen collection and diagnostic assessment for autism based on these specimens?	Needs Analysis study
RQ2	What are key features and functionalities of a smartphone-based capture system that allows parents to easily collect behavior specimens that have clinical utility?	The capture system usability study in controlled setting The in-home capture system evaluation
RQ3	What are the key features and functionalities of an online access system that enables clinicians to guide in-home behavior specimen collection and complete diagnostic assessment for autism based on behavior specimens?	The access system evaluation study

CHAPTER 2

RELATED WORK AND BACKGROUND

In this chapter, I discuss related work across three areas that include: 1) capture and access technologies to support data collection for naturalistic observation of behaviors; 2) efficacy of telemedicine for remote assessment and diagnosis of autism; and 3) clinical relevance of behavior specimens collected by parents.

2.1 Research-oriented systems for naturalistic observation of behaviors

Capture and access technologies, as defined by Abowd and Mynatt [29], allow for the recording (e.g., video and audio) of information from live events for review at a later time. Capture and access technologies has been explored for providing services to children with autism in different settings [30-40]. In this section, I focus on research-based capture and access systems specifically designed to support the collection of behavior data in natural settings like school and home environments.

2.1.1 Behavior data collection in school settings

CareLog, designed by Hayes et al, is a capture and access technology for behavior data collection in a school setting [41, 42, 43]. It facilitates teacher tracking of the occurrence and context of behavioral incidents exhibited by children with autism in a classroom. CareLog uses audio and video buffering to allow selective archiving as well as a human-controlled mechanism for retroactively recording events of interest, which supports deeper reflection on the context of the behavior. Selective archiving, as defined by Hayes, is a capture and access model that constantly buffers data but permanently stores it only when explicitly triggered by the user [41,42]. A pre- and post-trigger window of data is stored for retroactive analysis of context around the triggering point.

This approach has several benefits. First, it puts the user in complete control of when the data is stored, simultaneously addressing privacy and storage management concerns that arise from continuous data capture of video recordings. Second, with the human in the loop, irrelevant data is implicitly filtered, saving resources both in the present (disk space) and in the future (time spent in viewing or analyzing the video data). CareLog was deployed in four classrooms at a special-education school for five months. Teachers performed a functional behavior analysis, which involves noting the occurrence, antecedents (events preceding) and consequences (events following) of individual behavior incidents, using a standard paper and pencil format as well as using CareLog. Results showed that teachers made an average of 43.4% fewer false negative errors (missed incidents) with CareLog than with the traditional pen and paper method. Furthermore, the teachers reported feeling less burdened and more confident in the results of their assessments. This work in an educational setting demonstrates the potential for selective archiving to support contextual analysis of behaviors of concern.

In contrast with CareLog, which was designed for teachers to collect video evidence in the classroom, the capture system that I have designed and developed targets in-home collection of video evidence of behaviors by parents. The home is a more dynamic space, with the child having the freedom to move from room to room. This poses technical challenges to ensure camera coverage of the child's movements. Moreover, in a classroom setting, the teacher is dedicated to watching over the children, unlike parents at homes who may be busy with other household routines. In addition, unlike CareLog, where the data collector is also the data consumer, in my scenario the clinician is the consumer of the data collected by parents. This introduces a need for guided collection in which clinicians can explicitly prescribe what they would like parents to collect and share.

A commercial implementation of selective archiving, BI Capture by Behavior Imaging Solutions (BIS) [44] is now making a commercial implementation of selective archiving that can be used in a variety of clinical and educational settings. The opportunity for using BI Capture in a home setting is what inspired my current work on the clinician-directed capture and access system.

2.1.2 Behavior data collection in home settings

Marcu et al. assessed the parent-driven use of cameras worn by children to record their activities and interactions from a first-person perspective [45]. Based on a five-week field study with five families, they found that the wearable system helped parents to: 1) see the world from their child's perspective; 2) increase their understanding of their child's needs when their child is uncommunicative; and 3) help them encourage their child's social engagement. As compared to this system, the clinician-directed capture and access system is not a wearable device. Based on my discussion with clinicians during the Needs Analysis study (described in Chapter 3), I found that for clinical significance it is important to not just capture the child, but also the objects and individuals with whom the child interacts. A wearable system for the child, or even for parents, that only captures images may impose constraints on capturing those interactions that are key ingredients of a behavior specimen that is collected for diagnostic assessment.

Furthermore, research has shown that an appropriately designed capture and access system can increase collaboration among caregivers [46, 47, 48]. One such system is Abaris, which is a capture and access tool that was designed to record instructional data during structured one-to-one discrete trial training (DTT), a widely used therapy for children with autism [46]. Abaris consists of a desktop application that enables customization of the child's daily therapy regimen and printing of specialized data sheets that are integrated with a digital pen. These written records are synchronized with audio and video recordings from a fixed environmental camera and microphone. Abaris was

deployed for four months with a single home-based DTT team. Results showed that Abaris increased collaboration among the therapists. However, as this system is deployment-intensive, it would be difficult for families to set up and use such a system independently. For this reason, I designed the Capture system around a smartphone, which is portable and does not require a complicated setup.

In addition to Abaris, Kientz et al. developed KidCam, which helps parents to capture and archive video evidence of sentimental moments of their child, such as their first steps, to share with family, as well as their child's pediatrician [47]. Photos and videos collected via KidCam can synchronize with another software application (Baby Steps), which supports tracking of specific developmental milestones [48]. The two systems were deployed for three months with eight families. The results from this deployment showed that parents had a statistically significant increase in their collaboration with their pediatricians. Similarly, pediatricians also rated their collaboration with parents higher at the end of the study. KidCam and Babysteps are parent-initiated systems whereby parents capture evidence at their own discretion. In contrast, the clinician-directed capture and access is clinician-initiated as the clinicians (being the consumers of the data) prescribe what parents should capture so that they can complete diagnostic assessment of autism.

2.2 Commercial capture and access systems for behavior observation

Numerous off-the-shelf technologies are available that facilitate behavior evidence collection to support the care of children with autism. Recently, smartphone- and tablet-based applications have become readily available to support assessment and intervention of children with autism. iBAA (iPhone Behavior Assessment App) [49], Student On-Task Observation [50] and ABC data [51] are some examples of such applications designed for school professionals to observe and record behavioral data in school settings. Another similar commercial product is BTP (Behavior Tracker Pro) [52].

It is designed for the iPhone and allows caregivers such as clinicians, teachers and parents to record and share a child's behaviors of concern in homes and schools. BTP allows uploading data to a team portal for advanced online charting, team collaboration, and video messaging. The clinician-directed capture and access system is different than these commercial systems, since through embedded prescriptions and guided capture it ensures collection of highly relevant data. In addition, the clinician-directed capture and access system is explicitly focused on enabling remote diagnostic assessment of autism.

Another commercially available technology provided by Behavior Imaging Solutions is the Behavior Imaging Tool Set [53]. It includes the Behavior Capture tool to capture and store behaviors and events that are recorded through a webcam on a laptop via a remote control. Data captured can be shared with remote professionals using another tool called Behavior Connect. In collaboration with BIS and SARRC (Southwest Autism Research and Resource Center), we are working on potential commercialization of the Clinician-directed capture and access system as a tool to support remote diagnostic assessment of children at risk for autism.

2.3 Telemedicine for autism assessment and diagnosis

There has been a growing recognition of the potential of telehealth technologies to improve access to care for individuals with autism [54-67]. In a recent literature review, seven of the eight studies reviewed reported successful implementation and positive outcomes of services delivered via telemedicine [58]. The authors of the review concluded that telemedicine is a promising service delivery approach for individuals with autism. Research studies have also shown that telemedicine can be used to deliver treatment and diagnostic services to children with autism in underserved rural communities [22, 59, 66]. In addition, a few research studies have investigated the reliability and validity of autism educational and diagnostic assessments using telemedicine [58, 60]. Reese et al. explored the use of telemedicine in the diagnosis of

autism to determine if autism could be accurately diagnosed, if families were satisfied with the diagnostic process, and if gold standard instruments for the diagnosis of autism were equally reliable when conducted via telemedicine as compared to traditional in-person assessment [60]. Twenty-one children between the ages of three and five were recruited, half of them with an existing diagnosis of autism, and the other half with general developmental delays. Children were randomly assigned to either a telemedicine or in-person assessment condition. Results indicated that accuracy of diagnosis, family satisfaction, and reliability of gold standard assessments did not differ between the in-person condition and the telemedicine condition. This study provides preliminary evidence that autism diagnostic assessments can be reliably conducted using telemedicine without loss of parent satisfaction with the assessment process.

These telepractices are based on technologies that support synchronous (real time) audio and video interaction between the clinician 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 communication based system is that it demands parents and clinicians 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. In addition, with most of the telemedicine systems employed for assessment and diagnosis of autism, 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 clinician's instructions during the remote session. Whereas, a store-and-forward solution may enable parents to easily record and share their child's natural behavior in their home and in the course of day-to-day activities. This solution also avoids any possible reactivity due to the remote presence of the clinicians or the artificial setup of clinic or center setup. Finally, the child may not exhibit the target

behaviors in the presence of a clinician 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 clinicians asynchronously. However, a clear advantage of synchronous communication is that clinicians 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 clinician-directed capture and access system has embedded recording instructions that guide parents through the desired interactions with the child while recording. In addition, a clinician-directed capture and access system also allows clinicians and parents to asynchronously communicate during the in-home behavior specimen collection process.

2.4 Clinical relevance of child data collected by parents

Studies have shown that even though parents have a high desire to collect and share their children's health data with health care professionals, there is a disconnect between the information parents think they need to keep and information the health care providers expect from them [68]. Thus, for an in-home video collection system that parents will use to record their child behaviors, it is important to establish the clinical relevance of behavior specimens collected by parents. In order to investigate this, I conducted a research study to systematically analyze whether parents who are asked to record video evidence of their child's problem behavior in the home can successfully record behaviors that match clinicians' established definitions for severe problem behavior [69]. Findings from this study have informed the concept and initial design of the clinician-directed capture and access system.

In this exploratory study, parents of children who were on the wait list for a local behavior treatment clinic were asked to record examples of their child's problem behaviors in their home. The recordings were captured using a PC-based multi-camera

system, CRAFT (Continuous Recording and Flagging Technology), which I designed to conduct this study (see Figure 2).

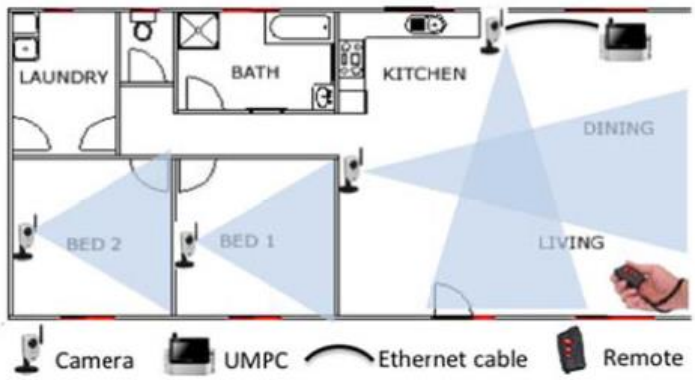

Figure 2: CRAFT system design

Figure 2 shows schematic of a typical deployment of the CRAFT system, with 4 cameras placed throughout the family's home, along with a computer that collects both the video data (continuously recorded video to enable subsequent ground truth annotation) and a clicker for parents to indicate onset of a behavior.

CRAFT was deployed in eight households, each with a child diagnosed with autism or other developmental conditions, for an average of 16 hours at each house. Parents were asked to flag occurrences of their child's problem behaviors with a remote clicker. At the end of the deployment, a team of clinicians independently reviewed the continuously recorded videos captured through CRAFT and identified all instances of the child's problem behaviors, based on their pre-established clinical definitions of problem behavior. Next, the clinicians compared instances that they identified (from continuous recording) with the ones that parents identified (using the clicker). Results showed that without any training or prior discussion, parents were able to successfully identify (by clicking the remote) 55% of all the problem behaviors identified by the clinical experts, but were not able to identifying a remaining 45%. Of all the behaviors identified by parents, 63% of them did not match the standard clinical definition of problem behaviors. Since in this study parents were not given explicit instructions, I wanted to explore if and

how an explicit clinician prescription would affect the clinical utility the collected behavior specimens.

In addition, a review of the continuously recorded videos revealed several usability issues that home-based video collection systems need to address. For example, there were cases when parents used the clicker to flag the occurrence of a problem behavior, but the child was off-camera so the behavior was not captured on video. Thus, it is extremely important for parents to have a simple and easy-to-operate collection system, and they should be able to easily view the camera's field of view and, if necessary, to be able to move the camera around the house. For this reason, we designed the collection system around a smartphone, which is portable, allows for a clear view of the captured scene (for adjusting field of view), and does not require a complicated setup.

In the next chapter, I describe a Needs Analysis study designed to explore the concept of in-home behavior specimen collection and sharing, and clinical assessments based on it.

CHAPTER 3

CONCEPT EXPLORATION AND ANALYSIS

A Needs Analysis study was conducted to explore the notion of 'in-home behavior specimen collection and sharing for clinical assessment" with key stakeholders and to understand factors that contribute both to parents' willingness to record behavior in the home and share it, and clinicians' openness to base their clinical assessment on in-home behavior specimens. This chapter describes key findings from the study and resulting design guidelines.

3.1 Goals

The goal of the Needs Analysis study was to identify parents' and clinicians' current practices with respect to in-home recording and sharing of behaviors, and to derive concrete design guidelines based on key stakeholders' (parents and clinicians) reflection on potential design opportunities and adoption challenges towards a technology solution that facilitates in-home behavior specimen collection for clinical assessment of autism.

3.2 Participants

Participants in this study included parents (n=7) and clinicians (n=11) of children with autism. Participants were recruited through word-of-mouth and fliers. Table 2, below, summarizes participants' demographics for parents and their children who were diagnosed or at a risk for autism and related conditions. The children did not participate in this study. Information about the children was collected from parents in order to situate parents' feedback within their experience of their child's condition.

Table 2: Needs Analysis study: Participant parents' demographics

#	Parents demographics					Child(ren) demographics
	Participant	Age(yr.)	Gender	Ethnicity	Education	Age(yr.), Gender, diagnosis
P1	Mother	25-34	F	White/Caucasian	College	6 years daughter girl diagnosed with autism and had feeding issues
P2	Father	25-34	M	Asian	College	4 years old girl diagnosed with autism
P3	Mother	35-44	F	Hispanic/Latino, African American, White/ Caucasian	Middle school	16 years old girl diagnosed with ADHD/Bipolar and 18 years old son diagnosed with autism
P4	Mother	45-54	F	African American	College	14 years old son diagnosed with autism and learning difficulties.
P5	Mother	25-34	F	African American	Middle school	3 years old son diagnosed with autism
P6	Mother	45-54	F	White/ Caucasian	College	14 years old son diagnosed with autism
	Father	45-54	M	White/ Caucasian	Post-graduate	

All participant clinicians regularly interact with (on a daily basis) and provide services to children with autism. Five participant clinicians were experienced in diagnosis and treatment, whereas, six others were experienced only in treatment. Participant clinicians had various levels of experience, varying from 4 to 20 years. Additionally, some of the clinicians (n=4) were providing in-home interventions at the time of the study. This variety of expertise helped to identify a range of potential applications of the proposed system. Table 3 below includes details about participant clinicians' demographics.

Table 3: Needs Analysis study: Participant clinicians' demographics

#	Qualifications	Primary responsibility (with respect to autism)	Experience(Y)	Age(y) range	Gender
C1	Occupational therapist	Occupational therapy	6	25-34	F
C2	Feeding therapist	Feeding therapy	9	35-44	F
C3	BCBA, MS in Applied Behavior Analysis	Treatment planning, parent training.	5	35-44	F
C4	BCBA, MS in clinical psychology and applied behavior analysis	Teach caregivers behavior management strategies	4	25-34	M
C5	BCBA, MS education psych	Develop and implement treatment plan to increase language and learning skill.	8	25-34	F
C6	PhD school psychology, BCBA, School psychologist	Manage school consultation and home consultation, diagnostic assessment	18	35-44	F
C7	BCBA, MS applied behavior analysis	Assessment and treatment of severe problem behavior	12	35-44	M
C8	Child and adolescent psychiatrist, MD	Psychiatrist, telemedicine, diagnostic assessment	10	35-44	F
C9	PhD clinical psych	Diagnostic assessment and evaluation	20	35-44	F
C10	PhD experimental psychology, Certified ADI-R and ADOS.	Diagnostic assessment and evaluation	20	45-54	M
C11	PhD: Special education,	College professor, diagnostic assessment and evaluation	15	35-44	F

3.3 Method

This section describes the Needs Analysis study protocol and an initial design of the clinician-directed capture and access system that was used as a probe during the study.

3.3.1 Study protocol

During the Needs Analysis study, a single, two-hour, one-on-one session was conducted with one participant at a time (either a parent or a clinician). At the beginning of the session, the participant was asked to fill out a pre-questionnaire (see Appendix A

for questionnaire) that included questions about parents' current practice regarding in-home video recording and sharing with clinicians and participants' point of view about the value and limitations of in-home video evidence of behaviors. Next, the proposed system concept was explained with a live demo of the initial clinician-directed capture and access system prototype (see Figure 3). The pre-questionnaire was conducted before this step in order to avoid any possible biases. After the interactive demo, participants were asked to fill out a follow-up questionnaire (see Appendix A for questionnaire) and answer questions in a semi-structured interview to obtain their feedback about the specific features that can make it practical for parents to record and share, and useful for clinicians in successfully completing clinical assessment based on in-home behavior specimens.

3.3.2 Initial design of the clinician-directed capture and access system

A horizontal prototype of the clinician-directed capture and access system was developed to use as a probe in the Needs Analysis study. The prototype includes a smartphone-based capture system for in-home behavior specimen collection by parents, and a web-based access system for clinicians to guide the in-home collection process and conduct assessment based behavior specimens (see Figure 3). Through the access system, clinicians can prescribe a list of behavior specimens that parents need to capture. The collection system is then automatically preset with the list of behaviors prescribed by clinicians. Parents can start recording of a prescribed behavior through the smartphone screen or a wireless remote. The wireless remote was added with the assumption that it would be useful when the capture device (smartphone) is on a mounting device. After a behavior specimen is captured, parents can edit it, if required, before uploading it. Once uploaded, behavior specimens are immediately available through the access system for clinical assessment. This initial design of the clinician-directed capture and access system

has asynchronous messaging feature to allow clinicians to guide the in-home behavior specimen collection procedure.

Step 1. Prescription

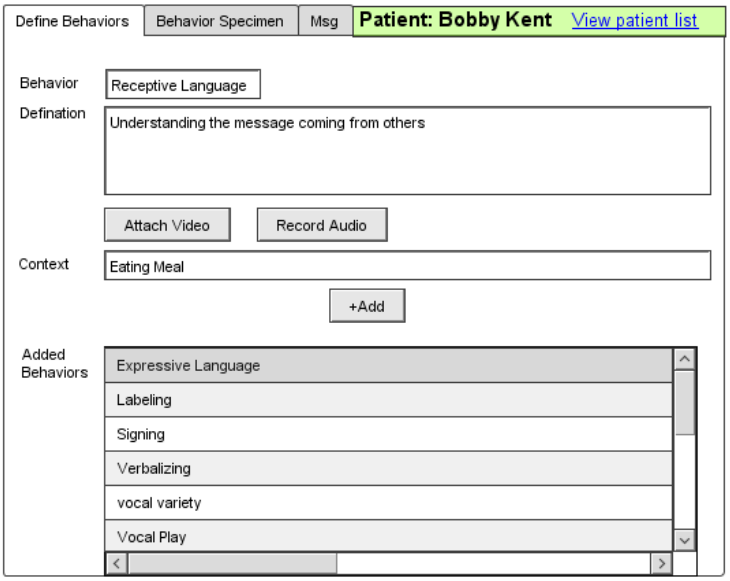

Figure 3a. Web-based access system for a clinician to prescribe behavior specimens

Step 2. Collection

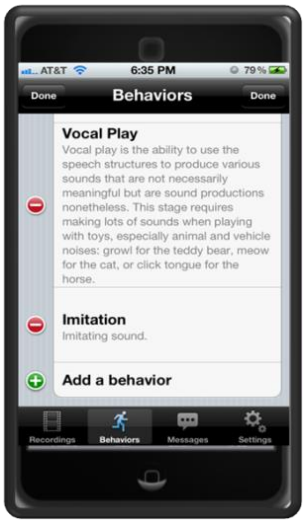

Figure 3b. List of prescribed behaviors and an option for parents to add custom behaviors

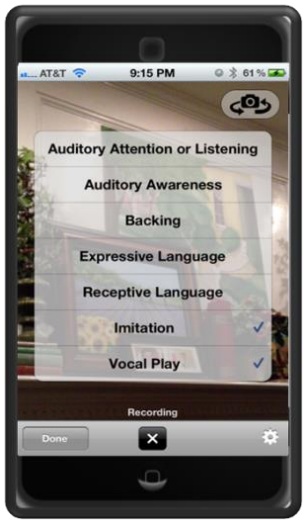

Figure 3c. Annotation of recording with predefined list of behaviors

Figure 3d. Wireless remote to start/stop video and mounting device

Step 3. Clinical assessment

Figure 3e. Web-based access system for clinician for assessment of specimens

Figure 3f. Web-based access system's messaging interface for clinician to send and receive messages from parents

Figure 3: Initial prototype of the clinician-directed capture and access system

3.4 Data analysis

Data collected from the Needs Analysis study was subjected to a qualitative and quantitative analysis. Data consisted of pre- and follow-up questionnaires and transcription of the audio recorded during the semi-structured interviews. For data analysis, I conducted an initial round of open coding to create thematic connections using a data-driven approach [72]. In parallel to this, all data was divided into four sets and given to four other researchers, who independently coded their data set and derived their themes (blind to both each other's themes and the ones I extracted). Next, we combined all themes, extracted statements of interest, and grouped them until a set of distinct themes emerged.

