DECISION SUPPORT FOR CAREGIVERS THROUGH EMBEDDED CAPTURE AND ACCESS

A Dissertation Presented to The Academic Faculty

by

Julie A. Kientz

In Partial Fulfillment Of the Requirements for the Degree Doctor of Philosophy in Computer Science

Georgia Institute of Technology

August 2008

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DECISION SUPPORT FOR CAREGIVERS THROUGH EMBEDDED CAPTURE AND ACCESS

Approved by:

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

Dr. Rebecca E. Grinter School of Interactive Computing *Georgia Institute of Technology*

Dr. Elizabeth D. Mynatt School of Interactive Computing *Georgia Institute of Technology* Dr. Mark S. Ackerman School of Information, EECS University of Michigan

Dr. Thomas Rodden Department of Computer Science University of Nottingham

Date Approved: July 7, 2008

To Shwetak, whose unending enthusiasm has inspired me greatly.

ACKNOWLEDGEMENTS

The work presented in this dissertation would not have been possible without the help from the many wonderful people in my life with whom I have been fortunate enough to know. I would like to use this space to thank everyone and give them credit for how they were able to help me complete this work and my degree.

First and foremost, I want to thank Shwetak Patel. First you were a friend and lab mate, and your enthusiasm and constant passion for accomplishing so much inspired me to strive to great levels as well. Then, you became someone whose influence will affect me for the rest of my life and for that, I am very grateful. You were always there for me when I needed you and helped me accomplish so much more personally and professionally than I ever would have alone. I very much look forward to spending our lives together and am so glad we were fortunate enough to meet.

I next want to thank my family, who has always been very supportive of me in all that I have pursued. Thank you to my parents, Tom and Carol Kientz, who have always told me that I could always do anything I set out to accomplish and have always been so optimistic about what I would be able to do in my life. Thanks for always encouraging me to explore my own path and never settle for anything. I also want to thank my brother and sister-in law, Jeremy and Shawna Kientz, and my adorable nephew Jacob. Even from afar, you have always been supportive of my work and my life, and Jacob served as such a fun inspiration for the Baby Steps and KidCam work. To my advisor, mentor, and friend Gregory Abowd, I wish to thank you for everything you have done for me, both professionally and personally. I really could not have asked for a better advisor, and I feel so fortunate that you gave me the opportunity to work with you and to trust me with a research area that is so important to you. You challenged me enough to get me to do the things I needed to do, provided me with inspiration with your passion and dedication to important causes, and taught me the importance of working on research projects that were personally motivating. That inspiration gave me the will to choose research agendas that were of social importance, which I will always strive to do throughout my career. I also wish to thank the rest of my thesis committee, Beki Grinter, Beth Mynatt, Mark Ackerman, and Tom Rodden, for your supportive comments and advice that helped me shape much of my work. Thank you for allowing me the honor of working with you, and I hope that we will continue our collaboration throughout the rest of our careers. Also, thank you to Rosa Arriaga for your valuable help and advice on my dissertation work.

I next would like to thank the past and present members of the Ubicomp Research Group. All of you are like a family to me, and I want to thank all of you personally for providing me with advice, collaboration, mentorship, and friendly competition, all of which have helped me to succeed and enjoy graduate school. Thank you in particular to Shwetak Patel, Gillian Hayes, and Khai Truong. I have thoroughly enjoyed our research collaborations and strong friendships that have grown over the past five years. Also, thank you to Heather Richter, Jay Summet, Anind Dey, Jen Mankoff, Giovanni Iachello, Kris Nagel, Lonnie Harvel, Erich Stuntebeck, Lana Yarosh, Mario Romero, Tae Jung Yun, Sunyoung Kim, Arwa Tyebkhan, and Aras Bilgen. I am glad we got the opportunity to know each other and work with one another, and I look forward to continued collaborations.

To Anind Dey and Jennifer Mankoff, I want to thank you personally for helping me to get where I am today. You took a chance on someone from an unknown school who did not really know what she wanted to do with her life and introduced me to research, the field of Human-Computer Interaction, and the concept of applying my passion for computing to problems that addressed important human issues. More importantly, you gave me the confidence to apply to Ph.D. programs in the first place and the desire to continue my education in this field.

I also want to thank the many members of the individual project teams that comprised this dissertation work. It is very difficult to accomplish large research projects alone, and many of these projects would not have been successful without your assistance. For the Abaris for Homes project, I want to thank Sebastian Boring, Gillian Hayes, and Beki Grinter for their help in developing Abaris, conducting the study, and analyzing the results. I also wish to thank the participants in the study, including Integrated Behavioral Solutions and especially Aidan Abowd. For the Abaris for Schools project, I wish to thank Mark Harniss, Susan Sandall, Ilene Schwartz, Shane Herriott, Tina Wang, Roman Savaryn, Arwa Tyebkhan, and Shwetak Patel for your assistance in designing and conducting the study and the development work for the redesigned version of Abaris. Also, thank you to the Experimental Education Unit teachers and students who allowed us to experiment in their classroom and try our technology.

For the Baby Steps and KidCam projects, I wish to thank Stefan Puchner, Yi Han, Arwa Tyebkhan, Tracy Westeyn, Krystian Alberciak, Sunyoung Kim, Marshini Chetty, Jahmeilah Richardson, Rosa Arriaga, and Shwetak Patel for your help in conducting the formative study, help in developing the Baby Steps and KidCam prototype applications, and conducting the final deployment study. Thank you to the pediatricians and staff at Johns Creek Pediatrics for allowing me to work with you and your patients on this work and thank you to the families for your participation in the study. Finally, I would like to acknowledge the Centers for Disease Control employees involved in the ActEarly campaign for serving as the inspiration for this work.

This work also would not have been possible without the generous funding from various organizations. Thank you to the National Science Foundation Graduate Research Fellowship, the Google Anita Borg Scholar Award, and the P.E.O. International Scholar Award for providing me with generous fellowships that have funded me over the course of my Ph.D. Thank you also to the National Science Foundation and the Cure Autism Now/Autism Speaks Foundation for providing research funding for the Baby Steps and Abaris work.

Last, but definitely not least, I want to thank all of my friends who have helped me along the way and made graduate school a much more enjoyable place. Thank you to Arya Irani, Sooraj Bhat, Tracy Westeyn, Chris Wojtan, Valerie Summet, Helene Brashear, Shan Shan Huang, Tammy Clegg, Elaine Huang, Raffay Hamid, Brian Landry, Ed Clarkson, Jason Day, Andrea Grimes, Marshini Chetty, Mark Nelson, Christina Strong, Sarah Osentoski, Paul Schultz, Daniel Avrahami, Andrew Cantino, David Roberts, Liam Mac Dermed, Denise Chew, Peng Zang, Hilary Nichols, and Santi Ontañón. All of you have been fantastic friends over the years, and I am glad to have gotten to know you all.

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LIST OF SYMBOLS AND ABBREVIATIONS

| ASD | Autism Spectrum Disorder |
|------|---|
| CDC | Centers for Disease Control and Prevention |
| CHOA | Children's Healthcare of Atlanta |
| CSCC | Computer-Supported Cooperative Care |
| CSCW | Computer-Supported Cooperative Work |
| DATA | Developmentally Appropriate Treatment of Autism |
| DSS | Decision Support System |
| DTT | Discrete Trial Training |
| EEU | Experimental Education Unit |
| GUI | Graphical User Interface |
| IEP | Individualized Education Plan |
| JCP | John's Creek Pediatrics |
| PDD | Pervasive Developmental Disorder |
| UMPC | Ultra-Mobile Personal Computer |
| UW | University of Washington |
| WCV | Well Child Visit |

SUMMARY

The care of individuals with concerns about development, health, and wellness is often a difficult, complicated task and may rely on a team of diverse caregivers. There are many decisions that caregivers must make to help ensure that the best care and health monitoring are administered. For my dissertation work, I have explored the use of embedded capture and access to support decision-making for caregivers. Embedded capture and access integrates simple and unobtrusive capture and useful access, including trending information and rich data, into existing work practices. I hypothesized that this technology encourages more frequent access to evidence, increased collaboration amongst caregivers, and decisions made with higher confidence.

I have explored this technology through real-world deployments of new embedded capture and access applications in two domains. For the first domain, I have developed two applications to support decision-making for caregivers administering therapy to children with autism. The first application, Abaris, supports therapists working with a single child in a home setting, and the second application, Abaris for Schools, extends the ideas of Abaris for use in a school setting for many teachers working with multiple children. The second domain I have explored is decision-making for parents of newborn children. In particular, I developed and evaluated embedded capture and access technology to support parents, pediatricians, and secondary childcare providers in making decisions about whether a child's development is progressing normally to promote the earlier detection of developmental delays.

CHAPTER 1

INTRODUCTION AND MOTIVATION

The care of individuals with concerns about development, health, and wellness is an important but complex and often difficult process. There are many aspects of caring individuals such as the elderly, children, or individuals with chronic conditions that need to be considered. In extreme cases, the people receiving care cannot take part in the care process or even give input as to how their condition is progressing and whether or not they are comfortable. Thus, people in these situations must rely on one or more caregivers to manage their well-being and help make decisions for them. In some cases, the person giving the care will be a trained professional, while other times, it may be a family member or friend with little or no training.

While caregivers may seek the best treatment possible for those for whom they care, it is difficult to know which treatment is best for a particular person. Additionally, it may be cumbersome to sort through masses of information to find the relevant pieces that will allow them to make the best decisions about whether or not treatments are effective. Caregivers often work independently to collect data about those receiving care; thus parents, teachers, physicians, and specialists must make sense of the data from many diverse sources. Examples of the types of questions various caregivers may answer are:

- Is the current treatment effective in addressing the relevant issues?
- Is the benefit of the current treatment worth the costs associated with it?
- Are the current treatments enough or should we do more?

- Is everything going normally or should we take preventive measures?
- Can we make a decision with the data at hand or do we need more information?
- Should we bring in a new care team member into the decision-making process?

These decisions are often made with the aid of some type of data identifying the current and past status of the person. Current practices involve varying degrees of data collection to make these decisions, ranging from no data at all, in which decisions may be based solely on the caregivers' impressions or recollections, to large amounts of medical or behavioral data collected or logged daily. Depending on the type of data being collected, it can be difficult to keep long-term, meaningful data records and for the caregiver to both provide adequate care and keep useful records.

Although data can be useful in making decisions, sometimes caregivers believe the cost of recording can outweigh the benefits it provides in making decisions about care. Even if data of certain types are easy to collect, it may be very difficult to find the useful information, especially if there is a large amount of it with little organization. Adding to the difficulty of just taking data, there is often much difficulty with compiling data into a useful form, such as creating graphs to show trends.

Caregivers often discuss, either formally or informally, observations about the patient or child's overall wellbeing and make decisions about the course of action. These caregivers may be distributed, amongst a team of similar caregivers, or completely heterogeneous in their work practices and schedules. Practices vary in how data collected is shared amongst caregivers, including variations in what data is shared, how often,

where, when, and with whom. Thus, there are elements of the decision-making process that may be collaborative in nature. The different backgrounds and experiences of each caregiver can be difficult to convey using traditional means of discussion, and thus artifacts may become important to help make decisions.

Although data-based decision-making is an important component of chronic care management, it is not a trivial task. Many times, the task of collecting data is so burdensome that caregivers do not have time to collect it properly (Heath & Luff, 1996). Improper data collection may include missing data points, such as events that happen when no one was expecting them, or unreliable data based on an overburdened caregiver's retrospective memory, perhaps reported minutes, hours, or days after a moment of interest occurs. Even when data is collected, it might not be presented in a way that is amenable to synthesis and understanding, or it might not be consulted regularly enough to impact the trajectory of treatment in a timely fashion. Additionally, much of the data collected in these settings is paper-based, so it is difficult to make changes, share with others for discussion, make connections between different views of data, and review richer data such as videos or images.