3.5 Findings

Themes that emerged from the Needs Analysis study were categorized under six main categories: 1) current practices; 2) value addition; 3) potential use cases; 4) clinical utility of behavior specimens; 5) diagnostic assessments based on in-home behavior specimens; and 6) barriers to adoption. This section describes these categories of themes and the resulting design guidelines.

3.5.1 Current practices

<u>In-home recording and sharing of behavior evidence is not a common practice</u>

All participant clinicians and parents reported that in-home recording and sharing of behavior is not a common practice mainly due to three reasons: 1) complex capture and share procedures: Recording and sharing requires additional effort by parents who are already overloaded with caregiving tasks; 2) lack of a medium for sharing: There is no dedicated medium for sharing video with clinicians other than during the limited time of the in-person appointment and; 3) sharing is not immediate: When clinicians can only

view parents' recorded video later during the appointment, it may not be useful if the child is no longer exhibiting that problem behavior.

However, in some situations, parents, on their own or on explicit request from a clinician, record and share video recordings of their child's behavior(s). These occur often in those situations when a clinician's chance of direct observation of a target behavior is limited (e.g., target behavior is infrequent, target behavior is triggered at home in certain contexts but not at a clinic) and it is critical to observe behaviors for intervention planning. As stated by a clinician:

C4-NeedsAnalysis "I had one parent who said, 'I need to record this and show it to you because it's just not happening while you're here.' It might be an interaction with a particular sibling or caregiver. But then that sibling or caregiver is not present while I'm there because of some sort of scheduling issue. They volunteered to video tape."

At times during home visits, clinicians or their staff may video record child behaviors. This happens mostly when they want to decide which type of treatment service the child needs to receive within their clinical practice, or to provide feedback to staff who deliver in-home interventions.

Parents' methods for in-home recording and sharing of behavior evidence

When required to video record their child's behavior, parents often use their phone and personal cameras to record and later show these recording to clinicians during in-home or in-clinic appointments. Clinicians often look at the videos on the parents' device during the appointment and do not get a copy of it.

Design considerations based on current practice: *1) simplify parents' capture and sharing experience; 2) capture and sharing should be coupled together; 3) allow clinicians to remotely analyze in-home behavior specimens; and 4) phone can be used as a potential platform for a capture system.*

3.5.2 Value addition

When asked in the follow-up questionnaire about the potential usefulness of an in-home recording and sharing system for clinical assessment on a scale of 1 (not useful) to 5 (very useful), on average, clinicians and parents rated it as 4 and 4.3, respectively.

Observing evidence of otherwise inaccessible behaviors

Participant clinicians and parents considered in-home specimen collection and sharing particularly valuable for allowing clinicians to observe evidence of inaccessible behaviors (behaviors that they typically wouldn't be able to observe, e.g., infrequent behaviors). Below are some example statements from clinicians on this topic.

C3-Needs Analysis "What would be nice about this system is being able to capture those moments that I can't be there for."

C5-NeedsAnalysis "It would be very helpful for us, especially for those things that either the behavior only occurs once every two to three weeks and the chances of it happening during the time that we are sitting in that house are very slim."

C8-Needs Analysis "If I could see a video of that symptom as it's happening because sometimes when they come into the office those behaviors aren't happening or the appointment they have with me is so much later that the symptoms are gone."

Observing behavior in its natural context

All participant parents and clinicians highlighted that in-home video evidence of behaviors would allow clinicians to observe a behavior in its natural context. As stated by a participant clinician:

C9-NeedsAnalysis "any comprehensive approach to evaluation and diagnosis is that you have to have not only that child's history, which comes from the parent and caregivers, but a knowledge and understanding of that child's presentation in their real life context – not in the clinic."

Richness of video data

All participants liked the inherent richness of video data. Parents emphasized that it would be easy for them to communicate through video instead of explaining a behavior verbally or in writing to the clinicians. As stated by a participant parent:

P5-NeedsAnalysis: "video can have better explanation of child behavior than on paper or verbally explaining it."

Enables new communication channels

All participants suggested that an in-home behavior collection and sharing system would enable new communication channels. One of the participant clinicians highlighted that in-home video evidence of behaviors would allow integrating the child's family into the overall intervention plan:

C10-Needs Analysis "I use video recording for so many things, like, not only watching the child's behavior, but I want to see whoever's working with that child, I want to watch parent's interaction … when you have a child with delays and you want to teach people how to work with delays, I'm not only changing the child's behavior, but we're changing the whole family unit behavior…it's the whole family not just one child approach. It's a family approach."

Immediate access to the behavior specimen

The clinicians highly appreciated the fact that the clinician-directed system can allow parents to share specimens with clinicians as soon as they are recorded. Clinicians emphasized that immediate access would help them provide on-time intervention if and when necessary. As stated by a participant clinician:

C11-NeedsAnalysis "I think the immediacy that this is – uploading the video; I could watch it that afternoon if I were able to. It could go real quick. Right now they have to put it on a DVD and mail it to me because we don't have a lot of HIPAA

compliant ways to view video from afar. We can't just put it on YouTube. It's not immediate. It's definitely a couple of days before I have a video in hand mailed to here and I've got to get it and then watch it."

Design Considerations based on the system's perceived value addition: *1) allows communication between parents and clinicians; 2) provides parents with an option to share immediately after completing a recording.*

3.5.3 Potential clinical use cases

Participant clinicians proposed a number of potential use case scenarios for an in-home behavior specimen collection and sharing system. These include autism remote diagnostic assessment, treatment planning, treatment follow-up, evidence-based training of caregivers, evidence-based intervention planning and monitoring, triage to prioritize long waiting lists in autism centers, etc. Participant clinicians also suggested that a system based on prescription, collection and assessment model would be valuable to provide remote health services (e.g., screening and diagnostic assessment, treatment and follow up, evidence based intervention planning, training of caregivers, etc.) not only for autism but for other development-delay-based conditions well as.

These recommended use cases are described later in Chapter 9. Remote autism diagnosis is one of the use cases and is briefly discussed below, since it's the focus on this thesis.

Remote autism diagnostic assessment

All of the five participant clinicians with experience in autism diagnosis considered in-home video based behavior specimens as evidence from the child's natural environment, and hence useful for diagnostic assessment. As stated by one clinician: *C10-NeedsAnalysis "The home video or in school video or both would be incredibly*

helpful to the diagnostic process because you are seeing what the skill level is in an actual environment".

All the clinicians agreed that such a system would be most useful for quick diagnosis of children who have classic symptoms of autism. Three of these clinicians highly stressed that the children who have more subtle characteristics of autism would need a more thorough and comprehensive in-person evaluation, and in such cases, video evidence should be used to complement the in-person diagnosis, not to replace it. Below is statement from one of these three clinicians.

C9-NeedsAnalysis "it's a wonderful compliment, because we always want the parent report of what happens in the home, or out in the community, or in a familiar environment that aren't the lab. But that's not the entire diagnostic evaluation. For waiting room diagnoses, where somebody can see child and say, "That's classic autism," this is something that could be very useful in this case."

Design recommendation based on potential use cases: *1) Design of the capture system should be driven by its access system use case scenario(s) and 2) additional evidence in addition to video evidence might be required for children with subtle conditions.*

3.5.4 Clinical utility of behavior specimens

Based on discussion with clinicians, I identified that there are a number of attributes that may affect the validity and usefulness of a collected behavior specimen. Some of the attributes are static, such as audio and video quality, field of view, and lighting conditions. However, other key attributes are dynamic and depend on the specific application or clinical purpose of the behavior specimen collection. For instance, a clinician prescription about a behavior specimen's attributes, such as duration of recording, content of the recording specimen (interactions: pointing, response to name

call, requesting), may vary depending on whether it will be used for diagnosis of the child or parent training. As stated by a participant clinician:

C9-NeedsAnalysis: "If I'm doing it for diagnosis then I'd wanna see a lot of the different criteria either of them doing it or not doing it. If I'm doing it to help figure out what kind of treatment then it's – I wouldn't necessarily – I would just wanna see the behavior."

All clinicians highlighted that the specimen should not only have the target child in the camera view but should also capture other objects and individuals the child is interacting with.

C3-Needs Analysis: "if we only have video recording of a child, I can't see how other members of the family are interacting with that child or how that child interacts with other members of that family."

In summary, all clinicians highlighted that the key attributes that make a behavior specimen valid and useful can only be defined within the context of its clinical purpose for collection. Therefore clinicians highly emphasized the need for features that can allow them to prescribe customized behavior specimens (e.g., type of behavior, context, required number of behaviors, required interactions, and duration of recording).

Design recommendations based on specimen validity*: 1) clinician prescription should be included for capture; 2) prescription should explicitly state the desired content of the video specimen (defined within the context of their clinical usage); and 3) use portable mounting device for mounting camera in environment to allow parents to interact and be in the field of view.*

3.5.5 Behavior specimen assessment

All clinicians found tagging and auto-population of the summary in the access system very useful. However, three of the five clinicians experienced in autism diagnosis mentioned that while analyzing the video, the clinician should have the option to tag both

"presence" and "absence" of instances within the specimen. For example, the clinician may want to tag instances of good eye contact as well as when eye contact is poor, or when there was no eye contact. Hence, they would like to tag what the child did not do but also what child was able to do. They want to see both sides to determine how atypical the behavior is. In addition, these two clinicians suggested that instead of directly (automatically) filling out the DSM checklist (see Appendix E for details) in the course of tagging a video, they would tag the video first, and then later, based on tag summary, and any follow up with the parent (if required), they would like to manually fill out the DSM checklist.

Design recommendations related to assessment: 1*) incorporate tags representing both presence and absence of behaviors; 2) support clinicians' decision-making through built-in tag list and auto mapping of assigned tag to its assessment criteria; and 3) give clinicians control over final decision-making in the final assessment.*

3.5.6 Barriers to adoption

All participant clinicians and parents reported that they would be motivated to use this system. However, participants also highlighted potential barriers to the adoption of such a technology.

<u>System complexity</u>

All parents and clinicians highlighted that the system should be simple and easy to use. As stated by a participant clinician:

C8-Needs Analysis "it should be easier to use…because, in the heat of a moment, when the kid is acting up and you wanna record something you don't want it to be complicated anyway."

Privacy concerns

A common notion is that there would be high privacy concerns with respect to in-home video recording and sharing. However, when parents in our studies were asked about their privacy concerns, they were less reluctant than would be expected. I found a number of reasons that reduce parents' level of privacy concerns, including 1) they feel protected due to various privacy acts in place and hope that clinicians would not misuse health data; 2) they are willing to sacrifice some of their privacy concerns in order to get help with their child's condition; and 3) the system gives explicit control over data sharing (i.e., being able to delete and choose not to share a video on the recording device with the clinicians).

As stated by a parent: *P4-NeedsAnalysis "Yeah .I mean that's the only way the child going to get the help they need...I'm saying just let it go. That's the way I feel about it."*

Reactivity

Parents and clinicians raised a concern about the possible reactivity of the child to the recording device. Clinicians also mentioned the possibility of parents' reactivity due to recording and being observed by clinicians. In this context, reactivity refers to a person changing their behavior simply due to their awareness of being observed. Minimizing reactivity is critical for a home-based capture and access system, as it may alter the child behavior and hence would restrict clinicians' ability to see the natural occurrence of behavior. In my discussions with parents and clinicians I found that although reactivity is a major concern and may affect validity of the in-home behavior specimen, it does not necessarily always make a video specimen invalid. Children may get used to the camera over time, and a camera may not necessarily be more distracting than other items

typically present during a clinical assessment such as toys, etc. One of the participant clinicians mentioned:

C6-NeedsAnalysis"Some kids don't notice the camera at all. Other kids are very, very, distracted by it. One kid I saw would peekaboo with himself because he could see himself in the camera And he was actually still responding to what the therapist was trying to get him to do, but he was also distracted by it. But I'll also say he's usually distracted when I'm there as he wants to play, so I don't know that a video camera is more or less distracting than an actual person – depending on the kid. And that's the only way to observe, is if either me or a video camera are there."

However, the form factor of recording devices can influence the level of a child's reactivity. For instance, parents and clinicians mentioned that because the recording application is on a smartphone, it can introduce as well as limit reactivity.

Here is an example statement from a clinician about the phone limiting reactivity: *C5-Needs Analysis "I mean iPhones exist in this environment. They're everywhere so I don't think it would be the same as if you have a video camera."* Here is another example statement from clinician about phone introducing reactivity: *C7 –Needs Analysis "It's because I want to play with the phone or I want to play with the iPad that I normally get to play with … and it becomes a toy."*

Other than form factor, parents' strategy for handling recording device can influence the level of the child's reactivity, e.g., parents and clinicians believed that that a mounting device as compared to holding a recording device in hand can reduce chances of reactivity. According to parents and clinicians, when a recording system is mounted somewhere, children will get used to it and will not pay full attention to it after a while. As mentioned by one of the clinicians:

C3-Needs Analysis "one of the things that I like about this that you're proposing is that it would sit in the cradle so it wouldn't be a new thing in the room. It could be something that everybody's always seen in the room. That is definitely a plus."

Design recommendations based on barriers to adoptions: *1) give parents full control on collection and sharing and 2) allow a portable mounting device for mounting the capture system in the environment.*

3.6 Conclusion

Findings from the Needs Analysis study suggest that in-home video recording and sharing of behavior by caregivers for clinical assessment is not a common practice. Though it can be valuable, the complexity of recording and absence of a proper sharing medium makes it less practical and burdensome. This study identified design guidelines for a clinician-directed capture and access system. Key design guidelines are:

- Simplify parents' capture and sharing experience; capture and sharing should be coupled together.
- Allow clinicians to remotely analyze in-home behavior specimens.
- Allow communication between parents and clinicians.
- Allow immediate sharing on the capture system and on-demand access on the access system.
- The design of the capture system should be driven by its access system use case scenario(s).
- To increase clinical usefulness of collected specimens, incorporate the clinician's prescription for capture.
- The prescription should explicitly state the desired content of the video specimen (defined within the context of clinical usage).
- In the access system, incorporate tags representing both presence and absence of behaviors.

- Give clinicians control over final decision-making regarding the final assessment.
- Give parents full control of collection and sharing.
- Include a portable mounting device for mounting the capture system in the environment, which will allow parents to interact and be in the field of view, as well as helping to control the child's reactivity.

CHAPTER 4

ITERATIVE DESIGN OF THE CAPTURE SYSTEM

The initial design of the capture system (described in Chapter 3) was iteratively improved through a usability study conducted with families of children with autism in a home-like laboratory setting. This chapter includes the details of the study and the resulting design of the capture system.

4.1 Capture system usability study design

4.1.1 Goals

The goal was to: 1) iteratively improve and inform the design of the capture system based on findings from a usability study conducted with parents of children with autism in a controlled home-like setting; 2) identify specific features of the capture system that enable parents to *easily* collect videos that have *clinical utility* ; and 3) analyze the usage pattern of the capture system by observing parents using it in a controlled but still home-like setting (e.g., how parents use the capture system, how they carry the capture system while recording and otherwise, how children react to it, etc.). Metrics for ease of use and clinical utility are defined in Table 5, 11 and 6 respectively.

Overall, the usability study enabled us to iteratively modify and verify that the capture system is easy to use for parents and facilitates collection of clinically meaningful behavior specimens prior to its deployment and evaluation in actual homes of children with autism.

4.1.2 Participants

Participants in this study were parents accompanied by at least two children under 10 years of age, one of whom was diagnosed with autism or a related condition. Four

families participated in each of the two phases of the study. Across the two phases, a total of 7 families participated, including 8 parents (one family included both parents), 8 children with autism (average age 4.7 years), and 12 siblings. F1 was the only participant family asked to participate in both phases, in order to get comparative feedback on capture system improvements from phase-I to phase-II. Table 4 describes participants' demographics.

Table 4: Capture system usability study phase I & II – Participants' demographics

#	Phase	Parents			Participant children with autism & sibling
		Parents	Age range	Ethnicity	
F1	Phase 1& II	Mother	35-44yrs	African American	Child with autism diagnosis (3yrs old male) and 1 twin sibling (3yrs)
F2	Phase-I	Mother, Father	25-34yrs	African American	Child with autism diagnosis (5yrs old female) and 3 sibling (1-7yrs)
F3		Mother	35-44yrs	African American	Child with autism diagnosis (6yrs old male) and 2 sibling (9-12yrs)
F4		Mother	45-54yrs	Hispanic/ Latino	Child with autism diagnosis (5yrs old male) and 1 sibling (7yrs)
F5	Phase-II	Mother	25-34yrs	African American	Child with autism diagnosis (6yrs old male) and 2 sibling (8-12yrs)
F6		Mother	25-34yrs	African American	Child with autism diagnosis (4yrs old female) and 1 sibling (9yrs)
F7		Mother	25-34yrs	Asian	Child with autism diagnosis (5yrs old male) and 1 sibling (3yrs)

4.1.3 Method

This study was conducted in the Aware Home, a living lab facility at Georgia Tech, in order to evaluate the usability of the capture system in a controlled but home-like environment. During the study, participant families were asked to use the capture system to record four videos of their child over a two hour period while engaging in prescribed everyday activities like snack time and play.

In the Aware Home, fixed ceiling cameras were installed in the living area and in the kitchen (see Figure 4) and connected to a computer in a different room. This way, we were able to see a live view of the parents using the capture system while observing from

a different room. The live view enabled us to watch in real time how parents capture activities and the challenges they face without causing interference. This avoided any possible reactivity on the child's or parent's part due to our presence at the time of capture system use. In addition to the live view, video was recorded from the fixed ceiling cameras for retrospective analysis.

Figure 4: Ceiling cameras view in the capture system usability study

As mentioned earlier, this was a two-phase study, with four families participating in each phase. In phase-I, the initial prototype of the capture system (discussed in Chapter 3) was used by the parents for recording. In phase-II, a revised capture system, informed by the usability findings of phase-I, was used and evaluated. Furthermore, in phase-II notification containing additional recording instructions was sent to the capture system while parents were in the midst of the recordings. This feature was added in order to mimic and evaluate a key functionality of the final capture and access system, namely the ability of clinicians to send notifications to parents though the web-based access system to guide them during the specimen collection phase. At the beginning of the session parents were informed that they may or may not receive such notifications on the capture device. The same notification was sent to all four families in phase-II, and consisted of an instruction to improve the lighting conditions in the room by closing the blinds. This notification thus included an observable act that could be verified by reviewing the recording from the ceiling. For both phases of the study, each two-hour session consisted of the following steps:

Step 1: Pre-questionnaire

Each of the participant parents were asked to fill out a pre-questionnaire. This questionnaire was similar to the one used in the Needs Analysis study (described in Chapter 3), and covered questions such as the demographics of participant parents and their children, and current practices and challenges with respect to in-home behavior recording and sharing.

Step 2: Tutorial

In phase-I, at the beginning of the study session the participants watched a 3-minute video tutorial (presented on a laptop) on what/how to record. In phase-II, families did not watch this initial tutorial but were given a deployment kit (see Figure 5) containing the capture system, a mounting device, and a sheet describing how to turn on the device (smartphone) and login. Upon logging in the participants could watch a two-minute video tutorial, launched automatically, that described what to record and how to record. The procedure in phase-II was intended to mimic the procedures that would be followed in the real-world deployment of the system in families' homes.

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Figure 5: Capture system deployment kit.

Included in the kit are a) iPod with capture system application, b) iPod charger, c) iPod mounting device, and d) printed instructions sheet.

Step 3: Recording tasks and notifications

The four recording scenarios were previously determined by a collaborating clinician, based on his previous research on the effectiveness of the Naturalistic

Observation Diagnostic Assessment (NODA) scenarios for diagnostic assessment [35]. These scenarios had also been discussed with the clinicians in the Needs Analysis study, who confirmed that these scenarios would be valuable and reflect common activities that a clinician may wish to observe the child participating in. These scenarios include: 1) child playing alone, 2) the child playing with the sibling, 3) family meal time, and 4) a parent concern. During the usability study, parents were asked to record these scenarios in any order they wished, within the living area and the kitchen at the Aware Home. Both areas were staged prior to the parents' visit to the Aware Home (see Figure 6). Toys were placed on the floor in the living area, and food was placed on kitchen counters and in the fridge so parents could serve it during the "family meal time" recording task. This allowed us to analyze how parents multitask (e.g., using capture system while at the same time arranging food on the table), something they frequently do at home.

Figure 6a. Toys were placed in the living areas.

Figure 6b. Food in fridge for family meal time task

Figure 6c. Food on counter top for family meal time task

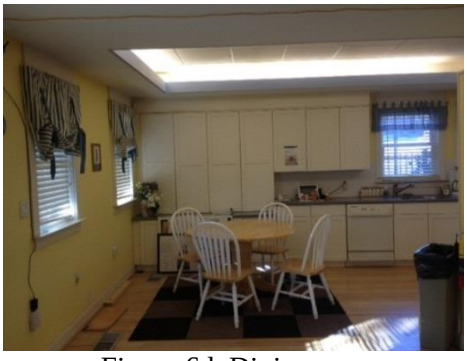


Figure 6d. Dining area

Figure 6: Aware Home setup for the capture system usability study

Step 4: Follow-up questionnaire and semi-structured interview

Once parents finished the recording tasks using the capture system, they were asked to fill out a follow-up questionnaire (see Appendix B for detail). It included questions about their experience of using the capture system At the end of the session an audio-recorded semi-structured interview was conducted to discuss issues participants encountered while using the system, and their recommendations for improvements.

4.2 Data Analysis

At the end of each phase, the data collected was subjected to qualitative and quantitative analysis. Data consisted of pre- and follow-up questionnaires, notes and transcription of audio recordings of semi-structured interviews. The video recording from the fixed ceiling cameras showing parents using the capture system as well as specimens recorded by parents using the capture system were also analyzed for understanding patent use of the system. Specimens collected in phase-II were also rated for their potential clinical utility. These ratings of clinical utility were completed by the collaborating clinician, who took into consideration two factors: whether the specimens were of sufficient quality that they would be ready to be reviewed and tagged by a clinician in the access system, and whether any additional specimens would need to be collected.

The specific metrics for assessing ease of use are listed in Tables 5 and 11 for the controlled settings and in-home study respectively, whereas Table 6 lists the metrics for clinical utility measured in the phase-II and in-home study.

4.3 Analysis and findings: usability study phase-I

4.3.1 Ease of use

The table below, (Table 3) shows the exact metric for ease of use. The notification feature was only tested in phase-II, so analysis of notification compliance was only done for phase-II.

Table 5: Phase-I and II: Ease-of-use metric

Ease of use parameters	**Description**
Parent's rating	On a scale of 1 (difficult to use) to 5 (easy to use)
Parent's report	In the follow up interview, parents were asked to reflect on the overall ease of use of the system interface as well as specific steps in the collection procedure (setting up capture system, environment, mounting device, etc.)
Parent's use of the capture system	Analysis of parents' use of the system was done through the ceiling camera how (they carry the capture system while recording and otherwise, how children react to it, etc.).
Additional clarification about interface	Number of times parents asked for additional clarification about the design during the recording tasks
Number of videos collected	Analyzed if number of the videos recorded by the parent are according to the given instructions
Length of videos collected	Analyzed if parent's recorded videos duration is according to the given instructions
Noticing and following notifications (only for phase-II)	Through the ceiling camera it was analyzed whether parents noticed the notification and whether they followed it.

Parent rating and report

Figure 7 shows the ease of use ratings from the follow-up questionnaire for each participant. On average these participants rated the system as a 3 on a scale from 1 (difficult to use) to 5 (easy to use).

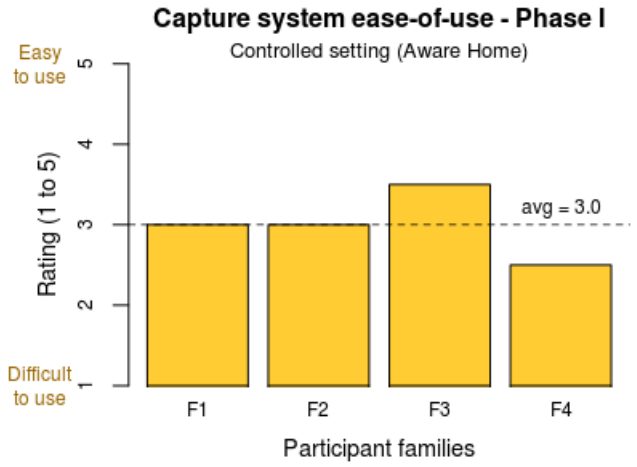


Figure 7: Usability study phase-I: Ease-of-use rating by parents

During the follow-up interview parents also reported that they encountered a number of interface issues while using the capture system. These issues are discussed towards the end of this section.

Number and length of videos recorded

Each family was asked to record 4 videos of NODA scenarios (family meal time, plays with other, play alone and parent concern) with each video at least around 5 minutes long. Analysis of the recorded videos shows that only F1 and F2 recorded all four required scenarios. F3 and F4 recorded five and three videos respectively. In the follow-up interview, F4 explained that it was not clear in the interface how many scenarios had been recorded, so they forgot to record the parent concern scenario. F3 recorded one additional video for 'play with other' since the first video was short in length. F3 reported that, due to confusion about the elapsed time, the video was stopped too soon. The length of the recording also varied across videos, and on average, parents recorded 5.2 minutes (2.3 minutes to 10 minutes) per video. 6 out of 16 videos recorded by all parents were shorter than 5 minutes. During the follow-up interview parents

reported a number of usability issues due to which the number and duration of the recorded videos were not according to the instructions.

Additional clarification about interface

Based on discussion during the follow-up interview, only F1 accessed the help menu on the capture device during the session, specifically the 'how to view a video from the media gallery' item. Participant families were asked to give an indication by signing to the ceiling camera if they encountered a problem that they could not resolve so that we could go to the recording area to help them sort the issue. During the recording session F3 was not sure about the elapsed time and requested help.

4.3.2 Usability issues during phase I

Based on parents' subjective feedback, my observation of the live feed from the ceiling cameras, and analysis of the recorded video specimens, it was clear that parents encountered a number of usability issues during the study. Some of the most frequent issues are listed below:

Issue: Confusion about recording status

Two parents had difficulty with the recording status (recording status, time elapsed) and often went up close to the recording system to check the status (see Figure 8c for an example) and hence the system needed their consistent attention. In the follow-up interview, parents also reported that they would often confirm through the video gallery if the video had indeed been recorded and saved.

.Issue: Difficulty with set up

Parents had difficulty setting up the environment and capture system. In 63% of the videos (10 out of 16), parents started the recording while they were still finalizing the field of view and positioning of the mounting device. Figure 8a shows the beginning of a

scene from a specimen capture where the parent is still setting the view during recording, which adds no extra value to the specimen, occupies more disk space, and will require the clinicians to spend extra time skipping through this portion of the specimen. Also, in 69% of videos (11 out of 16) parents either did not set up a correct field of view (e.g., toys/sibling/parents/child's face not completely in view of the camera) or they did not adjust it during the recording (e.g., child may move in and out of the view). Figure 8b is an example of a family mealtime where the target child's face is not facing the camera. Another common issue was that parents held the camera in their hand, or mounted it, but continued to carry the mounting device in their hand. This had two disadvantages: 1) since parents were holding the recording device, they were not in the field of view, which is critical since clinicians in the needs analysis study stressed that they would like to see parent-child interaction in the video, and 2) the video was shaky because parents were holding the device and moving. Analysis of parents' recorded video specimens and the ceiling cameras' recordings shows that 44% of the recordings (7 out of 16) included parents holding the capture system in their hand (directly or mounted) at some point during recording. Mostly for the parent concern and play alone scenarios parents had the capture system in hand (directly or mounted in the mounting device).

Fig 8(a): Image from meal time specimen video: Difficulty with staging

Fig 8(b): Image from meal time specimen video: Difficulty with staging

Fig 8(c): Image from ceiling camera: Recording status confusion

Figure 8: Challenges faced by parents during usability study phase-I

Issue: Difficulty with remote

All parents had issues with the remote due to a number of reasons. There was no clear feedback on the remote about the video recording initiation and status of the recording, so parents continued to press the remote several times. It was difficult to carry the remote, and one of the parents even lost it. Although the remote could be clipped to clothes, most parents found it difficult to do so. As stated by a participant parent (*P3-AwareHome) "it was very small so hard to manage with kids around."* One parent completely forgot to use the remote. In various instances, children started noticing the remote and would even start playing with it.

Issue: Difficulty in annotating video

The interface of the capture system required parents to select annotations for each specimen before or after it was recorded. These annotations consisted of selecting the activity name from a list (e.g., family meal time), see Figure 9a. Results showed that all families assigned multiple redundant annotations. One key issue was that they failed to uncheck previously selected annotations, despite the fact that directions to do so were given in the introductory tutorial.

4.4 Improved design of Capture system based on usability study phase-I

Below are three key design changes that were implemented to fix the usability issues that parents encountered during phase-I.

4.4.1 Clear representation of prescribed recording scenarios

To resolve the annotation problem, the revised system's home screen has iconic representations and direct mapping of the clinician's prescription (see Figure 9b). The parent can simply select one of the prescribed behavior specimens to start recording it (one-to-one mapping), which eliminates the need for explicitly assigning annotations. As

before, there are four types of prescribed behaviors (based on NODA): (1) the child playing alone, (2) the child playing with the sibling, (3) a family meal time, and (4) a parent concern.

Figure 9a: Capture system initial prototype interface for annotating an activity

Figure 9b: Capture system updated design after phase-I. The collection system home screen is preset with clinician's prescription. Parent can select one of the prescribed behavior specimens to start recording it.

Figure 9: Updated layout for prescribed scenarios

4.4.2 Embedded capture instructions about staging and social presses

To resolve the problem of correctly setting up the environment and capture system and framing the recordings, explicit recording instructions for each scenario were compiled and embedded in the capture system as a clinician's prescription for the parent to follow. Each of the scenarios has its own embedded prescription consisting of two types of instructions: staging and social presses. Staging refers to camera and environment setup: mounting the camera on the tripod ahead of time, making sure the child's face, as well as relevant objects and social partners, are in the field of view of the camera, and suggestions for appropriate items (toys and books) and inappropriate items (toys that make noise) for the play scenarios. Social presses were specific instructions

about the frequency and type of interactions with the target child, such as "Call child's name three times", "Point to object," etc. These instructions were added by the collaborating clinician as these represent the types of "social presses" that clinicians would typically conduct while interacting with the child in person. In the updated design, upon selecting a scenario to record from the main screen, its respective recording instructions (see Figure 10) appear along with a sample image depicting a scene representing the ideal setup. Figure 10 depicts the prescription for the family meal time scenario.

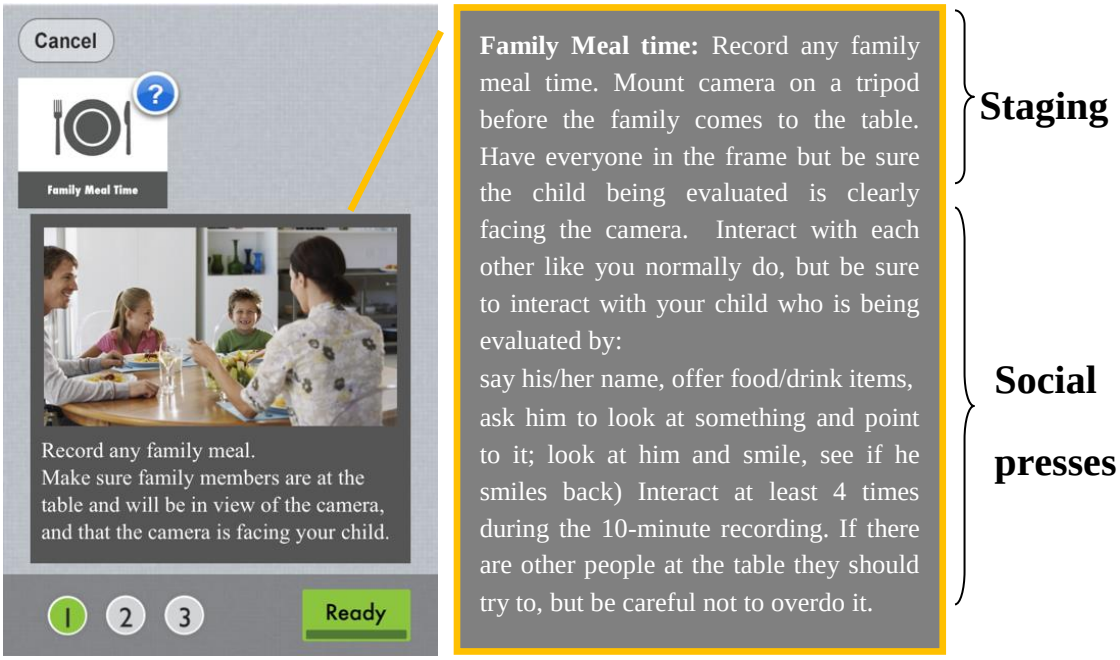


Figure 10a. Updated design of Capture system. Recording instructions appear upon selecting a scenario to record.

Figure 10b. Recording instructions for family meal time.

Figure 10: Embedded recording instructions (embedded prescription)

4.4.3 Explicit recording status

To resolve the ambiguity of the recording status, in the revised design a clear and visible time-elapsed indicator was included (see Figure 11). It serves two purposes. It

indicates that recording has started and it conveys recording status (time elapsed). Additionally, the green box reinforces that video recording is in-progress.

(11a) Initial prototype used in phase-I.

(11b) Revised design after phase-I includes redundant status representation.

Figure 11: Updated recording status indicator

Since parents were having difficulty with the remote, the remote was excluded from the revised design.

4.5 Findings specific to usability study phase-II

During phase-II families used the updated system informed by usability study phase-I findings. Below are findings from phase-II.

4.5.1 Ease of use

Parents rating and report

In the follow-up questionnaire, on average participant parents (n=4) rated the ease of use as 4 on a scale of 1 (difficult to use) to 5 (easy to use). Recall that in phase-I, the average ease-of-use rating was 3. Overall there were minor usability issues with the

revised Capture system, but in general all four parents in phase-II found the revised design of the Capture system easy to use (see Figure 12). F1, who participated in both phases, rated the ease of use of the revised system as 4, compared to their rating for phase-I which was 3. During the follow-up interview families reported that the capture system was easy to use.

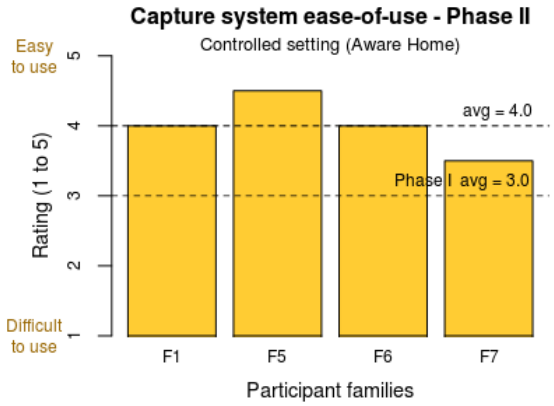


Figure 12: Usability study phase-II: Ease-of-use rating

Number and length of recorded videos

Parents were able to record all scenarios. The average duration of the videos was 5 minutes. Families consistently recorded videos around 5 minutes (as per given instructions).

Additional clarification about interface

During the follow-up interview only one family (F7) indicated accessing the help menu, to clarify confusion between saving a video and sending (uploading it).

Notification noticed and followed

All parents followed the specific instructions about recording that they received through notification features within the Capture system (the instruction was to close the blinds, which could be independently verified through a review of the ceiling camera videos).

Minor usability issues

In the capture system interface a user is required to send video (videos get uploaded to the access system when 'Send' is clicked) once it is saved. However, one participant parent (F7) thought that 'Save' was equivalent to 'Send'. In fact, clicking 'Save' only saved the recording on the Capture device, and did not upload the recording to the Access system. To address this issue, a 'Send' option has been added to the 'Save' option in the message box that appears when a recording is completed. If parents choose to only save a recording, they have an option to 'Send' it (upload it to Access system) later through the home screen. See Figure 13 below for screen shots representing these two steps. The reason for keeping both options of 'Send' and 'Save' in the message at the end of recording was to indirectly reminder the user that these are two different tasks.

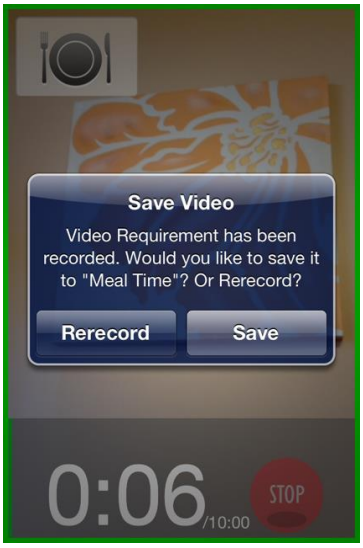


Figure 13(a): earlier interface

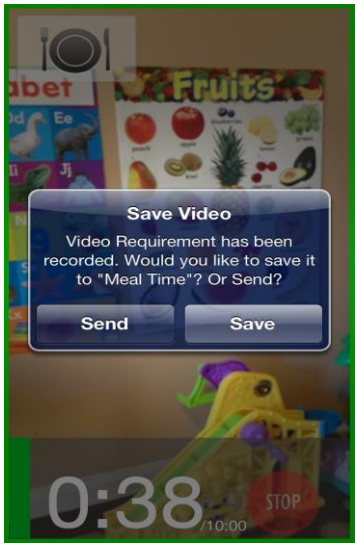


Figure 13(a): Updated interface

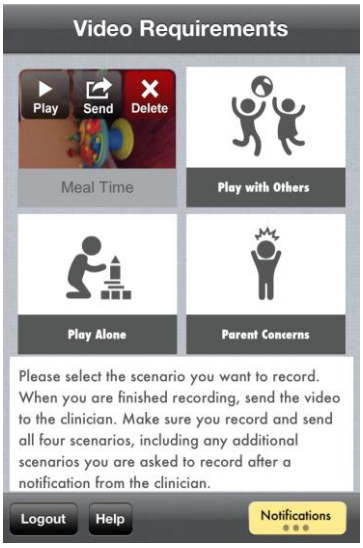


Figure 13(c): Alternative option for sending.

Figure 13: Capture system design improvements: 'Send' vs. 'Save'

4.5.2 Clinical utility of the video specimen

In order to explore the clinical utility of the collected specimens from a clinician's perspective, the collaborating clinician who is an expert in autism (18 years of experience in autism diagnosis), completed a clinical utility questionnaire for each of the videos

recorded by the families in phase-II. The questionnaire for clinical utility that I designed in consultation with a researcher in autism domain is listed below in Table 6.

Table 6: Clinical utility questionnaire

Q1	**Would you consider this video ready to review and tag?** Please check one of the below options and explain your choice. *Option 1: No, I would ask parents to re-record this scenario.* Note: This option should be interpreted as: "The captured video is not useful at all. The clinician would not review and tag it, but would ask the parent to re-record it." *Option 2: Yes, but I would ask the parent for additional recording(s)* Note: This option would be interpreted as "Clinician can go ahead and review and tag the video as there is some relevant content in it. However, the clinician may also ask the parent for additional recording(s) of either the same or different scenario(s)". *Option 3: Yes. There is no need for additional recording related to this scenario.* Note: This would mean that the captured video is good, includes all required content, and the clinician would go ahead and review and tag it without requesting any additional recordings related to this scenario.
Q2	**Did parents capture this video as per given recording instructions?**
Q3	**What sort of notifications if any would you like to send to the parents after watching this video?**
Q4	**Are there additional videos that you would have wanted the parents to record?**

Question 1 in the above clinical utility questionnaire for a given video can be interpreted as a) this video has behaviors that are useful to tag b) this video has enough behaviors to tag for the associated scenario. Option 1 represents situation when both 'a' and 'b' are false. Option 2 represents situation when 'a' is true and 'b' is false. Option 2 represents ideal situation when both 'a' and 'b' are true. Table 6 below explains this interpretation of question 1 (Would you (clinician) consider this video ready to review and tag?).

Table 7: Clinical utility rating interpretation

	This video has behaviors that are useful to tag.	**This video has enough behaviors to tag for the associated scenario.**
Option 1 (not useful and would need to be re-recorded)	True	False
Option 2 (useful sample but would need additional recording)	True	False
Option 3 (useful and no need for additional recording)	True	True

Detailed analysis of the collaborator clinician's ratings on the clinical utility questionnaire (listed in Table 4) shows that out of a total of 16 videos collected by four families (four scenarios per family), 31% of videos were assigned a rating of 3 (good and sufficient sample), 50% of videos were assigned a rating of 2 (good sample and could be used for clinical assessment, but parents would be asked for additional video as well) and only 19% of videos were assigned a rating of 1 (not a good sample; would not be useful for assessment and would need to be rerecorded).

Further analysis of the clinician's feedback shows that there are a number of factors that the clinician identified as major reasons for assigning a video rating of 2 (good sample but would ask for additional samples) or 1 (not a good sample and would need rerecording). These factors that reduce the clinical utility, listed in Table 8, can be divided into two categories: 1) Factors related to the staging of the environment (with toys and other props) and the capture system (field of view, in hand vs. on stand, etc.), and 2) factors relating to parents' or siblings' interactions with child (e.g., name call, pointing). In the case of staging, the most common problem across all videos was 'incorrect field of view,' whereas in the case of social presses, the most common problem was an imbalance in the level of interaction by parents. In some cases parents would interrupt and insert themselves into the interaction far more than the instructions called

for. According to the collaborating clinician, if parents dominate the interaction then it would be hard for the clinicians to assess the child's social and communication skills. At the same time, in some videos parents did not present enough of the social presses that clinicians would like to see in order to understand the child's behaviors sufficiently.

Analysis of these problem factors separately for each scenario (see Table 9) shows that the most frequent problem factor during the mealtime scenario is that there is too much interference from parents. Ideally the clinician wanted to see how the child follows directions when the interaction is guided by the parents, but also how the child interacts with less guidance by parents. In the case of the play alone scenario, the most frequent problem factor was that parents were overdoing the interaction and would dominate the play sessions. In the case of the play with others scenario, "not enough interactions by parents or sibling" as well as "holding camera in hand instead of using stand" contributed to reduced quality of videos from the clinical perspective. In the case of the parent concern scenario, since parents have an option to record any behavior of concern, it was difficult for the clinician to clearly understand what parents wanted to show without knowing any context or description from parents. This problem is unique to the parent concern scenario, since in all other scenarios clinicians know the context in advance. This was one of the reasons why two of the three videos rated as 1 (not useful and rerecording needed) were of the parent concern scenario.