Technology that is unobtrusive, easy to use, and easy to share with others can assist these caregivers in the decision-making process. Thus, I have explored the design, development, and evaluation of a class of applications I call *embedded capture and access*. Embedded capture and access involves the use of technology for data recording (capture) and review (access), especially in such a way where the technology is seamlessly integrated into existing work practices and is unobtrusive to everyday activities. The data capture and access can be accomplished through automated data recording and indexing, peripheral or proactive notifications of trend information, or by taking advantage of existing motivations. Embedded capture and access expands upon the previous notion of capture and access defined by Abowd & Mynatt (Abowd & Mynatt, 2000) by ensuring that not only the data capture is ubiquitous, but both the data capture and access portions of applications are ubiquitous.

I have explored two specific domains in this research: the evaluation of treatments for children already diagnosed with autism or another developmental disability and the evaluation of young children's developmental progress. These domains present several interesting challenges for technology design and evaluation, due to the complex and diverse nature of treatment types, wide range of caregivers, and differences in the level of knowledge about the care process by the caregivers.

1.1 Motivation for Decision Support for Caregivers

I was motivated to explore caregiving domains where there was a good chance of technology having a large impact on improving the process and that had the potential to have a significant social impact. The two domains were both in the domain of caring for children, but have different long-term goals and caregiver motivations and backgrounds. This allowed me to explore using embedded capture and access techniques for decision-making among two caregiving domains, but that were different enough to allow me to explore a variety of issues. In this section, I talk about motivations for working on the two particular domains I chose.

1.1.1 Therapists of Children with Autism

Autism is a life-long developmental disability first appearing in young children and is characterized by deficiencies in communication, social skills, and creative and imaginative play (American Psychiatric Association, 1994). The care of children with autism can especially benefit from support in data-based decision-making, because it is often the case that individuals receiving the care cannot speak for themselves. Additionally, the behaviorists who are central to the treatment of these children are particularly interested in numerical data, especially trends over time (Hayes, Kientz, Truong, White, Abowd, & Pering, 2004).

One particular method of caring and teaching children with autism is through a type of therapy called Discrete Trial Training (DTT). Developed in the 1970's by O. Ivar Lovaas (Lovaas, 1981), DTT has evolved as a specific method from the field of Applied Behavior Analysis (Alberto & Troutman, 2003). Though slightly different from Lovaas' original conception, DTT is currently a best-practice method for teaching basic skills to children with autism and other developmental disabilities (Heflin & Simpson, 1998). In DTT therapy, teams of trained therapists conduct one-on-one sessions with a child to teach basic skills in a structured setting. These skills can include both academic, such as object identification or letter formation, and life skills, such as hand washing or asking for help.

Therapists collect large amounts of data, both qualitative and quantitative, to help determine the effectiveness of the therapy at teaching certain skills. They meet regularly to review these data and adjust the therapy regimen as needed. Because therapy is often administered individually or is prescribed by a different person than the one administering it, collaboration efforts are important in ensuring that therapy is conducted correctly and consistently. Using recorded data as evidence to support decisions can be crucial for effective treatment.

I chose to work with DTT therapists after meeting with several therapists and observing their meetings and practices as part of a general study understanding the needs of caregivers of children with autism. The DTT process was a well-defined, structured system that relied on large amounts of data where the traditional method was largely based on human input and calculations data was stored on paper. Therapists spent large amounts of time processing paper-work rather than working with the child, and thus there was an opportunity for computing technologies to help alleviate some of the burden of data collection. In addition, technology had the opportunity to facilitate the automatic integration of data across different levels of detail, resulting in collaboration tools that can enhance the group decision process.

Prior to beginning on this project, I had very little exposure to individuals with cognitive disabilities, and especially autism. My main personal motivation came through a desire to use my knowledge of computers help others who were at a disadvantage, either because of poor health, a disability, or who were lower income. Though I had had exposure to education via my mother's profession as a teacher and people with illness through volunteer work at the hospital, my own personal experiences with individuals with cognitive disabilities was still limited to what I had heard or read about in the mass media. The motivation to work with caregivers of children with autism came from my advisor, who had a personal motivation to work on autism due to his two sons having a

diagnosis on the Autism spectrum. Thus, my general desire to help those at a disadvantage was made more specific by his goals.

1.1.2 Caregivers of Young Children

It is estimated that as many as 10 percent of children will have a developmental delay (Simeonsson & Sharp, 1992). Many of these disorders are not apparent at birth and can manifest anywhere between the ages of 2 and 6, or even later. Many advocates argue that early detection is the key to improving the livelihood of these children, and previous research has shown that the earlier interventions are started with atypically developing children, the more effective they are in helping the children cope with the disabilities (Shore, 1997).

One way of improving the chances of early detection is through regular visits to the pediatrician and detailed record-keeping of when children meet different developmental milestones. Not meeting specific milestones by a certain age may be an early warning sign of any of these disorders. Thus, the Centers for Disease Control and Prevention in the United States (CDC) launched a national campaign, called "Learn the Signs: Act Early," to educate new parents about the warning signs of developmental delays (Centers for Disease Control and Prevention, 2008). The aim of this campaign is to equip parents with the knowledge to detect problems with their children and seek treatment as early as possible. The CDC website lists approximately 200 developmental milestones that parents can use to gauge the progress of their children's development.

Although tracking developmental progress of every child is an important public health goal, the job is largely left to parents to complete. Manually tracking every milestone is a daunting task for new parents, on top of the many additional responsibilities in their lives. Additionally, parents may not have the knowledge or motivation to identify and document these records. Consulting a paper book or a manual every few months may be too cumbersome and not interactive enough, and parents may be so overwhelmed by parenting that they forget to record the many new things their children are doing. In addition to just noting which milestones their children have achieved, parents may also need to track whether or not their children have lost any of the previously attained milestones or have slowed developmental progress overall, because signs of developmental delay can also manifest as a regression of skills or a plateau in skill development.

Many parents already engage in record-keeping tasks for new children, such as making photo albums or writing down important firsts, such as the date of the first tooth, in a baby book. Thus, there may be a desire to conduct record-keeping for sentimental reasons. Additionally, computing technology has the ability to address some of the difficulties and tedium associated with manually tracking milestones. Furthermore, this technology can be persuasive in nature and be used to motivate parents to collect data in the first place. Thus, there may be an opportunity for appropriately designed technology to aid parents and caregivers in tracking and recording their children's developmental milestones.