Table 8: Factors that influence the clinical utility of specimens

Issues relating to staging	
Field of view issues (narrow field of view, Child's face not in the view, Parents/sibling/toys not in the view all the time)	10
Camera not mounted and in hand	3
Camera not set beforehand	2
Toys scattered and not in one place	1
Total staging related issues	***16***
Issues relating to social presses	
Too much interference by parents	6

	Not much social presses by parents	5
	Too much interference by siblings	3
	Missing context for Parent concern (so difficult to understand what is their concern)	4
	Total social presses related issues	***17***

Table 9: Scenario-based analysis of factors influencing clinical validity

	Family Meal time	Play alone	Play with Others	Parents' concern
P1	Option 2	Option 1	Option 2	Option 2
P2	Option 2	Option 2	Option 2	Option 1
P3	Option 2	Option 2	Option 3	Option 1
P4	Option 3	Option 3	Option 3	Option 3

Option 3 (good specimen and enough evidence), option 2 (good specimen but need additional evidence), option 1 (not good sample and should be re-recorded).

Overall, based on collaborating clinician rating, 81% (31% option 3 and 50% option 2) of videos collected in the usability study phase-II were valuable for clinical assessment. Below are some example statements from the collaborating clinician about the usefulness of specimens: *"Good video… lots of behaviors are obvious.", "Good vide! good opportunity to judge language, play, interaction, etc."*

For one of the participant children (family F4) all videos were assigned option 3 (good and enough samples) and hence gave the clinician sufficient evidence of the child's behavior to proceed with an assessment. As stated by the clinician: "I would suspect that this video (parent concern videos of F4) in combination with the other 3 videos (meal time, play alone and play with other of F4) would be enough to diagnose."

4.6 Improved design of Capture system based on usability study phase-II

Based on the findings from the clinical utility analysis, the instructions embedded within the Capture system were revised to address some of the factors summarized in Table 8. Major revisions included clearer instructions about the initial setup and the recording and required field of view for each scenario. A sample image depicting the scenario was included in the instructions so that parents can get a clear idea of the optimal scene and field of view. Specific instructions about the extent/frequency of interaction with the child for each scenario were compiled. For example, for the play alone scenario, parents were asked to interact with the child and then after two minutes withdraw and let the child play alone. For all scenarios except parent concern, parents were asked to mount the capture system on a tripod in the environment. In the case of parent concern, since it is less predictable than the other scenarios in terms of timing and how it occurs (e.g., child might be running or moving, etc.), allowing the parent to hold the capture device in hand would allow parents to follow the child if required. For the parent concern scenario, the instructions now ask that the parent explicitly state at the beginning of the recording what their concern is.

The complete set of revised recording instructions is listed in Appendix C. In addition to these major changes, there were a few minor interface updates such as including the ‘send’ option in addition to the ‘save’ option in the message box that appears when recording ends (the rationale for this was discussed in previous section).

4.7 Quantitative feedback on behavior specimen collection

4.7.1 Value of behavior specimen collection

The usability study helped to validate some of the findings from the Needs Analysis study. Since all parents in the usability study were also parents of children with

autism, they gave extensive feedback about the potential value of a clinician-directed capture and access system for diagnostic assessment of autism.

Like parents in Needs Analysis study (described in Chapter 3), most parents in the usability study (6 out of 7) reported that even though they do not regularly record and share video evidence, they found the concept of in-home behavior specimen collection extremely valuable. As stated by one parent:

P1-AwareHome:" I really think that it may have been more helpful with the whole process of him being diagnosed. When he is at the doctor's he is much more compliant. I kinda wish I could have this system to show doctors his behaviors. One doctor, she just didn't see his behavior and I wish I could have showed her some things like videos recorded… 'Cause it was almost as if she felt like we were maybe over looking into. I wish I would have had this system.".

One parent (F4) in the capture system usability study phase-I mentioned that she uses two behavior tracking apps on her iPhone to record her child's behaviors and intake every day. She also frequently shares this information with her child's psychologist, developmental pediatrician and neurologist. One of the key reasons reported by this parent is that she records and shares video evidence of her child's behaviors with clinicians to make sure her child is not experiencing any seizure episodes.

P4-AwareHome "Video recording has helped me with the epilepsy because I can record and share its videos with neurologist for consultancy. One thing is talking and describing, but another one is looking at the actual video where they can see everything that I might miss."

Unless there is a strong motivation like in the case of participant P4 of the usability study phase-I, parents do not often record and share video evidence due to the complexities mentioned in section 3.5.1.

4.7.2 Reactivity

As discussed earlier during the Needs Analysis study, parents and clinicians raised a concern about the possible reactivity in the child behavior due to the recording device. During both usability studies there were cases when children (the target child with diagnosis as well as a sibling) noticed the recording device. Figure 14 illustrates some examples of such reactivity. The first picture in Figure 14 is from a ceiling camera and the remaining are from specimens collected through the capture system. However, in agreement with the parents' and clinicians' report in the Needs Analysis study, during the usability study children paid less attention to the recording device when it was mounted in the environment than when parents carried it in their hand during the recording.

Figure 14: Reactivity during collection system usability study

4.8 Conclusion

A usability study was conducted in a controlled home-like setting to iteratively improve the design of the capture system and to get it ready for the in-home evaluation (described in Chapter 7). This study in the control setting has helped in identifying features that contributes towards the ease of use of the capture system and the higher clinical utility of the collected behavior specimens. An easy to use of the capture system is critical since the complexity of capture and access was one of the fundamental reasons (highlighted in the needs analysis study) that restrict parents from collecting and sharing in-home video specimens.

In order to achieve higher clinical utility of the collected behavior specimens, clinical prescriptions are embedded in the capture system. This study in the controlled setting helped in systematically understanding factors (related to the staging and social presses) that effect the clinical utility and hence helped in iteratively improve embedded clinical prescriptions based on it.

CHAPTER 5

CAPTURE SYSTEM IN-HOME EVALUATION

This chapter includes details of the evaluation of the final updated design of the capture system in natural settings (in-home with parents).

5.1 Goals

The goals of this study were to: 1) evaluate whether parents in their own homes can *easily* (define in Table 11) record prescribed behavior specimens through the capture system that have *clinical utility* (defined in Table 6 in the previous chapter); 2) investigate features that contribute to ease of use, and factors that affect the clinical utility of a recorded video; and 3) identify the limitations of the capture system and make *recommendations* for further improvements based on parents' feedback.

Behavior specimens collected through the capture system in this study were used by clinicians in the access system evaluation study (described in Chapter 7) to conduct diagnostic assessment for autism.

5.2 Participants

For this study, five families were recruited through word of mouth and by distributing pamphlets at local autism centers and inclusion schools. Four of these families had a child with autism with different levels of functioning: low, moderate and high. These levels were based on the report from the child's previous in-person diagnostic assessment, and generally reflected the child's cognitive and language level, as well as the severity of the child's autism symptoms. This recruitment criterion was imposed so that we could ultimately analyze whether the access system facilitates diagnostic assessments for children with different levels of functioning (as described in

the next chapter). We also recruited one family with a typically developing child so that we could ultimately confirm that the access system supports clinicians in determining that diagnostic criteria for autism have not been met (details presented in the next chapter). All children were between 2 and 5 years of age (average = 4 years). Table 7 describes the participant families' demographic information.

Table 10: Capture system in-home evaluations: Participants' demographics

#	**Parents**		**Participant children and their sibling**		
	Participant	Ethnicity	Child's age/gender	Child's previous diagnosis/profile	Sibling Age/gender
F1	Father	White	2yrs & 5mons female	Autism (PDD-NOS): High functioning (verbal, stronger skill sets)	5yrs old brother (PDD-NOS)
F2	Mother	Arab	3yrs & 2mons female	Autism (Autistic disorder): High functioning (verbal, strong skill sets)	None
F3	Mother	African American	2yrs & 10mons male	Autism (Autistic disorder): low functioning, non-verbal , moderate hearing loss , feeding issues	None
F4	Mother	African American	3yrs & 9mons male	Autism (Autistic disorder): moderate skills, speech delay	5yrs old sister
F5	Mother	African American	2yrs & 4mons female	Typically developing	None

5.3 Method

As in the usability study phase-II, families were not given any training and were simply given a deployment kit containing an iPod with capture system installed; an iPod charger and a portable mounting device (see Figure 4 in Chapter 4). The deployment kit also included printed recording instructions (the same instructions were also embedded in the capture system application) and a "quick-start" sheet that included instructions such as login information and a reminder to charge the capture system. At first login, the capture system launched a video tutorial of what to record and how to record. Families were asked to record the same four scenarios as in the usability study (family meal time, play with others, play alone and parent concern), though this time in their homes. On

average, families took two weeks to complete the collection of in-home behavior specimens using the capture system. Due to an upload bug during the deployment, families had the systems for a longer time than expected.

During the deployment, the first step for a family was to fill out a web-based registration form and a child developmental history form. The developmental history form included five questions about the child's early developmental milestones and medical conditions (see Appendix D). The next step was to record all four scenarios and follow any additional instructions if they received any from the clinician. Families were informed that they may or may not receive additional instructions from the clinician asking them to record additional videos.

The collaborating clinician guided parents through the in-home video specimen collection process. He reviewed each video uploaded by a family and decided whether it was good enough to conduct an assessment, or whether the family should re-record the scenario. For the first family, the collaborating clinician sent such notifications using the one-way notification feature built into the access system. These notifications appeared as alerts within the capture system. Upon completing the first family, the clinician requested the option of two-way communication with parents. Due to the considerable amount of time and development effort that would be required to implement a two-way communication feature within the capture system application, this was accomplished by setting up a dedicated email account on the capture system before deploying it to each of the remaining four families. The email was set up as an alert so that families would immediately notice when the clinician had sent them an email. This workaround enabled us to qualitatively and quantitatively analyze if and when parents would communicate to the clinician and for what purpose.

Once families collected all specimens according to the given specifications, the deployment kit was collected and a follow-up questionnaire and semi-structured

interview were conducted to solicit parents' feedback about their experience using the capture system. In addition, the collaborating clinician who had guided the parents' capture was asked to fill out the clinical utility questionnaire (described in the previous chapter in Table 6) for each video specimen collected by parents, as had been done in the usability study phase-II. In the questionnaire, the clinician was asked to rate the clinical utility of each of the collected videos and list any factors that reduced the quality of the video.

During the in-home deployment, an activity log of the capture system was automatically generated and stored on a server, which could then be accessed through a web service. The activity log was implemented to track each user's actions on the capture system when used in the actual home (previously in the controlled setting it was analyzed through the ceiling cameras). The activity log was also used to monitor system stability during the in-home capture process.

The capture system design evaluated in the in-home study is listed in Appendix G.

5.4 Data Analysis

Data collected from the capture system evaluation in homes was subjected to qualitative and quantitative data analysis. Data used in the analysis was included from the activity log of the capture system, videos collected by parents, the video quality questionnaire from clinicians, email log, notifications log, follow-up questionnaires, and a semi-structured interview with parents.

The focus of the analysis was on the ease-of-use of the capture system and the clinical utility of the recorded specimens, as defined in Tables 6 and 11 respectively.

5.5 Analysis and findings

5.5.1 Ease of use

The table below was used to measure ease of use of the capture system.

Table 11: In-home evaluation of capture system: Ease-of-use metric

Ease-of-use parameters	Description
Parent's rating	On a scale of 1 (difficult to use) to 5 (easy to use)
Parent's report	In the follow up interview, parents were asked to reflect on the overall ease-of-use of the system interface as well as specific steps in the collection procedure (setting up capture system, environment, mounting device, etc.)
Parent's use of the capture system	Analysis of parent use of the system was done through the capture system activity log.
Number of videos collected	Number of specimen collected as per instructions/ prescription
Length of videos collected	Duration of specimen collected as per instructions/prescription
Noticing and following notifications/emails	Analyzed through the activity log of capture and access system as well as through email records.
Access to help menu	Analysis of log activity to analyze how frequently the help menu was accessed
Ease of work flow for starting recording	Analysis of log activity to determine % of time parents followed shortest work flow from selection of a recording scenario to starting the recording (in least possible steps)

Parent's rating

Parents rated the ease of use of the system on average as 4 on a scale from 1 (not easy to use) to 5 (very easy to use). Figure 15 shows the individual ratings from each of the five families. Ease-of-use ranking by parents in the in-home study is comparable to what we observed in phase-II of the usability study. There were no major improvements in the interface design from phase-II of the usability study to the in-home study, so we expected ease-of use rankings to be same. Nevertheless, it was reassuring that parents using the system in the course of their day-to-day lives and over a two-week period found the system as easy to use as parents who had used it in a controlled setting over just a two-hour period.

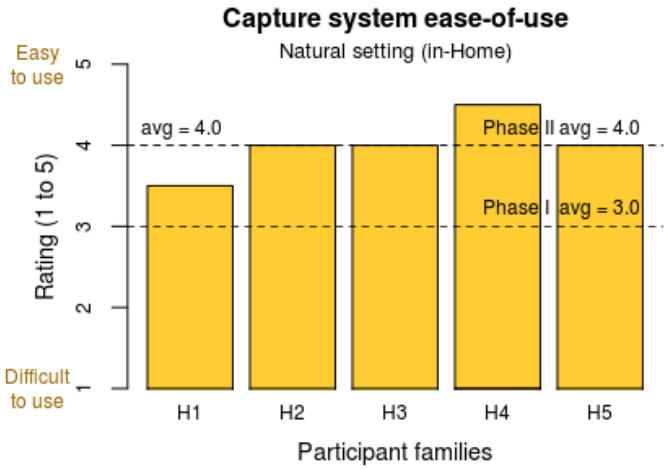


Figure 15: Capture system in-home evaluation: Ease-of-use ratings

Video collected

During the access system in-home evaluation parents collected 27 videos. Table 12, below, shows the details of the number of videos captured by each family for each scenario. During the in-home behavior specimen collection process the collaborating clinician guided the capture by sending notifications (in case of F1) and emails (the remaining four families). The collaborating clinician asked some families to rerecord, therefore there were, in total, 27 videos instead of 20 (4 videos per family-one for each of the scenarios). Analysis of the notification and email messages shows that there were few issues due to which the collaborating clinician asked for recordings. Some examples of these issues are: the child's face was not in the camera view, clinicians wanted parents to introduce social presses such as offering a toy and holding it at a distance so that child would request it, background music being too loud, etc. However, two families out of five collected all good videos in their first attempt without any additional guidance (notification/alert) from the clinician.

Table 12: Capture system in-home evaluations: Video specimens collected

	#Family Meal time videos	#Play with others videos	#Play alone Videos	#Parent concern videos	Total video / family
H1	3	2	2	1	8
H2	1	2	1	2	6
H3	1	1	1	2	5
H4	1	1	1	1	4
H5	1	1	1	1	4
Total	7	7	6	7	27

Subjective feedback from the follow-up interview

In the follow-up interview parents reported that the capture system interface was intuitive and easy to use. They particularly liked the fact that the system requires only three clicks from selecting a record scenario to completing a recording. Parents did not report any problems with interpreting the recording status of the system. One improvement suggested by two of the parents was that reading the recording instructions requires too much attention, so perhaps the system could have audio narration or video depiction of what is required instead of a written prescription within the system.

Log analysis of help access and workflow patterns

Analysis of the capture system's activity log indicated that parents did not rely much on the 'help' feature within the capture system. During the deployment, two families out of five accessed the help menu, one and two times respectively. None of the remaining three parents accessed the help menu. Because there was no in-person training and parents got a deployment kit and had to figure out what to record and how to record though the startup tutorial, infrequent use of the 'help' feature indicates that parents can use the capture system independently. In addition, analysis of the log of the workflow that parents followed showed that parents clearly followed the correct steps, from selecting a scenario to record, to starting record and then stopping it. Analysis of the log shows that on average, 73% of the time the shortest path was taken from scenario

selection to the 'start recording' option (least number of steps-> Step1: select scenario, Step 2: press 'Next' to proceed to embedded instructions screen, Step 3: press 'Start recording' button). Since there could be reasons other than complexity of the system that can contribute to stopping a recording and not completing it, analysis of the workflow focus only on scenario selection to starting a recording.

Completion of prescription

Without any training about the use of the capture system or discussion about the recording scenarios, all parents were able to record all four scenarios after watching a startup video on the capture system. All families were able to follow the clinician's instructions if given to them either through the notification feature (in the case of one family) or through the email account (in the case of the remaining four families).

Guided capture

Across the five families, parents recorded a total of 27 videos (see Table 8). Two of the families (H4 and H5), recorded a good example of each scenario on their first attempt and the clinician did not ask for additional videos. The remaining three families received a total of 10 notifications/emails from the clinician. 6 of these notifications/emails were about instructions to improve recording and 4 messages were regarding status of recording (e.g., clinician will ask if parents recorded more videos, etc.).

5.5.2. Clinical utility of the in-home behavior specimen

Like usability study phase-II, the clinical utility of the video specimens collected was determined by the collaborating clinician, based on the scale included in Table 6. In total, five families collected 27 video specimens. Analysis of the video quality questionnaire indicates that, out of the total of 27 videos, 26 (96%) were assigned option

2 and 3, with 76% assigned option 3 (good enough sample) and 20% assigned option 2 (good but requires more evidence). In the case of the usability study phase-II, clinical utility was 81% (31% option 3, and 50% option 2). So there was a substantial improvement in the clinical utility of the collected video in the in-home study, in which not only more good videos were collected but also the percentage of the highest scored videos increased from 31% to 76%.

The clinician assigned option 1 (not a good sample since the child's face was not in the camera view) to only one of the videos collected in the in-home study. Out of the 27 videos, the collaborating clinician recommended 24 videos for conducting diagnostic assessment for autism (during the access system evaluation by clinicians described in the next chapter). Among the three discarded videos, one was discarded since it was not a good sample (assigned option 1). The remaining two, although assigned option 2, were still discarded. In one of the videos the parent wanted to show the child ignoring instructions to take a shower (in the video the child was fully dressed and did not take a shower, but the collaborating clinician still chose to discard the video). In the second video the collaborating clinician felt its contents were captured in the subsequent video that parents collected based on his request.

In order to further validate the clinical relevance of parent-collected videos, clinicians in the access system evaluation (described in next chapter) were asked to rate the usefulness (1-not useful to 5-very useful) of videos for diagnostic assessment after they conducted diagnostic assessment based on these videos. On average, clinicians rated these videos as 4. Details about clinicians' feedback about the quality of videos for diagnosis are mentioned in Chapter 7.

At the end of this study the embedded text-based prescription was converted to video-based prescription, where actors were asked to introduce social presses while interacting with the child actor, and also staging was demonstrated in the video as well.

Parents in the controlled study, as well as the in-home study, suggested that a video-based prescription would be more useful, since visuals will give them a good idea about setup (field of view, etc.) as well as social presses.

5.5.3. Parent-clinician communication

The activity log of the capture system and the email record shows that parents were able to notice and follow clinicians' instructions given to them through either the notification feature or email alerts. However, parents found it cumbersome to check for new notifications multiple times a day. Two of the parents suggested that they should receive notifications on their personal phone for ease of tracking new notifications and timely response to clinician's instructions. Additionally, parents expressed a desire for a quicker response (at least within 24 hours) from the clinician if the videos they uploaded are of good quality and sufficient, so that they feel connected to the clinician and can finish the collection in a timely manner.

One important question during the design process was about the potential value of the two-way communication between parents and clinicians. Our assumption was that parents might ask clinicians questions to clarify the instructions given in the notification. One concern was that parents might ask too many questions to clinicians, and as a result the two-way communication would place an undue burden on the clinician. Results from the study show that although all families noticed and acted on the notifications or email instructions from the clinician, only one family (out of four that were provided the two-way messaging capability) communicated back to the clinician, and did so on two different occasions. These messages were only confirmatory messages acknowledging that they received the clinician's notification or uploaded a requested video, rather than questions about the notification. However, the clinicians in the access system evaluation (described in the next chapter) considered two-way communication would essentially be extremely be helpful for clinicians to get parents' response to specific questions about the

child's developmental history and/or to clarify clinicians' queries about a certain video observation.

5.5.4. Analysis of time spend on active collection of behavior specimens

On average, families had the capture system for two weeks in their homes. Due to technology issues (mainly issues with upload) the system was collected back from two families for bug fixing and was returned afterwards. For one family, troubleshooting was done remotely to fix a capture system bug. These issues halted the collection process, which meant that the collaborating clinician was not able to send timely feedback, since videos were not uploaded successfully in the access system. Two families who did not face technology issues completed video specimen collection within 4 days. If we eliminate the time wasted due to bug fixing, then on average it took families four and half days to complete data collection tasks. This includes getting the deployment kit, filling child developmental history in the online system, collecting all scenarios and then following clinicians notification/email message if they received any and finally returning the deployment kit when indicated by clinicians that sufficient specimens have been collected. During the data collection period on average the clinician was able to respond back to the family on the quality of the shared videos within two-and-a-half days (eliminating time wasted on technology issues and a time period of a week when the clinician was away for a conference).

5.5.5 Quantitative feedback on behavior specimen collection and assessment procedure

Like parents in the Needs Analysis study and usability study phase-I and phase-II, parents in the capture system in-home evaluation found the in-home behavior specimen collection system useful since it enabled them to share their child's behavior in the natural environment with the clinician. Parents highlighted that since the clinician can

observe their child within the home context, they could perhaps also guide parents about how to provide intervention within the home environment.

Out of five families, three indicated that they had to wait for more than six months to get a diagnosis for their child due to delays in scheduling diagnostic assessment and long waiting lists. One of these three families had to pay out of pocket to get a diagnosis earlier than the scheduled date so that they could start interventions (insurance requires diagnosis before approving intervention services). They liked the fact that such a system has the potential for getting a quicker diagnosis, which may not be comprehensive, but would help them in getting intervention services on time. However, parents indicated a concern about not being able to directly communicate with the clinician. They suggested that after a clinician completed the assessment, either the clinician or some other qualified provider should discuss assessment outcomes with parents (in-person or on the phone) instead of just sending them the formal assessment report.

In addition, three of the five parents reported that their children noticed the recording device. However, in agreement with the families from the usability studies, they highlighted that children get used to the recording device after a while, especially when it is mounted somewhere in the environment rather the held by the parent.

Parents also reported a few concerns about the system and the overall approach. First, they mentioned that the scenarios did not involve their child interacting with strangers or peers. Parents wanted to show these types of interactions since their child not being social with strangers and peers was often one of their main concerns. We should note that the restriction of the play with others scenario to play with siblings or parents was only a limitation in the context of this research study because otherwise we would have had to obtain consent from any non-family members who would be captured in the videos. Future clinical applications of our system would certainly involve parents being able to include peers or strangers in their play with others scenario recording.

The second concern expressed by parents was that the prescription may impact the natural context. Two parents found that some of the recording instructions would make a given situation less natural for a child. For instance, one child would only eat in a high chair, due to feeding issues, and was fed by the mother separately from the rest of the family. Having child eat with family at a dining table would not be true reflection of the child's feeding time. Similarly, a parent concern for one of the parents was the child running across the room, but the parent felt it was impossible to mount the device as suggested because that would require the child to stay within a specified area and would affect the natural expression of the child's behavior. Another parent felt he had to first completely clean a room filled with toys in order to follow the prescription for play alone, which indicated that the setup should include just a few toys on the floor. According to the parents, such changes in the home environment make the resulting recorded behavior less naturalistic.

However, such concerns can be alleviated to a certain extent by a transparent prescription where the key purpose of the setup (staging and social presses) is made clear to parents so that they can adjust it to their daily routine without affecting its clinical utility or naturalness. For instance, in the case of the child who had feeding problems, parents recorded their daily feeding session of the mother feeding the child (not a family meal time) but clinicians found it extremely useful for diagnostic assessment. Instead of recording a family mealtime as prescribed, the parent recorded a routine feeding session because she wanted to show the child's behavior in its natural context. The clinician found the specimen to be valid and useful since it was a natural context and the parent did follow the instruction to include several social presses during the recording. In such cases clinicians are also open to some modification to the prescription. Furthermore, two-way communication between parents and clinicians might help resolve such conflicts or misinterpretations.

The third concern parents raised in the follow-up interview was the issue of self-image. Some parents were self-conscious about being recorded. For instance, one father emptied the whole living area to make sure the house looked clean. One mother refused to be on camera and asked her husband not to record her since she was in her pajamas. Another mother was concerned that she might be judged about her family's eating habits as there was a jar of syrup on the dining table. Some of this type of concerns can be lessened, if not completely resolved, by giving parents control over data capture and sharing. Also, system design can also play an indirect role. For instance, a video prescription or even text-based prescription that includes an image of the scene that shows characters in casual clothes and a cluttered house can make parents more comfortable and less conscious about such issues.

5.6 Conclusion

The capture system in-home evaluations established and validated the ease of use of the capture system and the clinical utility of the specimens collected by parents. It showed the effectiveness of the embedded prescription and the guided capture for higher clinical utility. The results from this study show a high increase in the clinical utility of the videos collected by parents as compared to usability study phase-II. There are a number of reasons that may have contributed to this. One clear reason is that the improved system tested in the in-home study has embedded prescriptions that were revised based on the findings of usability study phase-II. Video specimens show that parents followed the embedded prescription and hence recorded specimens had higher quality. For instance, in all parent concern scenario videos, parents clearly articulated within the first two minutes what concerning behavior they are going to record. The second reason is that the collaborating clinician was guiding parents. Families followed the clinician's instructions, which further improved the clinical utility of the resulting specimens. This also demonstrated and verified the effectiveness of guided capture by a

clinician, in addition to the embedded prescriptions. However, there are other reasons that are not verifiable, but might have contributed to the better clinical utility. This study was conducted in the natural environment for, on average, 2 weeks of deployment in each house, whereas, the previous usability study was conducted in controlled setting for a short 2-hour session.

The behavior specimens collected by parents in this study were used to conduct diagnostic assessment for autism by clinicians in the access system evaluation study (described in Chapter 7).

CHAPTER 6

ITERATIVE DESIGN OF THE ACCESS SYSTEM

The access system is a web-based portal designed to enable clinicians to 1) guide parents through the in-home behavior specimen collection process by sending them notifications with specific recording instructions; and 2) complete a diagnostic assessment for autism by first marking (tagging) relevant behaviors in the videos and then reviewing the tags and completing a standard diagnostic checklist for autism.

This chapter describes the access system that was iteratively designed based on a participatory design process involving a collaborating clinician and a researcher experienced in autism diagnosis. In addition the iterative design of the access system was also informed by key findings from the Needs Analysis study.

6.1 Access System Workflow

The access system enabled clinicians to guide the in-home specimen collection procedure and to complete a diagnostic assessment by first observing and tagging video and then completing a diagnostic checklist.

6.1.1 Guiding specimen collection

In addition to embedded recording instructions within the capture system, clinicians may further guide parents during the in-home behavior specimen collection process by sending them specific instructions through the notification feature. For instance, clinicians may ask parents to try to hold a toy away from the child to make him or her request it. Notifications sent from the access system are received on the capture system.

Figure 16a shows the access system interface on which the clinician can view videos shared by parents, and Figure 16b shows the interface that allows sending notifications.

Figure 16a. This window includes all videos from a single family that the clinician selected after the login. a) It allows the clinician to select and view videos shared by parents; b) A notification window is opened when 'Alert' or 'Request Evidence' is clicked.

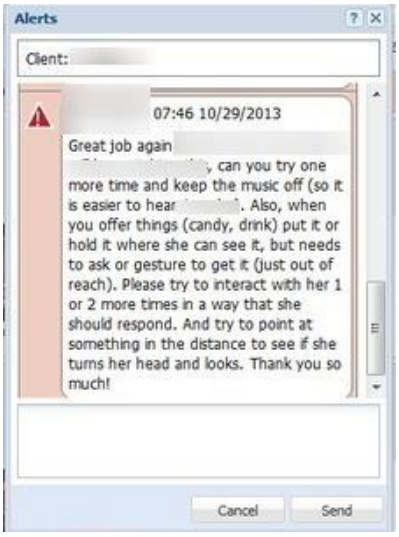


Figure 16b. Once the notification window is opened, the clinician can write instructions and send them to the parents. Data, time and the clinician's name are automatically embedded into the notification.

Figure 16: Access system: guiding in-home specimen collection

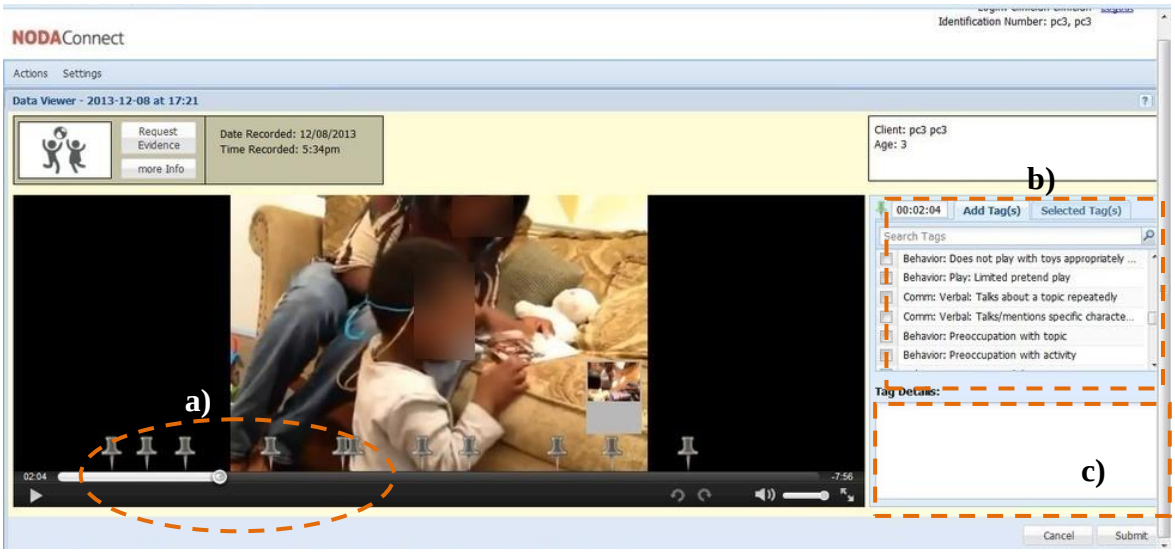
6.1.2 Video observation and tagging of behaviors

Once a clinician receives the video specimen(s) of the prescribed scenario(s) recorded by the parents with the help of the embedded recording instructions and clinician notifications (if any), the clinician can start reviewing the videos and tagging

them with behaviors relevant to diagnosing autism. To begin this step the clinician does not have to wait until all the specimens have been collected.

The clinician first selects a video (from the window shown in Figure 7), which opens in a video player (Figure 7). While watching the video, the clinician can 'Pause' the video and assign one or more tags to that specific moment in the video (see Figure 7a). The access system has a default preset list of tags, which includes behavior markers such as "no eye contact," "repetitive sounds," or "non-functional play". The examples of some tags are listed in Appendix F. These tags were based on standard autism diagnostic criteria know as DSM-IV (Diagnostic and Statistical Manual of Mental Disorders-IV; see Appendix E). The collaborating clinician and autism researcher went through each of the DSM-IV criteria (detail about DSM-IV are in next section) and for each, came up with a list of specific behaviors that a clinician would look for to determine if a child satisfies that criterion. Another clinical expert in autism diagnosis later reviewed the list before these tags were included in the system. In total there are around 66 tags finalized and implemented in the access system.

Figure 17 shows the Data Viewer interface, which enables the video observation and tagging of behaviors. The clinician can search for a tag in the search bar (see Figure 17b). While assigning a tag by selecting it from the list on the right hand side, the clinician can associate notes with the tag by adding text in the 'Tag Details' box (see Figure 17c). Once the clinician completes their tagging of the video they can click the 'Submit' button to save all of the assigned tags and their associated details.



Data Viewer window. a) Push pins indicate locations of tags that have been assigned; b) List of tags to select from and search box for tags; and c) Text box to add notes to a tag

Figure 17: Access system: video observation and tagging

6.1.3 Diagnostic assessment

Once all the videos from a family are tagged, the clinician completes a checklist based on the DSM-IV (see Figure 18). The DSM-IV has 3 main diagnostic categories: 1) qualitative impairment in social interaction; 2) qualitative impairment in communication; and 3) restricted repetitive and stereotyped patterns of behavior, interests and activities. Each category has 4 criteria. The complete DSM-IV checklist is included in Appendix E. A key feature of the access system is that it automatically maps the clinician-assigned tag to the relevant DSM criterion based on a mapping provided by the collaborating clinician and the autism researcher. Examples of few tags and their mapping to DSM criteria can be found in Appendix F. In the Access system version of the DSM-IV checklist, each criterion is automatically populated with the tags that the clinician has assigned during their observation of the video (see Figure 18a). Within the checklist, each tag appears as a video thumbnail that serves as a link to the moment in the video where the tag was assigned. The rationale for automated mapping was so that the clinician could see the associated tags that they assigned while they complete the DSM checklist and then decide

if a certain criterion is met or not. When a clinician selects a link associated with a tag it starts playing the original video the tag was assigned to, starting two seconds before the moment where the tag was inserted. This two-second gap was added to help the clinician recall the context for the tag.

Once the clinician reviews the assembled DSM checklist, he or she manually indicates, for each criterion, whether in his or her clinical judgment that criterion has been met or not. Next, the clinician makes a determination as to the child's diagnosis, based on how many criteria from each category were met. According to the DSM-IV, a child meets the diagnostic criteria for Autistic Disorder if he meets a total of six (or more) criteria overall, with at least two from category 1 (Social Interaction), and at least one each from categories 2 (Communication) and 3 (Restricted and Repetitive Behaviors).

This process for populating the DSM checklist (automatic mapping of tags but manual completion of checklist and diagnosis) was implemented based on feedback from clinicians during the Needs Analysis study (described in Chapter 3). In that study, the clinicians emphasized that they did not want the system to automatically fill in whether individual DSM criteria were met or not. They responded positively to having the system automatically associate tags with criteria but leave it to them to decide if each criterion has been met or not, and whether the child meets the overall diagnostic criteria for autism, based on their clinical judgment.

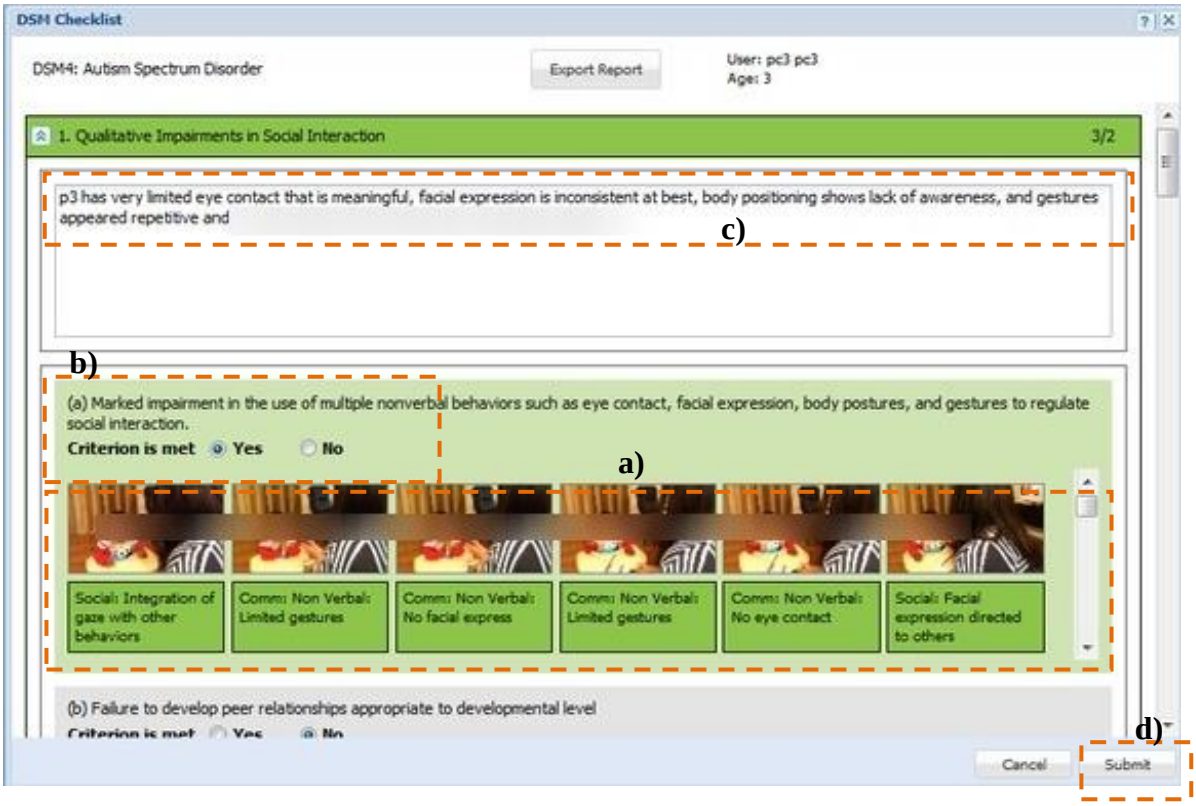


Figure 18. DSM Checklist.

a) Individual criteria within each category are automatically populated with the tags assigned by the clinician; b) The clinician completes the DSM checklist by manually indicating whether each individual criterion has been met or not; c) The clinician can add notes in the comment box associated with each category to clarify their decisions; and d) The clinician can submit DSM checklist by selecting the submit button.

6.2 Iterative design and pilot evaluation of the access system

The access system was iteratively improved based on the feedback from the collaborating clinician and autism researcher during the participatory design process. A weekly conference call that included the collaborating clinician, autism researcher, and members of the research teams at Georgia Tech and Behavior Imagining Solutions was used to review mock-ups of various aspects of the Access system interface. In addition, the collaborating clinician conducted a pilot evaluation of the access system by completing the diagnostic assessment using a subset of the videos collected during usability study phase-II and the capture system in-home evaluation (described in previous

chapter). During the pilot study, the collaborating clinician reflected on his experience after completing diagnostic assessment. Below are some key updates in the access system design that are informed by the clinician feedback in the pilot evaluation.

6.2.1 Addition of positive tags in addition to negative tags

The initial set of behavior tags included in the Access system all reflected behaviors that would be consistent with a diagnosis of autism (e.g., lack of eye contact, stereotyped speech, repetitive play). In the course of the pilot evaluation, the collaborating clinician recognized the value of tags that capture typical or positive behaviors, as most children with autism do show evidence of typical or positive behaviors as well. This insight was also reflected from the clinicians who participated in the Needs Analysis study, who also suggested the potential value of including tags to flag the presence of a behavior, in addition to tags that represent the absence of a desired behavior. For example, the clinicians may want to tag instances of good eye contact, as well as when eye contact is poor or when there is no eye contact. Hence, the clinicians may like to tag what the child does not do, but also what child is able to do. They want to see both sides to determine how atypical or typical the behavior is. The revised access system has both typical (n=9) and atypical tags (n=57).

6.2.2 Tag organization

In the pilot evaluation, the collaborating clinician noted that in the course of reviewing a video specimen, searching and identifying the appropriate tags takes a lot of time, even with the help of the tag-searching feature. Therefore, the tags were re-organized and grouped according to their respective diagnostic categories to enable easier and quicker scanning of the tag list. Tags were assigned to four categories: social (n=12); communication (n=24); repetitive behavior (21); and typical tags (9). These categories

were further classified into subcategories. Each tag was prefixed with the category and subcategory name and appears as category:subcategory:tag name (See Figure 19).

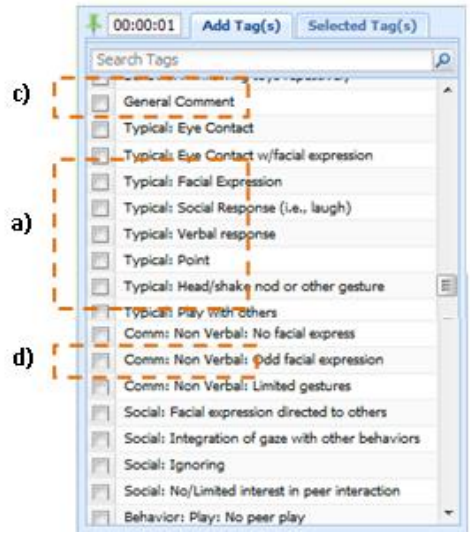


Figure 19 a) Typical tags; b) Tag organization with prefix and; c) General comment

Figure19. Built-in tag list

6.2.3 General comment

In agreement with the feedback from the clinicians in the Needs Analysis study, the collaborating clinician indicated the need for custom tags after completing the diagnostic assessment for autism during the pilot evaluation. Hence, a special tag called ‘general comment’ was included in the list of tags to allow clinicians to use it as a custom tag by adding specific details in its “detail box”. For instance, a clinician might want to add a “visual inspection” tag, which is not available in the preset tag list. In this case, the clinician can create a custom tag by adding a ‘general comment’ and specifying ‘visual inspection’ in the detail box.

6.3 Summary

This chapter summarized the design of the access system that allows clinicians to guide in-home collection process and complete a diagnostic assessment for autism. This chapter also provided a high-level description of the major design improvements that resulted from the iterative design and pilot evaluation conducted with the collaborating clinician autism researcher, and that were suggested by the participant clinicians in the Needs Analysis study. Collaborating clinicians had 20 years of experience in autism diagnosis. It was important to have a domain expert with a rich experience to be part of the participatory design. It was important especially because clinician-directed capture and access system for autism diagnostic assessment is a novel approach, and transferring the current clinical practices to this technology-based approach required domain expertise. The next chapter describes the detailed evaluation of the access system when clinicians used it to complete the diagnostic assessment based on videos collected during the in-home study (described in the previous chapter).

CHAPTER 7

ACCESS SYSTEM EVALUATION BY CLINICIANS

In the access system evaluation, clinicians experienced in autism diagnosis and with no previous experience or exposure to the access system used it to complete autism diagnostic assessment solely based on video specimens collected by parents during the in-home evaluation of the capture system (described in Chapter 5). This chapter includes the study design and key findings from the access system evaluation. Based on in-depth analysis of clinicians' use of the access system, further improvements in the design are suggested.