Proactive technologies that are also motivating or fun to use can prompt parents to look for specific milestones at key times or even help contact a healthcare professional if parents have any questions. Thus, I wanted to explore design requirements and technology solutions to help motivate and organize new parents in tracking and documenting developmental milestones and alert them to contact their pediatrician if there are any signs of developmental delay.

The main inspiration for this work came after seeing a presentation by the CDC at the 2004 Organization for Autism Research Conference. I had a personal desire to work in an area that focused on a more diverse and widespread population than Discrete Trial Training and addressed a larger social goal. Thus, when I needed an opportunity to generalize the application of embedded capture and access to a new domain, this domain seemed to be an obvious next step. Prior to beginning this work, I had some experience with those who were raising children, such as close friends and family members, and with the notion of developmental milestones, but I had not gone through the experience of raising a child myself.

1.1.3 Bringing These Domains Together

I have explored these two domains because they both deal with similar issues in decision-making; however, they address two very different purposes. The domain of supporting therapists of children with autism is a specialized care setting with teams of trained individuals who are close-knit and are expected to follow a particular therapy regimen. Often, they have regularly scheduled meetings where they are forced to make decisions in order for the therapy to progress further. In addition, therapists follow a specifically defined protocol, and thus the main goal for technology might be to help therapists keep more closely to this protocol.

In contrast, the domain of supporting new parents represents a much wider audience, with varying degrees of experience, dedication, and resources. Raising children is often an activity where parents learn as they go, may have many strong social and cultural influences, and there is no single, correct way to do it. Thus, the decisions made in this domain are much more informal. However, the consequences of decisions may be more drastic. For example, if parents decide not to vaccinate their children, they may be putting their child at risk for many diseases. Additionally, if parents choose to have their child screened for a developmental delay, they may detect it early enough that therapies will help the child overcome it well enough to thrive once they reach school age. Thus, technology may be able to assist by suggesting activities parents may try with their children and educating them about the vast amount of resources on early childhood development.

In exploring these two domains, I had a good opportunity to explore various aspects of embedded capture and access. The two domains have some similar goals of making decisions to improve care, and thus common metrics could be used in studies to determine the effectiveness of embedded capture and access. However, the differences in the two domains allowed me to explore different methods of embedding capture and access into different aspects of a work practice. Thus, I used these two domains to explore edge cases for use among several dimensions, namely the structured/unstructured nature of the activity, the rigor of the decision-making process, the motivation of the caregivers, the levels of training of the caregivers with respect to decision-making, and the level of homogeneity of caregiver teams.

1.2 Purpose of Research and Thesis Statement

With computing technology, researchers have the opportunity to simplify data collection and analysis, thus assisting caregivers in the decision-making process. Automating some of the data collection process can ease some of the burden on caregivers. Digitized records are often easier to search, share, and distribute. It is also easier to create varying levels of detail, such as an overall graph of a trend in progress or a more detail, day-to-day record of the level of care administered.

Technology designed to integrate seamlessly into existing practices has the potential to improve the data collection and analysis process for teams of caregivers. However, researchers must first determine if there is a need for this technology in certain domains. Thus, in this dissertation, I studied the potential use of technology in care settings related to the support of caregivers administering a specific treatment regimen to children diagnosed with autism or other developmental delays. I also investigated this technology's ability to support decision-making for parents and other caregivers of newborn children to enable detection of developmental delay.

I first determined if there is a need or desire for technology support for decisionmaking in these domains and the design requirements for that technology. Next, I iteratively designed and developed prototype systems of this technology and deployed them in real-world situations. Through these deployments, explored the usability of these systems, but more importantly, I evaluated the usefulness and effectiveness in supporting decision-making.

The overall immediate goal of this technology was to enable caregivers to make better decisions. However, the notion of a "better" decision is difficult to measure; therefore, I aimed to measure specific qualities that are typically present in good-decision making. Brassard and Ritter (Brassard & Ritter, 1996) state that some qualities of good decisions are:

- based on facts and evidence, not just opinions
- supported by all people affected by it
- made knowing what the consequences should be
- timely, but not so quick as to ignore important evidence

Embedded capture and access technology for caregivers should aim to support decision-making among these four qualities of a good decision. First, technology should enable users to collect useful and more appropriate data in a way that is easy and unobtrusive. It should also provide better access to data, thus increasing the frequency at which it is accessed. Decisions are often made without sufficient use of data, and they can potentially be improved if data is more frequently accessed. Richer data, such as audio or video, can also provide more clues into how care is progressing that memory or numerical data alone cannot provide. However, the collection of data should not interfere with the caregiver's ability to provide appropriate care. In addition, data collection alone is not enough to improve decision-making, as caregivers may become so overwhelmed in data that they do not have time to analyze or review it. Thus, this data must be organized and easily accessed to help with information overload.

Second, computing technology can improve the decision-making process for a team of caregivers by allowing for better collaboration and coordination, and thus a goal for this work should be to have as many people as possible giving their input into a decision. Because many caregivers may work independently from one another, computing technology can help in sharing and coordinating data, so that all members of the care team have access to the same data. This can also help reduce the amount of redundancy in the data.

Third, computing technology must provide caregivers with the ability to make decisions knowing what the consequences should be. However, because it may not be possible to determine what the consequences should be, researchers can at least allow caregivers to make decisions with higher confidence. This can also potentially lead to timelier decision-making and lead to better care for the individual.

With those goals in mind, I propose the following thesis statement: When applied to data-based decision-making for early childhood development, embedded capture and access can 1) increase the quantity of data capture, 2) increase the frequency of access, 3) improve perceptions about collaboration and communication amongst members of care teams, 4) allow caregivers to make decisions with increased confidence, and 5) help caregivers make more timely decisions.