7.1 Goals

The goal of this study was to evaluate the usability of the access system when used by the primary stakeholders, who are clinicians with experience in diagnosing autism, for its intended use case of completing a diagnostic checklist for autism and rendering a diagnosis. The major focus was to systematically analyze how clinicians use the access system for conducting the assessment in order to identify 1) key design features that contribute to successful completion of diagnostic assessment; 2) challenges with respect to the concept and design, and potential design improvements. This study also served as a mechanism to further evaluate the clinical utility of the in-home behavior specimens previously collected though the capture system in the in-home evaluation, as well as the clinical utility of the NODA scenarios themselves.

7.2 Participants

Participants in this study were three clinicians experienced in autism diagnosis. Each clinician was a licensed clinical psychologist with a doctoral degree. Two clinicians

(C1 and C2) had no previous experience with using videos for conducting diagnostic assessments. C1 and C2 had 2.5 years and 5 years of autism diagnostic experience, respectively. The third clinician (C3) had 13 years of experience with autism diagnostic assessments, and had previously participated in other research involving video observations of behaviors. Details of participant demographics are listed in Table 13.

Table 13: Access system evaluation: Clinicians' demographics

	Gender & age	Title	Degree	Expertise	Experience	Interactions #children per week	Methods for diagnosis	Previous experience in video observation
C1	F 25-45yrs	Licensed clinical psychologist	PhD. Psychology	Autism diagnostic evaluation	2.5yrs.	1-5	ADOS, ADR-I	No
C2	M 35-44yrs				5-10yrs.	1-5	ADOS, ADR-I	No
C3	M 45-54yrs				13yrs.	21 and more	ADOS, ADR-I, EQ, EQ-SQ, Neuropsychological measures	Yes

7.3 Method

In this study video specimens collected by each family were independently reviewed by at least two of the clinicians, each of whom completed the autism diagnostic assessment using the access system. Table 10 shows the mapping between the clinician who completed the assessment and the families who supplied the video specimens during the capture system in-home evaluation.

Table 10: Mapping between clinicians and families.

Clinician	Assessment: In-home study Families
C1	H1, H2, H3, H4, H5
C2	H1, H4
C3	H1, H2, H3, H5

Prior to participating in the study, all clinicians participated in an orientation session conducted by the collaborating clinician to introduce the concept of remote diagnosis based on in-home behavior specimens. The focus of the orientation session was

to help participant clinicians relate the diagnostic assessment via the access system to the standard in-person diagnostic evaluation they are familiar with, and to provide general guidelines for how to approach this assessment. The clinicians were told that while tagging behaviors they should focus on marking all behaviors they notice irrespective of the diagnostic outcome at that stage. No details about the access system interface were disclosed during the orientation.

During the actual study, at the beginning of the session the clinician was first given a 5-minute demo of the clinician-directed capture and access system. The clinician was then given an opportunity to practice using the system for about 10 minutes or until he or she felt comfortable with the system. Videos from one of the families from the earlier usability study were made available in the system for the clinicians to use for practice. On average, the clinicians practiced for 11 minutes (range 10-12 minutes). Next, the clinician was asked to conduct a diagnostic assessment via the access system by tagging and then completing the DSM checklist for a single family at a time. To avoid any biases, the clinicians were told that the child may or may not have autism. Other than the child's age, no other information was disclosed to the clinician about the child's developmental history until the clinician completed the diagnostic assessment. All interface related actions of the clinicians during the assessment were recorded via a continuous screen capture of the access system interface.

After completing the DSM checklist, the clinician was prompted to assign the following two confidence ratings about the diagnostic outcome on a scale from 1 (not confident) to 5 (extremely confident): "How confident are you that the child has autism?" and "How confident are you that the child is typically developing?" The reason for including both of these ratings is that it allowed clinicians to indicate diagnostic uncertainty in cases where they were confident that the child does not have autism but also did not think the child was typically developing. In addition, the clinician also rated

each of the NODA scenarios on a scale from 1 (not useful at all) to 5 (most useful) based on how useful they were in providing examples of behaviors relevant to diagnosing autism.

Finally, each clinician participated in a semi-structured interview to discuss their experience of conducting the diagnostic assessment through the access system. The interview included questions relating to the usability experience, as well as questions pertaining to the clinical assessment itself, such as the appropriateness and completeness of tags and their mapping to the diagnostic checklist embedded in the system. The interview also included discussion of key features of the system that enabled clinicians to successfully complete diagnostic assessment. Towards the end of the interview, the child's developmental history and results of the previous in-person diagnostic assessment were disclosed to the clinician, and the clinician's reflection on value and limitations of the access system were documented. The interview also included questions about the content and sharing of a potential diagnostic report to be generated based on the results of the video-based assessment.

7.4 Data analysis

Data collected from the activity log of the access system (e.g., time spent reviewing videos, assigning tags, and completing the DSM checklist; total number of tags assigned; distribution of assigned tags based on their category, the scenario, and time), results of the diagnostic assessment via the access system and associated confidence ratings, the follow-up interview, and rating for quality of videos for diagnostic assessment were subjected to quantitative and qualitative analysis. Data analyses also included comparing the agreement between the diagnoses independently conferred by two or more clinicians via the access system, and comparing the results of the video-based diagnosis to the child's diagnosis in the medical record. The continuous screen capture of the access system user interface was also subjected to detailed analysis.

7.5 Findings

This section covers in-depth usage analysis of the access system. It presents an analysis of the time taken to complete the assessment and a breakdown of the time taken at each step, as well as an analysis of the tag assignments and the completed diagnostic checklists. Other aspects, such as the workflow adopted by the clinicians, are also described.

7.5.1 Tagging analysis

Time analysis

On average, it took 15.5 minutes to tag a single video for the family meal time, play with others, and play alone scenarios, and an average of 7.6 minutes to tag a single video for the parent concern scenario. The follow-up interview revealed that the key reason parent concern videos took less time to tag was that parents tended to record an entire 10-minute segment of the child engaging in the concerning behavior, but clinicians only needed to see 2-3 minutes of the behavior to get a clear sense of the behavior. It would be more useful if parents were to change the environment or situation so that clinicians can observe the child's reaction as well. On average, the total time taken to conduct the complete assessment through the access system (tagging and filling out the DSM checklist) was 65 minutes, with 84.6% of the time (55 minutes) spent on tagging and 10.7% of the time (7 minutes) spent on completing the DSM checklist. Although tagging took most of the assessment time, there was a clear reduction (about 14% on average) in tagging time between the first and second family. According to the clinicians, after tagging a few videos they became familiar with the tags (type of tags, granularity of tags, organization, etc.) and were able to locate and assign tags more efficiently.

Analysis of the end to end time required for in-home behavior specimen collection under the guidance of clinicians followed by assessment through access system shows that in the best case when we ignore time delays due to bug fixing or unavailability of the clinician it took on average 5 days to complete this process. In section 5.5.5 the analysis shows that it takes on average 4.5 days to complete the in-home collection under the guidance of clinicians. It was found that a notification, if required, requesting further action was sent to families on average within 48 hours of the video being upload.

Distribution of tags per scenario

On average, 35 tags were assigned to each video. In total the clinicians assigned 846 tags to all 24 videos collected by the families in the capture system in-home evaluation. Table 14 shows average number of tags assigned per video in each of the four scenarios. The results show that most tags per video were assigned to play alone scenario videos.

Table 14: Access system evaluation by clinicians: tag assignment by scenario

Scenario	Total videos	Average no of tags per video
Meal time	7	26
Play with other	7	43
Play alone	5	47
Parent concern	5	25.5
Total	24	35

Distribution of typical and atypical tags

Table 15 shows distribution of typical and atypical tags that clinicians assigned to in-home collected across all four NODA scenarios. Results show that 64% of all the tags assigned by the clinicians were atypical tags, those reflecting autism symptoms in the areas of communication, social interaction, and repetitive and stereotyped behaviors. Communication tags constituted 29% of all assigned tags and were assigned more often

than repetitive behavior and social interaction tags, which were assigned with almost equal frequency. Tags relating to typical behaviors made up 31% of the total assigned tags. However, if we exclude the typically developing child's tags (since all tags assigned to this child's video except one tag were typical tags), typical tags assigned to videos collected from children with a diagnosis of autism made up 19% of all tags. This shows that the clinicians used typical tags for child with autism. In the follow-up interview, clinicians reported that typical tags were useful for reaching an assessment outcome not only for typically developing child but also other children who had autism diagnosis. However, they also mentioned that the typical tags will be extremely useful evidence for determining a diagnosis for the children who were high functioning. In the case of the typically developing child, almost all the tags (99%) were tags relating to typical behaviors. One of the two clinicians who completed the assessment for the typically developing child assigned an atypical tag for odd/repetitive speech with the following explanation: "either singing or engaging in self-conversation, little repetitive but not very odd- typical for age."

Table 15: Distribution of type of tags

Tag type	**Subcategory % of the total tags assigned**		**% of the total**
Typical tags			31
Atypical tags	Communication	29	64
	Repetitive behavior	18	
	Social	17	
General comments			5

7.5.2 Adopted work flow

Consistency in clinicians' time spent on conducting assessment

Results also show that there was not much variability in the time taken by the two clinicians who independently performed diagnostic assessment on same videos of a child

via the access system. (In the case of one child it was 3 clinicians who performed independent diagnostic assessments via access system. This case is discussed in detailed later in the chapter.) The average difference in total time taken for completing the tagging for each scenario for the same child is 9.8 minutes (range: 2 to 16 minutes).

The average difference in tagging time for the same family is 6.6 minutes (range: 1-13 minutes) and for the DSM checklist it is 2.6 minutes (range: 1-6). This shows that there was less variability between clinicians' time spent on tagging, and filling out the DSM checklist. Variability was only evident in cases 1) when one of the clinicians was using the access system for the first time and hence took longer to get familiar with the access system and tag list in the access system and 2) when clinicians had conflict in assessment outcome. Results also showed that clinicians spent the least amount of time (37 minutes on average) on completing the assessment for the child who was typically developing (easy case) and the most time (73.6 minutes average) on the child who had a mild autism diagnosis (complicated case).

Reviewing assigned tags

In most of the cases, for a given family a clinician tagged the videos one by one. A number of times clinicians would go back and reanalyze a previously tagged segment of the same video, however, it was not common for clinicians to go back and forth between various already tagged videos. Furthermore, all but one clinician started filling out the DSM checklist only after they had tagged all of the videos.

Strategy for unavailable tags

There were cases when the clinicians wanted to mark the presence or absence of a certain behavior for which they did not find a tag in the pre-defined list of tags. The clinicians adopted different strategies to compensate for the missing tags. For instance, C3 assigned the tag that was most meaningfully close or a super tag (higher in

granularity) to the missing one, and included a specific description in the associated "Tag detail" text box. C1 and C3 added general comment tags as a replacement for the missing tags and again specified the tags they wanted in the detail box.

'General comment' tag usage

'General comment' tags represented 5% of all the tags assigned. In addition to substituting missing tags, clinicians C1 and C2 used the 'general comment' tag to log high-level observations about the child's level of function in one or more videos. According to these two clinicians, tags are behavior markers at a single instance of time (local tags) but they would like to flag the consistent lack or presence of a behavior throughout an extended time period (global tags). Hence, the 'general comment' tag was used in these instances to capture the clinician's commentary about the child's overall level of functioning, based on observations from one or more videos as opposed to a specific instance of a behavior marked with a tag. This is a judgment by the clinician based on observing the child over a period of time.

7.5.3 Analysis of diagnostic checklist

On average, it took the clinicians 7 minutes (range 5 – 9.5 minutes) to complete the DSM checklist. The most common sub-criteria that were met were 1a (impairments in nonverbal behaviors such as eye-to-eye gaze, facial expression, etc.), and 1d (lack of social or emotional reciprocity), whereas criteria 2d (lack of make-believe play) and 3b (inflexible adherence routines or rituals) were the least-satisfied criteria across all assessments conducted via the access system. Based on discussion with clinicians, it was found that it is difficult to conclude make-believe play and adherence to routines just through videos. Clinicians suggested that parents should be asked to report on these behaviors as part of the child developmental history so that clinicians can make better judgment of them while filling the checklist.

7.5.4 Comparative results from diagnostic assessments

The focus of the study was to evaluate the design of the access system when used by clinicians for its intended use case, namely diagnostic assessment of autism based on videos recorded by families in the home. However, since the clinicians assigned a diagnosis to the child upon completing the assessment, we were able to compare this diagnosis to the child's previous diagnosis as indicated in the child's medical record. In 80% of the cases (the typically developing child and three of the four children with previous diagnoses of autism), both clinicians independently arrived at the same diagnostic decision (with 4.87 confident rating) that also matched with the child's true diagnostic status (typically developing or autism). The average confidence rating for the video-based diagnosis for these 3 children with previous diagnosis of autism was on average 4.8.

Table 16: Comparison of diagnosis

Child	**Previous in-person diagnosis**	**Diagnosis via access system**	
		Clinicians agreement	Successfully diagnosed
1	Typically Dev	✓	✓
2	Autism (Autistic disorder)	✓	✓
3	Autism (Autistic disorder)	✓	✓
4	Autism (Autistic disorder)	✓	✓
5	Autism (PDD-NOS)	✗	✗

For the one child with a previous diagnosis of PDD-NOS (a milder form of autism), one of the clinicians concluded that the child is not typically developing (with high confidence) but stated that the video evidence was not sufficient to support an autism diagnosis (2-level of confidence). In particular, the clinician reported a shortage of

examples of repetitive behaviors, which must be present in order for the diagnostic criteria for Autistic Disorder to be met. The second clinician's assessment results were that the child has autism and that the clinician was very confident (5) in this diagnosis. Importantly, this clinician specified he felt the child had PDD-NOS, in complete agreement with the child's previous diagnosis. Due to the discrepancy between the two clinicians, a third clinician was asked to review the videos from this child. He also concluded that the child has autism, and assigned a confidence rating of 5.

Overall, in the case of this child, all three clinicians rated with high confidence that the child is not typically developing. Two clinicians confidently (highest level 5) concluded that the child has autism (but with mismatching sub categorization). There could be numerous reasons that may have contributed to these discrepancies. First, the demographic analysis of the clinicians shows that the first clinician has less experience in autism diagnosis (2.5 years) as compared to C2 (around 5 years) and C3 (13 years). The two more experienced clinicians (C2 and C3) tagged several examples of repetitive behaviors, whereas the less experienced clinicians only assigned one repetitive behavior tag, and hence did not diagnose the child with autism. Importantly, the repetitive behaviors tagged by the more experienced clinicians (particularly C3) were also listed in the child's medical report. Secondly, once the clinicians completed the diagnosis, they were asked to look at the child's developmental history, in which parents clearly mentioned that the older sibling had PDD-NOS (there were no references to the target child's diagnosis). After reviewing the child's history, (before knowing the child's previous diagnosis) both C1 and C2 stressed that if they had known about the older sibling's diagnosis earlier it would have increased their confidence that the child has PDD-NOS. Finally, the results for this child supported feedback from the clinicians in the Needs Analysis study in which they highlighted that children who have more subtle characteristics of autism would be difficult to diagnose through behavior specimens.

These clinicians indicated that in such cases, more information may need to be obtained from multiple sources such as parent report, direct developmental evaluation (e.g., cognitive or language assessments), or in-person diagnostic observation session in order to complete the diagnostic assessment.

7.6 Discussion

7.6.1 Ease of use of access system

On average, the clinicians rated the ease of use of the access system as 3.6 on a scale from 1 (not easy at all) to 5 (very easy to use). Figure 16 shows individual feedback from the three clinicians about the ease of use of the access system. C3 rated the ease of use of the access system higher than C1 and C2. In the follow-up interview C3 reported he had previous experience with a system for conducting video observation that requires the assignment of tags to videos.

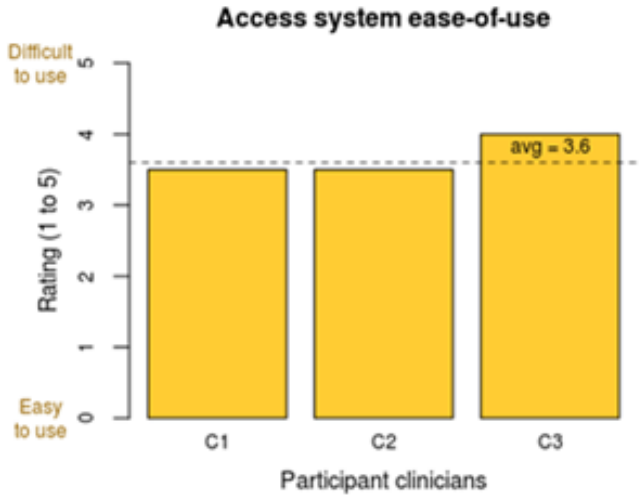


Figure 16: Access system: Ease-of-use rating by clinicians

In the follow-up interview the clinicians reported that they found the workflow easy, but the tagging cumbersome in terms of effort and time for two reasons. First, the system required the clinicians to submit tags once they complete tagging. Due to stability

concerns with the system, the clinicians were asked to submit the tags 2-3 times while reviewing and tagging a video. However, every time the clinicians submitted tags they had to reopen the video player and forward the video to resume viewing from the point where they were interrupted to submit the tags. Second, clinicians C1 and C2 frequently assigned the 'general comment' tag to compensate for missing tags. When the clinicians assigned the same missing tag repeatedly, they had to specify the same description in the 'general comment' detail box every time. For instance, C1 often document 'visual inspection' during direct behaviors while conducting assessment in day-to-day routine. This tag was not in the system (there was another tag for this behavior but not with the exact same name) and clinician wanted to assign this tag multiple times, so each time this clinician would assign a 'general comment' tag and added 'visual inspection' in the associated detail box, which demanded extra effort and time. The main problem was that the system did not have a feature that allowed for the creation of custom tags that can be saved and reused.

In general, other than the issues mentioned above, all the participant clinicians were able to use the access system after a one-time orientation session, a brief demo (5 minutes) and a practice session (average 11 minutes) conducted at the beginning of the study. They also stressed the importance of the orientation session with the collaborating clinician since it helped them relate the diagnostic assessment through the access system with their current practices for in-person diagnosis (mainly using ADOS - Autism Diagnostic Observation Schedule [73, 74]).

Analysis of the activity log and screen capture of the clinicians using the access system showed that the clinicians were able to follow the workflow without any difficulty. There were a few technology issues for the first few sessions (e.g., issues with video playing, etc.) that were fixed during the course of the session. By the last three sessions, the system was stable and robust enough for the clinicians to conduct the

assessment remotely from their office. Subjective feedback from the clinicians also indicated that other than stability issues of the access system in the first few sessions, they found the workflow easy to follow. However, the clinicians made a number of suggestions, particularly with respect to improving the tag organization to reduce the tagging time (which as mentioned earlier, made up 84.6% of the total assessment time).

7.6.2 Value of in-home behavior specimens

Clinical utility for diagnostic assessment

Once clinicians completed diagnostic assessment they were asked to rate the quality of all in-home recorded scenarios. For each family they rated the scenarios on a scale of 1 (not very useful) to 5 (most useful). Figure 17 shows the average rating assigned by clinicians for the utility of each of the four NODA scenarios for diagnostic assessment. On average the clinicians gave a rating of 4.0 for the utility of home videos for conducting diagnostic assessment.

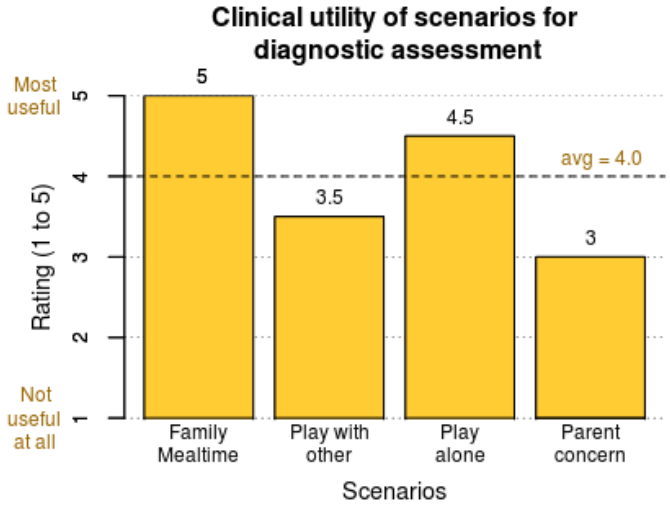


Figure 17: Average utility rating of in-home specimens for diagnostic assessment

During the follow-up interview the clinicians described specific reasons for utility ratings of the four scenarios. For mealtime, the clinicians found it a wonderful social

opportunity to observe a child's interaction and requesting skills. For play alone, the clinicians reported that a simple activity like play alone helped them understand the child's level of functioning when the child is working independently. For play with others, they found it useful since it allows them to observe how the child interacts with others. In addition, the clinicians wanted to observe how the child interacts with adults (parents, and, if possible, also with strangers) as well as same-age peers. Clinicians were concerned that some activities, such as book reading, are passive and do not provide enough interaction opportunity to the child, therefore should not be mentioned in the embedded recording instructions. For the more open-ended parent concern scenario, the clinicians liked that parents get an opportunity to show a behavior that they find concerning. However, clinicians also found that some of the videos of the parent concern scenario were redundant. Sometimes they could see the same behavior occurring in one of the other recorded scenarios. Second, some parents recorded the child repeatedly or continuously exhibiting the behavior of concern, but clinicians wanted to see how the child would react when the environment was changed.