1.3 Research Questions and Contributions

In this dissertation, I present the design, development, and evaluation of three systems to evaluate the effectiveness of computing technology to enhance the decision-making process for caregivers for two domains: administering therapy to children with autism and the record-keeping needs for parents of newborn children. The first two systems, Abaris for Homes and Abaris for Schools, support Discrete Trial Training therapy for children with autism. The first aims to support a dedicated team of therapists in a home setting, and the second supports a larger group of teachers working with many

students in a school setting. The third system, comprised of Baby Steps and KidCam, supports caregivers, including parents and pediatricians, who make decisions about the developmental progress of young children.

For each of these domains, I have conducted extensive formative work to determine the needs for embedded capture and access, which included interviews, focus groups, and participant observation with experienced members of the two domains. This has allowed me to determine the design requirements for the development of these technologies. Additionally, for each technology I have developed, I conducted a real world deployment study to determine the usability and usefulness of the applications. The first study was a 4-month deployment of Abaris for Homes with an in-home therapy team for a particular child with autism and his team of therapists. The second study was a 5-week deployment of Abaris for Schools in a school setting with a team of teachers working with 16 students with special needs. The third study was a 3-month deployment of the Baby Steps and KidCam systems to support the tracking of developmental milestones for parents of young children to keep track of progress and make decisions about the development of their child.

More specifically, during these deployments in the different domains, I aimed to answer several key research questions. The first question was determining whether or not embedded capture and access can allow caregivers to more frequently capture and analyze more data (Thesis Claims 1 and 2). To answer this question, I analyzed the data collected and accessed in all three studies. For the Abaris for Homes study, I looked at the therapists' ability to access various data artifacts during team meetings. For the Abaris for Schools study, I determined if embedded capture and access can provide better access to data to help make more timely decisions about the students' progress on skills. For the Baby Steps & KidCam systems, I measured the amount of data collected and accessed both with and without the use of the system.

The second main area I aimed to address in this dissertation is the ability for embedded capture and access to improve collaborative decision-making amongst teams of caregivers (Thesis Claim 3). To address this question, I evaluated the effects of the technology on collaboration in all three studies. For the Abaris for Home work, I evaluated the level of participation in team meetings for members both with and without the use of the system. For the Abaris for Schools work, I evaluated collaboration as reported by teachers in post-study interviews. For the Baby Steps and KidCam study, I evaluated the level of collaboration and communication between parents and doctors using the surveys administered after each Well Child Visit.

The third area addressed is whether embedded capture and access allowed care team members to make decisions with increased confidence (Thesis Claim 4). To determine this, I interviewed the Abaris for Schools study participants on their confidence in being able to make decisions both with and without the use of the system. For the Baby Steps and KidCam deployment, I had parents report their level of confidence for each of the milestones tracked with the system and also distributed paperbased surveys before and after the study where parents' rated their confidence levels.

The fourth area I addressed with this dissertation is whether applications with an embedded capture and access design can enable caregivers to make decisions on a timelier basis (Thesis Claim 5). To test this claim, I used the analysis of the children's records in the Abaris for Schools study to determine how much time was being spent on different skills. For the Baby Steps and KidCam applications, I determined timeliness by looking at how often records were recorded and how much time passed between when the parents used the system.

With this thesis, I address the following broad questions:

- What needs do therapists for children with autism have for embedded capture and access, and what are the design requirements? For this question, I used formative studies to determine the design requirements for developing capture and access technology to support caregivers in a variety of domains. This included qualitative methods such as interviews with domain experts, participant observation, and collection and analysis of various artifacts used in the decision-making process.
- What needs do parents of young children making decisions about developmental progress have for embedded capture and access, and what are the design requirements? Again, I used qualitative methods in answering this question. This included interviews and focus groups with a variety of stakeholders in the decision-making process, including new parents, experienced parents, secondary childcare providers, and medical professionals.
- Can embedded capture and access help improve the decision-making process for teams of caregivers? Though it is difficult to measure if "better" decisions are made, I assessed whether the technology can improve various aspects of the decision-making process, as addressed in the following questions.
- Can embedded capture and access enable caregivers to collect more data (Thesis Claim 1)? Ideally, caregivers will be able to use embedded capture and access to collect more data without too much change to their existing practices. This can

include embedding capture capability into the activities in which they are already engaged or motivated to do.

- *Can embedded capture and access enable caregivers to better analyze data (Thesis Claim 2)?* Caregivers often collect large amounts of data, but not have the time to properly analyze or review it. By making the process of compiling data easier and quicker, I aim to increase the likelihood of review. Additionally, by including aspects of access into existing practices, such as showing a graph of progress at the time data is recorded, technology may be able to increase opportunities for access to data.
- Can embedded capture and access improve collaboration and communication amongst teams of caregivers (Thesis Claim 3)? Because decisions are often made as part of a team, embedded capture and access should also support caregivers in collaboration and communication. This can come in the form of encouraging more discussion during meetings, increasing frequency of communication about data, or by allowing data to be easily shared across caregivers.
- Can embedded capture and access enable caregivers to make decisions with increased confidence (Thesis Claim 4)? Caregivers may feel as if the care they administer is not having an impact on those receiving care because they do not see immediate results. By allowing better analysis over time and more frequent access to data, embedded capture and access can ideally increase the confidence of caregivers in decisions they are making about progress.
- Can embedded capture and access enable caregivers to make timelier decisions (*Thesis Claim 5*)? Because the goal of embedded capture and access is to make the data collection and analysis process easier, another potential improvement in

decision-making is to see whether decisions are made more quickly than with previous methods.

- What are appropriate design guidelines for developing embedded capture and access applications? The findings from this work can generalize into guidelines other application designers may find useful for designing embedded capture and access applications or for designing in the explored domains (or other similar domains).
- What types of studies can evaluate the effect of embedded capture and access on the decision-making process? I aim to determine if the methods I used to study the effectiveness of the embedded capture and access applications will be effective in verifying if the decision-making process was improved. I also expect to determine which aspects of these studies might be useful and generalizable to other areas of Human-Computer Interaction.

1.4 Overview of Dissertation

This dissertation is divided into eight chapters, including this introductory chapter:

Chapter Two describes related work in the areas of meetings and decisionmaking, supporting the general problem of health and collaborative care, and then finally the more specific domains of supporting autism and the care of young children. In this chapter, I explain how this dissertation work builds upon and expands knowledge in these areas. For meetings and decision-making, I cover the areas of CSCW and traditional decision-support techniques. For health and collaborative care, I look specifically at how ubiquitous computing and HCI have addressed the problems of caregivers for different health domains, the collaborative nature of care, and how technology has been used to persuade people toward healthy behaviors. Finally, for the specific domains, I discuss related work in supporting family needs, the general problem of early detection of various disorders, and technologies to support the care of individuals with autism.

Chapter Three describes the formative studies I undertook to get a better understanding of the two domains for which I was designing. In particular, I describe the large study in which I participated that looked at the general problem of supporting caregivers of children with autism and then my experiences in exploring the domain of Discrete Trial Training therapy by becoming trained as a therapist. I next describe a formative study I lead to uncover the design requirements for technology to support the record-keeping needs of new parents. This study consisted of interviews and focus groups with various stakeholders in the care of young children, including new and experienced parents, secondary care providers, and medical professionals.

Chapter Four provides an overview of three embedded capture and access technologies I designed and developed to support the two domains I have studied. The first is Abaris for Homes, an application that uses digital pen and paper and voice recognition technologies to automatically collect information during Discrete Trial training therapy sessions and provides an access interface to be used for collaborative decision-making during meetings. The second application is Abaris for Schools, which was a redesigned version of Abaris for Homes designed to address the specific needs of individuals conducting Discrete Trial Training therapy in a classroom setting. The third application is a set of tools, called Baby Steps and KidCam, which I designed to support parents in gathering and analyzing data about their children's developmental progress. In this chapter, I describe the design process for each of the applications and then the final design and implementation details for each application.

Chapter Five provides details on the study I conducted for the Abaris for Homes application. This study consisted of a deployment of the Abaris application with a team of therapists over a four-month period. I present the study design details, the results, and a discussion of the findings. I also describe how Abaris for Homes was able to support therapists in using more reliable evidence in decision-making and improve collaboration during team meetings.

Chapter Six provides the details on the study I conducted in collaboration with the University of Washington on the Abaris for Schools application. Again, this study consisted of a deployment of the technology in a classroom setting using real children's data, this time for 5 weeks. I present the study design, results, and a discussion of the findings and further implications for embedded capture and access. In particular, I describe how Abaris for Schools enabled more timely decision-making and increased perceptions of collaboration and confidence among teams of teachers.

Chapter Seven describes the details of the study I conducted to test the effectiveness of the Baby Steps and KidCam applications in supporting decision-making for new parents. I explain the design of a study comparing an experimental version of the technology with a control version to understand whether the features deemed to be "embedded capture and access" were effective in supporting parents in making decisions about care. I then present the results and discuss the findings and their further implications for capture and access. In particular, I describe how the experimental version of the technology enabled and encouraged parents to collect more data about their child,

review it more frequently, improve communication with pediatricians, and make more timely decisions.

Finally, Chapter Eight ends the dissertation with an overview of the results of the studies I conducted, including concluding remarks about how the nature of embedded capture and access enables caregivers to make better decisions along the dimensions described in the thesis statement. I also provide a synthesis of various discussion points that came as a result of the applications studied, discuss what open questions remain, and outline the future of work in this area.

CHAPTER 2

BACKGROUND AND RELATED WORK

In this chapter, I discuss background and work related to several key areas of computing to support decision-making and caregivers. In particular, I describe how my work fits into the areas of meetings and decision-making, the general area of health and collaborative care, and the more specific domains of supporting families and individuals with autism. This section serves as an overview of related work in this area.

2.1 Meetings and Decision-Making

Decision-making in care settings is usually collaborative, and thus literature from the Computer-Supported Cooperative Work (CSCW) was particularly relevant to my research. In particular, this research involves supporting individuals who must work together to make decisions, such as in a collocated meeting setting where caregivers discuss information face-to-face, or through a more asynchronous method, such as emailing their child's pediatrician a question about their child's developmental progress.

2.1.1 Collaborative Data Review

A wide variety of technologies exists in both research and commercial products to support teams of people meeting together, in person or at a distance, synchronously or not, for large and small groups. Of particular relevance to my work is the strand of research, initiated in the ubiquitous computing research community and defined by Abowd & Mynatt (Abowd & Mynatt, 2000), concerning the automated capture of team meetings for perusal later by an individual or group. The Tivoli (Pedersen, 1993) and TeamSpace systems (Richter, Abowd, Geyer, Fuchs, Daijavad, & Poltrock, 2001) both relied on the artifacts created as part of the team meeting to provide cues to the user to access that information later. Furthermore, the eClass project (Brotherton & Abowd, 2003), and many other subsequent efforts, provided these capture and access services for a classroom setting. NoteLook (Chiu, 1999), NotePals (Davis, 1999), and StuPad (Truong & Abowd, 1999) all allow asynchronous annotation of videos in a collaborative setting, but are not designed for accessing multiple experiences as a collaborative activity. The work in this dissertation also differs from other capture and access systems, such as MyLifeBits (Gemmell, Bell, Lueder, Drucker, & Wong, 2002), the Personal Audio Loop (Hayes, et al., 2004), Audio Notebook (Stifelman, 1997), and MIT's personal memory aid (Vemuri, Schmandt, Bender, Tellex, & Lassey, 2004) in that these are designed for personal use of unstructured live experiences, rather than group access to a structured activity. Significantly, in my work, the capture and access systems were not used to document the meetings themselves, but to provide input to the discussions at the meetings. These applications typically focus on low-need access situations, whereas in my work, I focus on higher need situations, as in many times caregivers cannot progress further without accessing data.

There has been relatively little research into automated capture and access systems in which access is predominantly a synchronous, collaborative effort (Truong, Abowd, & Brotherton, 2001). However, there have been numerous computing systems designed to support collaborative, synchronous meetings, similar to the type of interaction Abaris for Homes was designed to support. For instance, Teasley *et al.*

examined how people in "war rooms" can effectively use technology to support collaboration (Teasley, Covi, Krishnan, & Olson, 2000). Wang & Blevis have investigated how technical design concepts can support a team of industrial designers (Wang & Blevis, 2004). Other individual technological design factors have also been explored. For example, shared displays can impact the collaboration of teams who are synchronously located (DiMicco, Pandolfo, & Bender, 2004), including large, shared displays (Russell & Gossweiler, 2001) and tabletop interaction (Deitz & Leigh, 2001). In my work, I expand on these ideas, especially in using shared artifacts for collaboration.