Unique aspect of video observation

Clinicians highlighted that, unlike direct observation, video observation allows them to go back in time and review and verify certain observations if required. Among the three participant clinicians, C1 and C2 had no previous experience with video observation. These two clinicians reported that before the study they were reluctant and skeptical about the value of in-home video recording for diagnostic assessment. The third clinician C3 had previously participated in other research efforts that involve video observation for assessment and interventions of children with autism and had found these methods useful. However, all the clinicians, irrespective of their previous experience and initial biases towards video observation based assessment, reported that after their

experience of completing diagnostic assessments via our system they found it extremely valuable and enlightening.

7.6.3 Specific components of the system contributing to its success

All three participant clinicians reported that the clinician-directed capture and access system has the potential to support autism diagnosis and, in particular, found two components of the system fundamental to successful completion of the diagnostic assessment.

Built-in prescription

According to the clinicians, the most vital component of the system is the built-in prescription in the capture system in the form of the NODA scenarios and the embedded recording instructions. Due to the explicit instructions, the parents were doing exactly what the clinicians 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. The clinicians reported that the embedded prescription makes the clinician-directed capture and access system unique compared to any other video capture and sharing system.

Connecting parents and clinicians

One of our design assumptions was that two-way communication would allow clinicians to guide parents during the in-home specimen collection by enabling them to send families' additional recording instructions as notifications and enabling parents to respond back and clarify any potential queries about the notifications. However, the clinicians suggested that the true benefit of allowing parents to communicate with the clinicians would be in allowing them to answer clinicians' queries about the child's profile. This suggestion was based on the fact that while conducting the assessment,

clinicians had a number of questions they would have liked to ask the parents, either to confirm their video observation or to get additional details about the developmental history of the child.

7.6.4 Improvements in access system

Tagging

Clinicians suggested that the system should allow the user to define customized tags that remain persistent in the system for that particular user. They also indicated that the clinicians should be able to map the customizable tag to its relevant DSM criterion.
In addition, the cclinicians stressed the importance of a feature that would allow them to add their commentary about the child while observing the video, e.g., if a child is consistently exhibiting or lacking a behavior.

Diagnostic checklist

As recommended by the clinicians, the DSM-IV checklist embedded in the access system has now been replaced with the newer DSM-V checklist, which was published earlier this year. Additionally, a significant update in DSM-V is that the separate diagnostic labels of Autistic Disorder, Asperger's Disorder, and PDD-NOS have been replaced by a single diagnostic category of "Autism Spectrum Disorder."

Diagnostic report

During the follow-up interview, the content and sharing policy for a potential access system-generated diagnostic report were discussed. Clinicians recommended four components for the report: 1) Child's profile: a summary of a child's demographics and developmental history and parents' reports collected through two-way communications; 2) Clinician observations: a description of the behaviors clinicians observed regarding presence or absence of behaviors that contribute to the final assessment about the child,

(e.g., consistent lack of eye contact); 3) Assessments: a summary of the DSM checklist and the final diagnostic outcome; and 4) Recommendation: the clinician's suggestions about further interventions and available resources (services) for families. However, clinicians stressed that these recommendations would be high-level, not a detailed intervention plan. According to the clinicians, the Clinician-directed Capture and Access system should not be targeted for comprehensive diagnosis where the goal is not only to diagnose, but to plan a complete intervention plan.

7.6.5 Challenges and limitations of the approach

Like the clinicians in the Needs Analysis study, the clinicians in the access system evaluation identified potential cases when in-home behavior specimens would not be sufficient to complete a diagnostic assessment of autism. These situations are: 1) when the child is too young (less than two years old); 2) when the child has very subtle characteristics of autism; and 3) when the child's level of functioning is very limited. According to the clinicians, in all these cases it is difficult for them to make a judgment about the child's development, which is required to compare with the child's social profile, and hence, makes it difficult for clinicians to complete a diagnostic assessment with confidence. In such cases, evidence in addition to video specimens would be required, which, depending on the situation, could be a parent report, a developmental evaluation, or an in-person meeting with the child

7.7 Conclusion

This chapter described the access system evaluation study with clinicians. It facilitated the systematic study of clinician's use of the access system for completing diagnostic assessment for autism. This study helped in identifying key components of the access system, limitations and potential future design improvements. In addition, clinicians in this study revalidated that in-home video specimens collected through the

capture system had high clinical utility after conducting diagnostic assessment based on these specimens. This study helped in refining the system design for the clinical study (described in Chapter 9) as well as the design of the clinical study itself. With regards to the system design, the major changes include inclusion of typical tags, extension of child developmental history form and incorporation of two-way communication. Typical tags will be part of the access system for the clinical study since clinicians used them frequently and suggested that these would be extremely useful when a child has a stronger skill set and would require comparative assessment of typical and atypical behaviors. In addition, child developmental history form was extended in consultation with collaborating clinician and based on findings from this study. Certain criteria were least assigned 'yes' by clinicians while completing diagnostic checklist and clinicians in the access system suggesting that these should be part of the child developmental history. Next, two-way communication is included in the clinical trial since clinicians in the access system highlighted its true benefit would be to get parents report or additional child development history form. Finally, DSM-IV is replaced with DSM-V for the clinical study. In addition to these system level changes, this study also played an important role in shaping the study design or protocol for the clinical trial. We found that it is useful to have a moderator clinician that guides parents through the collection process (the way the collaborator clinician did in the in-home capture study) and experienced clinicians should be involved once initial set of good quality specimens are collected and shared by parents. However, while performing the autism diagnostic assessment, experienced clinicians may request additional video specimens or may communicate with parents for additional information on the child's developmental history. In future the role of moderator could be replaced with an intelligent specimen quality assessment feature.

CHAPTER 8

CLINICIAN-DIRECTED CAPTURE AND ACCESS SYSTEM: A REFLECTION ON ITS GENERALIZABALITY

The clinician-directed capture and access system is based on the concept of '*clinician-prescribed in-home behavior specimen collection to support clinical assessment*'. Analogous to a traditional specimen collection and assessment procedure, this concept is based on a prescription, behavior specimen collection, and assessment model. In this chapter, I describe the high-level design specification and generalizability of this model by presenting various examples of its transferability to other use cases in addition to the case of autism remote diagnosis demonstrated in this thesis.

8.1 Generic Model

The clinician-directed capture and access system is derived from the generic prescription, behavior specimen collection, and assessment model. Particularly, the clinician-directed capture and access system for remote autism diagnosis is a demonstration of one successful implementation of this generic model.

The specific design adopted for the prescription, collection and assessment model in this thesis has two components: a capture system and an access system. The capture system allows simplified capture and sharing, and includes an embedded prescription to enable relevant behavior specimen collection. The access system allows observation of video and behavior marking (tagging) of the in-home behavior specimens to conduct assessment. The two-way asynchronous communication between the capture system and access system allows the access systems' user to guide the in-home behavior specimen collection procedure as well as to collect additional evidence (e.g., in cases of remote

diagnosis, clinicians can ask questions about the child developmental history and/or get a parent's report to confirm a specific video observation).

Although the prescription, collection and assessment model itself and its high-level design features (embedded capture, guided capture, tagging, video observation, assessment based on mapped tags) are generic, its implementation must be customized within the context of its end-use case scenario. The embedded instructions in the capture system can be contextualized by either editing them at compile time or run time through a new prescription pad feature within the access system. The prescription pad would allow the access system user (e.g., clinicians) to customize the prescription for the particular use case scenario (e.g., diagnosis, treatment or follow up, etc.). Like the capture system, the access system's main features of video observation and tagging and then conducting assessment are generic, but its specific implementation needs to be modified within the context of its end-use case scenario.

8.2 Transferability

The behavior specimen prescription, collection and assessment model is a generic model that is transferable to a number of use cases. A successful adaptation for remote autism diagnosis is demonstrated in this thesis as an example use case for this model. A number of other potential use cases were identified by clinicians who participated in Needs Analysis study and Access System evaluation study (described in Chapter 3 and Chapter 7). In addition to the clinicians' report, clear evidence of the transferability of this model is that Behavior Imaging Solutions (the collaborating company working on commercialization of clinician-directed capture and access system for autism diagnosis) has adopted the same model and design specification for an entirely different use case of medicine administration for children with autism. Below is the detail of the medicine administration use case and other potential use cases highlighted by the participant clinicians.

8.2.1 Medicine administration

The prescription, behavior specimen collection and assessment model and its high-level design specification were used to implement a capture and access system that assists healthcare providers in the management of medication for individuals with autism. In-home behavior specimens captured and shared through the smartphone based system (see Figure 18) allow physicians to observe patient behaviors and improvements in symptoms between office visits using the web-based access system. Behavior Imaging Solutions has also conducted a preliminary evaluation to determine the usefulness of this clinician-directed capture and access system customized for the use case of medication administration [32]. During the preliminary evaluation, two physicians and three caregivers of autism patients experienced the system and gave their feedback. In their feedback, physicians highlighted that this system assisted them in monitoring patients with autism spectrum disorder more comprehensively and accurately than using subjective reports provided by caregivers during office visits.

Figure 18: Med Smart Capture and Med BI-Connect

Next I will briefly describe the use case scenario for the prescription, behavior specimen collection and sharing model identified by the participant clinicians of the Needs Analysis study and the Access System evaluation study (described in Chapter 3 and Chapter 7).

8.2.2 Treatment

Participant clinicians of the Needs Analysis study and the Access System evaluation study highlighted that the prescription, behavior specimen collection and sharing model can be used to support treatment delivery. As stated by a clinician:

C5-NeedsAnalysis "We have families that we see them from 2:00 PM to 4:00 PM in the afternoon, but what we're working on is bedtime routines If we could get video of when those things are happening and what the difficulties are, obviously that would be fantastic."

Below is a statement from another participant clinician stating that video observation of in-home occurrence of target behaviors would help in replicating the behavior in the clinic for treatment purposes.

C7-Needs Analysis "It's very hard for us to set up an analogous situation where we're trying to see problem behavior without having seen it in the home situation first, and this would allow us to do that."

8.2.3 Follow-up

Participant clinicians highlighted that this model can be used to monitor follow up treatment at home. It can allow clinicians to analyze whether the child is maintaining the desired behavior at home and how parents are implementing the intervention plan. As stated by one of the participant clinicians:

C4-NeedsAnalysis:" I only work with a family typically for about 12 weeks. And then after those 12 weeks is up they're either going to get a referral to another program

or that's it. They're kind of left to their own devices. You know, this system can fill that space by helping us with follow-up."

8.2.4 Evidence-based training

Participant clinicians in the Needs Analysis study and the Access System evaluation study (described in Chapter 3 and Chapter 7) highlighted that a system based on the prescription, collection and assessment model could be extremely helpful for training parents and professionals. It is common practice for clinicians to train or guide parents on how to deliver a particular intervention at home. Through in-home video evidence, clinicians can monitor how parents are implementing a prescribed intervention plan, and provide feedback. Similarly, trained clinicians can provide feedback to junior or new clinical staff who deliver in-home interventions, based on recordings of their in-home sessions. One of the participant clinicians stated:

C7-NeedsAnalysis: I work solely pretty much as a parent trainer. So we would definitely need something where you could catch that interaction between the parent and child…But I am always, always hesitant about when I'm not there, are these things being implemented and things like that…It would definitely be helpful to be able to provide them feedback if they video record behaviors in that week."

8.2.5 Triage

A system based on the prescription, collection and assessment model could be used to sort and prioritize families on waiting lists for clinical services. For example, by reviewing videos collected in the home, clinicians could determine in advance if a child qualifies for services, and if so, how urgently, and which services might be most effective. Sorting and prioritizing the waiting list is crucial, since timely access to diagnostic and interventional services is often hampered by long waiting lists at centers and clinics [9].

8.2.6 Remote services

Participant clinicians in the Needs Analysis study and the Access System evaluation study (described in Chapter 3 and Chapter 7) reported that a system based on the prescription, collection and assessment model would be extremely valuable for providing services (e.g., assessment, diagnosis, treatment and follow up) to those children or adults with autism who are remotely located and do not have access to the clinic. As expressed by one of the participant clinicians:

C3-Needs Analysis: "I think that would be awesome – especially if we were doing some kind of remote consultation,– you know, if a parent are living at a more rural area I would still able to provide services because of this system"

8.2.7 Other use case scenarios

In addition to the above use case scenarios, the prescription, collection and assessment model can be applied for other use cases mentioned by the participant clinicians. However, in these use cases, instead of clinician-directed capture and access, the system would be consumer-directed capture and access system. The consumer in this case is the access system user.

- Behavior specimen collection at school to improve communication among parents and teachers.
- Presenting behavior evidence of progress or lack thereof during IEP (Individualized Education Program) meetings.
- Recruiting research participants. For example, study inclusion criteria may call for children with "classic" autism. Currently, costly in-person assessments are done to determine study eligibility. Resources such as time and money would be saved if such participant screening could be done remotely through video evidence.

- Measuring inter-rater reliability between two different clinicians for conducting a diagnosis or treatment.

Participant clinicians in the Needs Analysis study and the Access System evaluation study suggested that a system based on the prescription, collection and assessment model can be effectively used for various services not only for children and adults with autism, but for various other development-delay-based conditions.

8.3 Conclusion

This chapter discusses the generic prescription, collection and assessment model. This model and its design specification (embedded capture, guided capture, tagging, video observation, assessment based on mapped tags) are generic and transferable across various use case scenarios in addition to the remote autism diagnosis demonstrated in this thesis. Participant recruitment and inter-rater reliability are examples of use case scenarios, which are not even linked to health care. The generalizability of the model and its design specification is evident from the fact that it has been successfully transferred to an entirely different use case of medicine administration for individuals with autism.

CHAPTER 9

FUTURE DIRECTIONS

This chapter includes details about future directions for the clinician-directed capture and access system with respect to: 1) a clinical trial of in-home video-based autism diagnosis; 2) technology advancements towards a smart clinician-directed capture and access system; and 3) an assessment of large-scale field adoption.

9.1 Clinical Trial

In-field evaluation of the iteratively designed clinician-directed capture and access system demonstrated that it can enable parents to easily collect and share diagnosis-ready video and clinicians to complete diagnostic assessments for autism with high confidence.

The high usability and utility of this system is evident from the fact that it is currently being used in a clinical trial involving a large number of families (n=50) and clinicians (n=25). The goal of the clinical trial is large-scale validation of the reliability of video-based autism diagnosis in a sample of children who had not been previously diagnosed. The clinical trial is conducted by SARRC (Southwest Autism Research and Resource Center) in collaboration with our team at Georgia Tech, and Behavior Imaging Solutions, who are also working on the commercialization of a clinician-directed capture and access system. The clinical trial has two phases.

Phase-I:In-home video specimen collection using the capture system

For the clinical trial, 50 families with young children, ages 2 to 6 years, are being recruited. This includes 25 families who are seeking an evaluation for autism and 25 families who have a child diagnosed with another disorder (not autism, either medical or psychiatric condition or typically developing). All participant families will complete the

gold standard diagnostic assessment evaluation in person at SARRC, and will also complete in-home video collection to record four video scenarios through the capture system. These scenarios include: 1) a family meal time; 2) the child playing with others; 3) the child playing alone; and 4) behavior(s) that represent a concern that the parent has about their child. These in-home videos will be analyzed by the clinicians who have previous experience in diagnosing autism to conduct a diagnostic assessment for autism via the access system. In total, 25 clinicians will participate in the study. The study design for this phase is the same as that of the in-home capture system evaluation. The only deviation is that in the previous study the child already had a diagnosis and no in-person diagnostic assessment was performed. However, in the clinical trial, after home videos are collected, parents will come to SARRC for a 2-3 hour in-person assessment consisting of a standard direct observation and interview (the Autism Diagnostic Observation Schedule and the Autism Diagnostic Interview). These assessments will be administered by clinicians from SARRC, who will remain blind to the status of the child's remote diagnostic assessment.

Phase-II: Diagnostic assessment conducted by clinicians with experience in autism diagnosis

Videos from each family, along with the child's developmental history, will be analyzed independently by two clinicians, both blind to the child's in-person diagnosis. Each clinician will complete a diagnostic assessment for autism by tagging and completing the DSM checklist though the access system.

If the results of the independent diagnostic assessment (through the access system) from two different clinicians do not match, then a third clinician (blind to the assessments of clinicians 1 and 2) will be asked to complete a diagnostic assessment of the child though the access system. In this situation the final access system-based diagnostic assessment would be the one that came from the majority (2 out of 3). The

study design of this phase is similar to the one for in-home access system evaluation in Chapter 7. The only difference is that in the access system evaluation study, all children (except the typically developing child) already had a diagnosis and the assessment results from access system were compared to the previous in-person assessment. In this clinical trial a complete in-person diagnostic assessment will be performed and will be compared to the one resulting from the access system. If the final diagnostic outcome from both assessment methods matches, a report will be completed and provided to the family and/or their pediatrician. Otherwise, the clinicians who performed the assessment though the access system and the clinician who performed the traditional in-person assessment will participate in a consensus meeting to determine the best classification for the child (either autism or not autism) based on all available information. The results of the consensus meeting will be included in the final report for parents and pediatrician.

The clinical study will be an ecological validation of the diagnostic approach adopted in the clinician-directed capture and access system on a larger scale. A future plan after the clinical study is to conduct a multi-site clinical trial on a larger scale.

9.2 Technology Enhancements

Advanced technology features can be added to the existing system to make it a smart clinician-directed capture and access system.

9.2.1 Towards a smarter capture system

The capture system has embedded instructions within the smartphone application. These instructions include guidelines about staging and social presses. If parents miss any instruction while recording, then clinicians can give parents guidance about it through the access system notification feature. However, there are a number of factors associated with staging (such as lighting condition, audio quality, field of view, visibility of the

child's face in the view, etc.) and social presses (such as name call, determining the frequency of interactions by parents, etc.) that a smarter capture system could automatically detect before and during the video's recording to alert parents, instead of after-the-fact instructions they receive from clinicians. It could reduce the amount of valuable time a clinician spends on monitoring low-level details and save parents time from rerecording multiple times. It will also potentially reduce the turnaround time for the in-home data collection process.

9.2.2 Towards a smarter access system

Tagging the presence and absence of behaviors is the most time consuming step, taking clinicians 84.6% of the whole assessment time in our initial study (described in Chapter 7). An intelligent access system could support the tagging process in many ways. Automatic recognition of certain behaviors (such as response to name call, smile, giving or taking an object, eye contact, etc.) and suggesting tags based on it would be valuable. The clinician could make the final decision on assigning these tags. In addition, based on findings from the access system evaluation, clinicians tend to have their personal preferred tags that they frequently assign, so an intelligent access system could learn the user behavior and highlight the most frequently assigned tags so that clinician could efficiently use them. Also certain tags are more relevant to certain scenarios, for example the tag 'play' is more relevant to play alone/play with others as compared to scenario such as meal time. The system could highlight tags based on a scenario that a clinician is tagging. Another desired feature suggested by the clinicians in the access system evaluation is custom tags. Sometimes clinicians have individual preference for certain behaviors that they track continuously even in an in-person diagnosis. The system should allow clinicians to define or customized tags and associate them with the relevant DSM sub criteria.

9.3. Field Adoption

An open problem for future exploration is to design and validate the workflow model for the clinician-directed capture and access system's field adoption. One workflow model that we have envisioned along with our clinical partners at SARRC and commercial partners at Behavior Imaging Solutions involves a prescription for remote diagnostic assessment like any other lab tests. Pediatricians are typically the first medical professionals to flag children as potentially showing early signs of autism or developmental delays, and are responsible for referring families to a specialist for further assessment. In the proposed workflow, the pediatrician can prescribe our remote diagnostic assessment for children who he or she seems as showing early signs of autism. The way the prescription is then sent to the parents can happen in several different ways: parents can receive the behavior specimen collection kit in the mail (similar to the kit shown in Figure 5) or they can pick it up from a designated location (in the same way that a specimen collection kit is collected from the lab). A clinician at a participating diagnostic center who is experienced in autism diagnosis can then guide the in-home behavior specimen collection procedure. Once all specimens are collected, the clinician can complete the diagnostic assessment for autism through the access system. Finally, the outcome (a report generated by the system) can be shared with the pediatrician, who then shares it with parents. The report may include the diagnostic outcome as well as recommendation about potential interventions and/or suggested intervention providers. This is just one workflow model that we have envisioned, several variations can be considered. For example the clinician who diagnosed the child could communicate the report directly to the parents instead of doing so through the pediatrician. Another variation could be that at early stages of in-home collection a less experienced clinician can guide parents, and once good quality specimens are collected, an experienced

clinician (a more expensive resource) can perform the diagnosis and, if needed, can ask parents to record additional specimens.

Overall, this workflow model has two potential benefits. First it engages pediatricians, which is beneficial since research suggests that pediatrician involvement in the referral and diagnostic process can result in more timely diagnosis [75-78]. Since a pediatrician sees children at regular intervals during the early years of development, he or she, is in the best position to notice early warning signs of developmental delay and take appropriate timely action. Second, this workflow model will allow autism centers to serve more families by remotely assessing children. Children whose diagnostic outcome is not clear through this remote diagnostic procedure can be seen in person for a more comprehensive diagnostic assessment.

CHAPTER 10

CONTRIBUTIONS AND CONCLUSION

In this chapter, I summarize and reflect back on the thesis statement, the research questions regarding the thesis statement and the resulting contribution of the series of research studies conducted to address these research questions. This chapter also concludes this thesis work.

10.1 Summary of Research questions and contributions

My thesis statement is, "An appropriately designed capture and access technology can enable: 1) parents to easily collect in-home behavior specimens that have clinical utility, and 2) clinical experts to complete a diagnostic assessment for autism based on parent-collected in-home behavior specimens."