2.1.2 Supporting Decision-Making

Using computing technology to support individuals making decisions in the workplace and other settings has been a widely studied topic. One of the first sets of applications to evolve with the advent of distributed and personal computing was the concept of Decision Support Systems (DSS) (Power, 2003; Sprague Jr & Carlson, 1982). These systems have evolved over the last 35 years from simple attempts to quantify and record information about ideas, people, and organizations into complex applications that may provide a variety of features, including collaborative discussion tools and complex preference algorithms for individuals and for groups. The long history of these applications has included their use in analysis of complex problems by doctors in hospitals (Hunt, Haynes, Hanna, & Smith, 1998), managers in corporations (Turban, 1995), and in engineering and scientific pursuits.

Interestingly, DSS technologies often use information gathered from a large number of people and a large number of resources to generate models that are then used by a single person to make a decision. Furthermore, they typically distill rich information (such as preferences or measures of quality) into numeric representations, again to abstract the data for clearer decision support. In my research, I focus on an application designed to support a group of individuals making complex decisions about the care of children. Furthermore, the systems I have developed are much less complex and require far less overhead in learning and data population than traditional DSS.

Similar to the early studies of war rooms and air traffic control towers (Suchman, 1987; Harper, Hughes, & Shapiro, 1990; Mackay, Fayard, Frobert, & Medini, 1998) the CSCW community has had a long tradition of interest in fast-paced group decisionmaking phenomena. Despite the movement of healthcare from specialized clinics into people's homes, the majority of healthcare-related collaborative technologies have not had a focus in the home. Collaboration in emergency rooms and among emergency service workers has garnered particular attention as a unique set of situations in which workers must take advantage of the tools around them, technological and otherwise, to support cooperative activities for the good of the patients in need. Whalen, (Whalen, 1995) describes the coordination that can and must take place between callers and the emergency support staff through the lens of Computer Aided Dispatch (CAD). Similarly, Bowers and Martin (Bowers & Martin, 1999) focused on the collaborative work of dispatching ambulances for emergency paramedic care. Finally, the SOS project sought to uncover ways in which collaboration differed across emergency care situations based on the organization providing the care (Pettersson, Randall, & Helgeson, 2002).

Care teams studied as part of this project also use a variety of tools available to them to communicate among the team members, maintain mutual awareness of information, and distill ambiguities in directions and diagnosis. The pace of these decisions and this communication among the group is much slower, however, than in emergency care. Decisions are made with respect to the direction and specifications of the care only two to four times per month during discussions that can range anywhere from a few minutes to half an hour. Additionally, much of the work I am conducting takes place in a home setting, which does not have many of the resources available to offices and medical settings, and is a fairly new topic in coordinated care. Pinelle and Gutwin are a notable exception in their work in supporting home-based care teams (Pinelle & Gutwin, 2005).

Individual decisions are also very different, in part due to the pace of the care, but primarily due to a different understanding of what is at stake for the individual receiving the care. In the case of emergency work, a patient's life may well be at stake, and decisions must be made quickly and with respect for the severity of the potential consequences of a mistake. In the care of a young child, an individual's decision about the child's performance on a task or understanding how the child is progressing could have significant repercussions in terms of the child's ability to learn or future needs of the child. The child's life, however, is typically never in physical danger at the time of the decisions. Indeed, even the errors in learning or problems detected late can usually be corrected if caught by a caregiver within a relatively short (weeks rather than years) period of time.

One of the main differences between embedded capture and access and traditional capture and access is the focus on making both the capture and the access aspects ubiquitous. Traditional capture and access systems have primarily had low use for access

unless there was a high enough need to make an explicit action. One area of research that has sought to make access more ubiquitous is through the use of ambient or peripheral displays (Wisneski, et al., 1998). Ambient displays present information in the periphery of the user so as not to distract them during normal tasks, but present information in such a way that it can be understood if desired. Typically, ambient displays show information such as bus schedules (Mankoff, Dey, Hsieh, Kientz, Lederer, & Ames, 2003), stock market information (Ishii & Ullmer, 1997), or traffic status (Stasko, Miller, Pousman, Plaue, & Ullah, 2004), which are information needs without any specific goals. The work I focus on here is presenting information ubiquitously that is more relevant to a specific task and is comprised of data that the person themselves may have captured. One research project that has begun to explore this area is that of Hsieh et al.'s (Hsieh, Wood, & Sellen, 2006), which displays a person's handwritten notes as a screen saver to encourage them to reflect on past-written data.

2.2 Health and Collaborative Care

Many aspects of data-based decision-making and supporting caregivers have been explored in the healthcare domain, whether they are for individuals in a hospital, care for elderly in assistive living facilities, or care for sick individuals in home settings. There are many similar challenges in these domains as there are in caring for children.

2.2.1 Supporting Healthcare

Using ubiquitous computing technologies to "embed" data capture and access into health practices has become a popular topic in recent years. A regularly held workshop on "UbiHealth" at the Ubicomp Conference (Bardram, Korhonen, Mihailidis, & Wan, 2003) has brought together a large number of research projects, including work on supporting surgeons in the operating theater (Hansen & Bardram, 2005), coordinating triage tagging of disaster scenes (Massey, Gao, Welsh, Sharp, & Sarrafzadeh, 2006), and supporting information exchange between nurses at a hospital (Tang & Carpendale, 2007). Additional work has explored how technology can be used to support individuals with diabetes in managing their own health (Mamykina & Mynatt, 2005) and individuals requiring kidney dialysis to track the foods they eat (Siek, Connelly, & Rogers, 2006).