In particular, I address the following research questions in this thesis.

RQ1: What are the potential opportunities and challenges specific to the design and adoption of a technology solution that enables in-home behavior specimen collection and diagnostic assessment for autism based on these specimens?

For this question, I designed and developed an initial prototype of the clinician-directed capture and access system and used it as a technology probe in a Needs Analysis study with clinicians (n=11) and parents (n=7) of children with autism and related conditions (described in detail in Chapter 4).

Contributions

This study helped me investigate parents' and clinicians' current practices with respect to in-home recording and sharing of behaviors, and formulate concrete design guidelines based on key stakeholders' (parents and clinicians) reflection on potential design opportunities and adoption challenges towards a technology solution that

facilitates in-home behavior specimen collection for diagnostic assessment of autism. The clinician-directed capture and access system design is informed by findings from the Needs Analysis study (described in the Chapter 3). This study served as a mechanism to validate and explore the concept of "in-home behavior specimen collection and sharing to support clinical assessment for autism" with parents and clinicians of children with autism.

Subsequent iterative design of the clinician-directed capture and access system is informed by the design guidelines driven from this study.

RQ2: What are key features and functionalities of a smartphone-based capture system that allow parents to easily collect behavior specimens that have clinical utility?

For this question, the capture system was iteratively designed through a usability study in a home-like controlled setting, and the improved design was evaluated in the field (actual homes).

Capture system usability study in a home-like controlled setting

In this study parents were asked to use the capture system in a home-like controlled setting. This study was conducted in two phases. In phase-I, an initial design of the capture system was tested, whereas in phase-II the revised design of the capture system informed by the results of phase-I was tested. The goal was to identify functionalities and factors that contribute to the ease of use of the system as well as the clinical utility of collected behavior specimens, as rated by a clinician experienced in autism diagnosis. Based on findings from phase-I, major design improvements were made in the capture system design for ease of use. In phase-II, after experiencing the revised design, parents' rating of ease of use increased from an average of 3 to 4, on a scale from 1 (not easy to use) to 5 (easy to use). Unlike phase-I, parents did not encounter usability issues in phase-II, and the parent-collected specimens in phase-II

clearly followed the recording instructions that were given. In addition, in phase-II, based on detailed and systematic analysis of behavior specimens along with clinician ratings and feedback, factors that affect behavior specimens' clinical quality were identified. Analysis of the factors that affect the clinical quality of a video specimen facilitated the formulation of received recording instructions for parents that were later embedded as prescriptions in the capture system revised upon the completion of phase-II. Minor design changes were made in the revised capture system design as well.

Capture system evaluation in home

In this study parents used the revised design of the capture system that had been informed by the usability study in the controlled environment (study is described in detail in Chapter 5). Clinicians assessed behavior specimens collected through this study during the access system evaluation (described in detail in Chapter 6) for conducting autism diagnostic assessments. Analysis of the activity log and parents' ratings of ease of use showed that the system is easy to use in a home setting. Results showed that the specimens collected by parents using the improved capture system (revised recording instructions) and under the guidance of a remotely-located clinician had high clinical utility (96% with improved system during in-home study as compared to 81% in the controlled setting).

Contributions

Usability studies in the controlled and home environments established and validated a set of design features and functionalities essential for a capture system which is easy to use, and supports collection of behavior specimens that have clinical utility. For ease of use these features include clear representation of recording scenarios and implicit annotation, multiple and redundant ways to represent system status (recording mode, recording elapsed time) and clear prescription. For higher clinical utility the key features

within the capture system are embedded prescriptions and additional clinician guidance through notifications.

RQ3: What are the key features and functionalities of an online Access system that enables clinicians to guide in-home behavior specimen collection and complete remote diagnostic assessment for autism based on in-home behavior specimens?

For this question, I designed and evaluated the online access system by asking clinicians experienced in autism diagnosis to complete a diagnostic assessment for autism using the videos that had been recorded by parents in their homes. Two clinicians independently analyzed the videos from each family. Diagnostic assessments were solely based on in-home behavior specimens collected by parents during the capture system in-home evaluation and the clinicians were kept blind to the child's developmental history. The results of the diagnostic assessment via the access system were compared with the child's previous diagnosis as listed in the child's medical record. Results showed that for 4 out of 5 children, the clinicians were able to reach the same diagnostic outcome that matched the child's actual diagnosis (one child was typically developing and four children were previously diagnosed with autism). Results also showed that of all the assessments conducted through the access system, in 91% cases (10 out of 11 autism diagnostic assessments) clinicians were able to arrive at a diagnostic outcome with an average confidence rating of 4.5, on a scale from 1 (not confident) to 5 (highly confident). This high average rating was obtained despite the initial skepticism expressed by some of the clinicians before the study started about the potential diagnostic value of video observation.

Contributions

I established and validated a set of design features and functionalities that are needed within the access system to support a clinician in: 1) guiding in-home behavior

specimen collection; and 2) completing a remote diagnostic assessment for autism, based on in-home behavior specimens, with high confidence. These features include guided capture, video observation and tagging, a built-in list of behavior tags extracted from a standard diagnostic assessment measure (in this case, the DSM), mapping of assigned tags to specific assessment measures (for evidence), and allowing clinicians to complete a checklist based on the tagged evidence and their clinical judgment.

10.2 Conclusion

This thesis presents the concept, design, development, and evaluation of a clinician-directed capture and access system that can enable parents to collect behavior specimens in the home and can enable clinicians to use this data to conduct a diagnostic assessment for autism. In-field evaluation of the clinician-directed capture and access system, created through an iterative design process, demonstrated that it can successfully enable parents to easily collect and share video specimens that have clinical utility and can enable clinicians to complete a diagnostic assessment for autism with high confidence in the diagnostic outcome.

The contributions of this thesis are as follows:

- I explored and introduced the notion of in-home behavior specimen collection for clinical assessment of autism with key stakeholders (parents and clinicians of children with autism).
- I investigated parents' and clinicians' current practices with respect to in-home recording and sharing of behaviors and derived concrete design guidelines based on key stakeholders' (parents and clinicians) reflection on potential design opportunities and adoption challenges towards a technology solution that facilitates in-home behavior specimen collection for diagnostic assessment of autism

- I identified key features and functionalities of a capture system that can enable parents to *easily* collect clinician-prescribed behavior specimens that have *clinical utility*;
- I identified key features and functionalities of an access system that facilitates clinicians to guide behavior specimen collection procedure and to *complete* remote diagnostic assessment based on behavior specimens collected from a naturalistic home environment
- I demonstrated through an end-to-end field study with parents and clinicians that parents can easily collect behavior specimens through the capture system that are diagnosis-ready, and clinicians can complete a remote autism diagnostic assessment based on in-home behavior specimens via the access system with high confidence in the diagnostic outcome.

The *prescription, collection and assessment model* behind clinician-directed capture and access system is generalizable and transferable to various other use cases in addition to the remote autism diagnostic assessment demonstrated in this thesis. This model augments the traditional ubiquitous computing capture and access models emphasizing the role of the user of the assess system as the consumer of the collected specimens and one who directs or guides the capture process. In those cases when the users of the capture and access system are not one and the same, this model provides a mechanism for both users to be partners in the data collection process in order to support the collection of relevant and meaningful data.

APPENDIX A

NEEDS ANALYSIS STUDY: PRE AND FOLLOW-UP QUESTIONNAIRE

Needs Analysis: Clinician Pre-Questionnaire Participant: **_____**

Your Information

Please answer the following questions about yourself.

1. What is your age?

   18-24 25-34 35-44 45-54 55-64 65 or above

2. Gender (circle one):

   Male Female

3. What is the highest level of education you have completed? (*Circle one*.)

   Elementary Middle-school High-school/GED

   College Post-Graduate

4. If you have earned a college degree, what is your degree in?

   _____

   _____

5. What additional certifications or training have you completed?

   _____

   _____

6. What are your primary responsibilities at work (e.g. observation and assessment of behaviors)?

   _____

   _____

Your Experience

7. How long have you worked with children with developmental disabilities?

_____

8. How many individuals with developmental disabilities do you interact with regularly?

1-5 **6-10** **11 or more**

9. How would you describe their behaviors (e.g. non-verbal.)?

_____

_____

10. How do you assess a child's behaviors?

_____

_____

_____

11. Do you record a child's behaviors in the clinic? If yes, what approaches do you use? What are the issues you encounter?

_____

_____

_____

12. Do you record a child's behaviors at home? If yes, what approaches do you use? What are the issues you encounter?

_____

_____

_____

13. Do you use any technology or software to record child behaviors? If yes, please describe them.

_____

_____

14. How often do you record a child's behaviors?

Multiple times a day	Once a day	Multiple times a week
Once a week	Multiple times a month	Once a month

Other: _____

15. What are the issues you encounter while recording a child's behavior(with respect to the video recording system)?

_____

_____

16. If it was easier/faster would you record a child's behaviors more often?

_____

_____

17. Do you employ video observation of behaviors? If yes what are important factors you look for in a recorded video?

_____

_____

_____

18. How often parents share video recordings of their child? What are the advantages and disadvantages of those recorded videos?

_____

_____

19. Please add any other comment you may have :

_____

_____

Thank you for your participation!

Needs Analysis: Clinician Post-Questionnaire Participant:_____

Please answer the following questions

1. What do you believe was the main purpose or goal of the system you just used?

_____

_____

_____

2. How would you describe the system:

Difficult to use				Easy to use
1	2	3	4	5

Please explain your choice:

_____

_____

3. How useful would this system be to record behaviors of a child?

Not useful				Very useful
1	2	3	4	5

Please explain your choice:

_____

_____

4. How useful would this system be to assess/understand behaviors of a child?

Not useful				Very useful
1	2	3	4	5

Please explain your choice:

_____

_____

5. Would you use this?

No	Maybe	Yes
1	2	3

Please explain your choice:

_____

_____

6. How often would you use this system?

Multiple times a day	Once a day	Multiple times a week
Once a week	Multiple times a month	Once a month
Other: _____		

7. Can this system increase communication between parents and behavior experts?

No	May be	Yes
1	2	3

Please explain your choice:

_____

_____

8. Which features (if any) would you add to the current system?

_____

_____

9. Which features (if any) would you exclude/remove from the current system?

_____

_____

10. What did you like best about the system?

_____

_____

_____

11. What did you like least about the system?

_____

_____

_____

12. Please add any other comment that you may have about the system:

_____

_____

_____

Thank you for your participation!

Needs Analysis: Parent Pre-Questionnaire Participant: _____

Your Information

Please answer the following questions about yourself.

1. What is your age?

   18-24 25-34 35-44 45-54 55-64 65 or above

2. Gender (circle one):

   Male Female

3. What is your highest level of education completed? (*Circle one*.)

   Elementary Middle-school High-school/GED

   College Post-Graduate

4. What is your ethnicity? (Circle all that apply.)

   African-American Asian/Pacific Islander Hispanic/Latino

   White/Caucasian Other_____

Other Information

Please answer the following questions about your child

1. Child's age: _____
2. What is your child's diagnosis? _____

   _____

3. How would you describe your child's level of functioning: verbal communication skills, academics, level of independence, etc?

   _____

   _____

   _____

4. What are some situations your child struggles with?

   _____

   _____

5. Do you record your child's behaviors? If yes, what approaches do you use? What behaviors you record?

   _____

   _____

6. Do you use any technology or software to record your child's behaviors? If yes, please describe them.

   _____

   _____

7. How often do you record your child's behaviors?

Multiple times a day	Once a day	Multiple times a week
Once a week	Multiple times a month	Once a month
Other: _____		

8. How long does it take you to record your child's behaviors?

   _____

   _____

9. If it was easier/faster would you record your child's behaviors more often?

   _____

   _____

10. How do you communicate your child's behavior with behavior analysts and experts (e.g. verbally, written reports, video, email, phone call) and how often?

_____

_____

11. Which smart phones have you used and for how much time?

_____

_____

12. Please briefly describe your experience with video recording on smart phones(how frequent do you record, likes and dislikes about recording features)?

_____

_____

13. Please add if you want to share any other information.

_____

_____

Thank you for your participation!

Needs Analysis: Parent Post-Questionnaire Participant:_____

Please answer the following questions

1. What do you believe was the main purpose or goal of the system you just saw?

_____

_____

2. How would you describe the system:

Difficult to use				Easy to use
1	2	3	4	5

Please explain your choice:

_____

_____

3. How would you describe the tutorial session:

Difficult to understand				Easy to understand
1	2	3	4	5

Please explain your choice:

_____

_____

4. How useful would this system be to record behaviors of your child?

Not useful				Very useful
1	2	3	4	5

Please explain your choice:

_____

_____

5. Would you use this system to record your child's behavior?

No	Maybe	Yes
1	2	3

Please explain your choice:

_____

_____

6. How often would you record behaviors if you use this system?

Multiple times a day	Once a day	Multiple times a week
Once a week	Multiple times a month	Once a month
Other: _____		

7. Would such a recording system be intrusive to your privacy?

Very intrusive				Not intrusive at all
1	2	3	4	5

8. If you did not respond "5," please explain your choice:

_____

_____

9. Which features (if any) would you add to the current system?

_____

_____

10. Which features (if any) would you exclude/remove from the current system?

_____

_____

11. What did you like best about the system?

_____

_____

12. What did you like least about the system?

_____

_____

13. Can this system increase communication between you and behavior experts?

No	May be	Yes
1	2	3

14. Please add any other comment that you may have about the system:

_____

_____

Thank you for your participation!

APPENDIX B

USABILITY STUDY: PRE AND FOLLOW-UP QUESTIONNAIRE

Capture system usability. Parent Pre-Questionnaire Participant: _____

Your Information

Please answer the following questions about yourself.

5. What is your age?

   18-24 25-34 35-44 45-54 55-64 65 or above

6. Gender (circle one):

   Male Female

7. What is your highest level of education completed? (*Circle one*.)

   Elementary Middle-school High-school/GED

   College Post-Graduate

8. What is your ethnicity? (Circle all that apply.)

   African-American Asian/Pacific Islander Hispanic/Latino

   White/Caucasian Other_____

Other information

Please answer the following questions about your child

14. Child's Age: _____

15. Do you record your child's activity? If yes, what approaches do you use? What activities you record?

    _____

    _____

16. Do you use any technology or software to record your child's activity? If yes, please describe them.

    _____

    _____

17. How often do you video record your child activity?

Multiple times a day	Once a day	Multiple times a week
Once a week	Multiple times a month	Once a month

Other: _____

18. How long does it take you to record your child's activity?

_____

_____

19. If it was easier/faster would you record your child's activity more often?

_____

_____

20. Which smart phones have you used and for how much time?

_____

_____

21. Please briefly describe your experience with video recording on smart phones(how frequent do you record, likes and dislikes about recording features)?

_____

_____

22. Please add if you want to share any other information.

_____

_____

Thank you for your participation!

Capture system usability study: Parents post questionnaire

Please answer the following questions

1. What do you believe was the main purpose or goal of the system you just used?

_____

_____

_____

2. How would you describe the system:

Difficult to use				Easy to use
1	2	3	4	5

Please explain your choice:

_____

_____

3. How would you describe the tutorials session:

Difficult to understand				Easy to understand

1	2	3	4	5

Please explain your choice:

_____

_____

4. How useful would this system be to record activity(or behavior) of a child?

Not useful				Very useful
1	2	3	4	5

Please explain your choice:

_____

_____

5. Would you use this system to record your child's activity?

No	Maybe	Yes
1	2	3

Please explain your choice:

_____

_____

6. How often would you record your child activities if you use this system?

Multiple times a day	Once a day	Multiple times a week
Once a week	Multiple times a month	Once a month
Other: _____		

7. Was the recording (in the system) intrusive to your privacy?

Very intrusive				Not intrusive at all
1	2	3	4	5

Please explain your choice:

8. If you did not respond "5," please explain your choice:

_____

_____

9. How typically did your child behave while the system was recording?

Did not behave at all like he/she usually does				Behaved exactly like he/she usually does

1	2	3	4	5

10. If you did not respond “5” please explain how your child behaved differently than he or she usually does:

    _____

    _____

11. If you did not respond “5” Please explain what could be the reason(s):

Recording system	Change of environment
Other: _____	

12. Which features (if any) would you add to the current system?

    _____

    _____

13. Which features (if any) would you exclude/remove from the current system?

    _____

    _____

14. What did you like best about the system?

    _____

    _____

15. What did you like least about the system?

    _____

    _____

16. Please add any other comment that you may have about the system:

    _____

    _____

Thank you for your participation!

APPENDIX C

EMBEDDED RECORDING INSTRUCTIONS

Below are embedded instructions informed by usability study phase-I findings.

Family Meal time

Record any family mealtime. Mount the camera ahead of time. Make sure everyone is in the frame and the child is facing the camera. Interact with each other like you normally do. Interact with the child at least 4 times (say his name; offer food/drink; ask him to look at something and point to it; look at him and smile, see if he smiles back). Other family members should also interact with the child, but do not overdo it (if the child starts to talk/ interact, let him guide the interaction).

Play with others

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.

Play alone

Record your child playing with toys/fun items (NO ELECTRONICS). Set up 5-10 toys. Mount the camera ahead of time and make sure the child/toys are in view and the child is facing camera. Play with him briefly to get the play started (call his name; point to something saying "Look at that"; ask him where something is in the room "Where's the

dog?"; try to get him to smile without touching). After each interaction, wait and see what he does. After a few minutes of interaction, let him play alone.

Parent concerns

Record any time/activity that results in behavior that is of primary concern for you and that you would to share with the clinician. Set up the camera ahead of time. In the first minute of recording please say out loud what you would like the clinician to see ("This is Johnny ignoring me;" "This change causes a really bad temper tantrum"). Make sure the child being recorded is in view of the camera. If necessary, move the camera around, but try not to be obviously filming the child.

APPENDIX D

CHILD DEVELOPMENTAL HISTORY FORM

a. Child date of birth

b. Child picture

1. How old was your child when you first became concerned about his/her development? What made you concerned?

2. Does your child use single words? If yes, how old was your child when he/she started to use single words?

3. Does your child use phrases like, "I want_____?" If yes, how old was your child when he/she started to use phrases?

4. Does your child have any current medical conditions?

5. Have you ever had your child's hearing checked?

APPENDIX E

DSM IV

[The following is from *Diagnostic and Statistical Manual of Mental Disorders: DSM IV*]

(I) A total of six (or more) items from (A), (B), and (C), with at least two from (A), and one each from (B) and (C)

(A) Qualitative impairment in social interaction, as manifested by at least two of the following:

1. Marked impairments in the use of multiple nonverbal behaviors such as eye-to-eye gaze, facial expression, body posture, and gestures to regulate social interaction
2. Failure to develop peer relationships appropriate to developmental level
3. A lack of spontaneous seeking to share enjoyment, interests, or achievements with other people, (e.g., by a lack of showing, bringing, or pointing out objects of interest to other people)
4. Lack of social or emotional reciprocity (note: in the description, it gives the following as examples: not actively participating in simple social play or games, preferring solitary activities, or involving others in activities only as tools or "mechanical" aids)

(B) Qualitative impairments in communication as manifested by at least one of the following:

1. Delay in, or total lack of, the development of spoken language (not accompanied by an attempt to compensate through alternative modes of communication such as gesture or mime)
2. In individuals with adequate speech, marked impairment in the ability to initiate or sustain a conversation with others
3. Stereotyped and repetitive use of language or idiosyncratic language

4. Lack of varied, spontaneous make-believe play or social imitative play appropriate to developmental level

(C) Restricted repetitive and stereotyped patterns of behavior, interests and activities, as manifested by at least two of the following:

1. Encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus
2. Apparently inflexible adherence to specific, nonfunctional routines or rituals
3. Stereotyped and repetitive motor mannerisms (e.g. hand or finger flapping or twisting, or complex whole-body movements)
4. Persistent preoccupation with parts of objects

APPENDIX F

EXAMPLE TAGS AND MAPPINGS

Examples of built-in atypical behavior tags in the access system

DSM Checklist Information	Description	Modified Tag
Category 2. Qualitative Impairments in Communication	(a) Delay in, or total lack of, the development of spoken language (not accompanied by an attempt to compensate through alternative modes of communication such as gesture)	Comm: Verbal: No phrases
Category 2. Qualitative Impairments in Communication	(a) Delay in, or total lack of, the development of spoken language (not accompanied by an attempt to compensate through alternative modes of communication such as gesture)	Comm: Verbal: No words
Category 2. Qualitative Impairments in Communication	(a) Delay in, or total lack of, the development of spoken language (not accompanied by an attempt to compensate through alternative modes of communication such as gesture)	Comm: Verbal: Odd cry
Category 3. Restricted repetitive & stereotyped behavior, interests, activities	(d) Persistent preoccupation with parts of objects or sensory qualities of objects.	Behavior: Throwing toys repetitively

Examples of built-in typical behavior tags in the access system

Typical: Eye Contact
Typical: Eye Contact w/facial expression
Typical: Facial Expression
Typical: Social Response (i.e., laugh)
Typical: Verbal response
Typical: Point
Typical: Head/shake nod or other gesture
Typical: Play with others
Typical: Play with toys

APPENDIX G

CAPTURE SYSTEM DESIGN USED IN THE IN-HOME STUDY

The capture system home screen is preset with clinician's prescription (NODA). Parent can select one of the prescribed behavior specimens to start recording it

Recording instructions appear on selecting a scenario to record.

Recording mode

Option to send recorded video

Figure 19: Capture system design for in-home deployment

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