Due to the rising costs of healthcare and the higher demand for it as the world's aging population increases, there has been a large impetus to study the field of "aging in place," or supporting the elderly living independently in their homes as long as possible through the use of technology (Mynatt, Essa, & Rogers, 2000). These technologies may come in the form of using sensors to monitor individuals for falls (Sixsmith & Johnson, 2004) or supporting communication amongst remote family members caring for an elderly parent (Consolvo, Roessler, & Shelton, The CareNet Display: Lessons Learned from an In Home Evaluation of an Ambient Display, 2004). In my work, I will be exploring how some of these techniques might be applied to a different domain with a different set of challenges.

The use of computers in the collection of health data has also become a very broadly studied topic in Computer and Information Sciences. Many commercial and research efforts have sought to collect and track health records electronically to ease the burden of analysis and to allow for easy transfer and backup of records. Research groups have looked at the effects of long-term tracking of data on the identification of decline or other age-related or chronic disorders (Dishman, 2004; Hirsch, Forlizzi, Hyder, Goetz, Kurtz, & Stroback, 2000).

Of particular motivation for my work is Morris *et al.*'s work on *embedded assessment*, which seeks to collect data by embedding technology in games or activities in which adults already engage (Morris, Intille, & Beaudin, 2005). Their work focuses on measuring several aspects of health in individuals of advancing years who may be susceptible to a wide range of diseases associated with old age. These aspects include monitoring for changes in health, compensating individuals for any declines they see in health, and preventing further illness by encouraging healthy behaviors. Though my approach of embedded capture and access is similar in spirit, the main difference is my focus is unobtrusively capturing data and increasing opportunities for access of data to support timelier decision-making. In addition, my research is on caring for children, who have limited or no input into the care process, and thus relies heavily on external caregivers, whereas Morris *et al.*'s work focused on healthy individuals who have input into their own health and well-being.

2.2.2 Coordinating Care

Childcare is a collaborative task, like many other coordinated care activities. Consolvo *et al.* coined the phrase Computer-Supported Coordinated Care (CSCC) to describe the research area of using computing systems to help teams of caregivers (Consolvo S., Roessler, Shelton, LaMarca, Schilit, & Bly, 2004). Others have explored coordination issues in the medical domain (Reddy & Dourish, 2002). The Digital Family Portrait (Mynatt, Rowan, Craighill, & Jacobs, 2001) and the CareNet display (Consolvo, Roessler, & Shelton, 2004) are examples of research systems designed to help coordinate care amongst caregivers of elderly parents. The care of children has many similarities to the care of individuals with other needs or chronic conditions, as Abowd *et al.* outline (Abowd, Hayes, Kientz, Mamykina, & Mynatt, 2006). Pinelle & Gutwin (Pinelle & Gutwin, 2005) and Bardram *et al.* (Bardram, Bossen, & Thomsen, 2005) have explored coordinating teams of caregivers within home settings for people with physical therapy needs or chronic conditions. With respect to coordination care for newborns, Gronvall *et al.* explored the coordination of caregivers for premature babies in an intensive care unit (Grönvall, Marti, Pollini, Rullo, & Bertelsen, 2005). While in a similar domain, this work has a different focus in that the care of premature children is typically temporary, while the care of individuals with autism or young children is more constant.

2.2.3 Motivating Healthy Behaviors

As with many applications aimed to support healthy lifestyles or better living, any technology I build to help parents keep better records on their own will require some amount design for motivation. This area of work is being defined in a new research domain termed Persuasive Technology (Fogg, 2002) and includes using elements of persuasion and other techniques to encourage some change in behavior. Typically this involves encouraging the other person to engage in healthy behaviors, such as eating better or getting more physical exercise (Lin, Mamykina, Lindtner, Delajoux, & Strub, 2006). It can also be used to discourage healthy behaviors, such as watching too much television (Nawyn, Intille, & Larson, 2006) or helping others to quit smoking (Healthways, Inc., 2008). Persuasive elements may include techniques such as games, support from social groups (Consolvo, Everitt, Smith, & Landay, 2006), or feedback from a virtual character or robot (Kidd & Breazeal, 2007). My research uses some elements of this type of persuasion to help caregivers be motivated to enter more information about those for whom they care. I use elements of entertainment, such as collecting sentimental records along with developmental records, and use of social groups, such as sharing videos with others, to encourage parents to enter information about their child. There are also many similarities to motivating healthy childhood development as there are in motivating healthy aging, as described by Intille (Intille, 2004). Some relevant recent work has used persuasive and ubiquitous technologies to encourage children to do healthy behaviors, such as eating a meal (Wu, et al., 2007) or properly brushing their teeth (Chang, et al., 2008). Though these technologies deal with children, they mostly focus on encouraging the children themselves to do a certain behavior, rather than in my work where I focus on motivating the parents.

2.3 Supporting Young Children and Individuals with Autism

Though the two particular domains I explored with this dissertation work are both relatively new for Human-Computer Interaction, there is still significant work in Computer Science and especially the domain of autism research and supporting families with children that my work builds upon. This research includes supporting family needs, supporting early detection of disabilities, and technologies to support children with autism.

2.3.1 Supporting Family Needs

Foucault et al. conducted a cultural probe with new parents to determine their technological needs (Foucault, 2005). While that study broadly examined all ways of supporting new parents, my work is particularly focused on helping parents keep better records and detect developmental delays as early as possible. Dalsgaard *et al.* examined using technology to improve the relationship between older children and their parents, but their focus was on improving relationships and not on record-keeping or decisionmaking (Dalsgaard, Skov, Stougaard, & Thomassen, 2006). Other work has explored how families use and share technology (Brush & Inkpen, 2007) and how parents seek to coordinate schedules for busy families (Neustaedter & Brush, 2006). This work tends to focus on families with older children and does not particularly focus on younger children as my work does. Researchers have also explored ways of preserving memories, such as through annotating and organizing home movies through the Family Video Archive (Abowd, 2003), ContextCam (Patel & Abowd, 2004), and through storing memorabilia in various "memory boxes" (Stevens, Abowd, Truong, & Vollmer, 2003; Frohlich & Murphy, 2000). Although these technologies primarily serve as tools for enjoyment, they serve as inspiration for my work as solutions for storing health-based data in a way that is enjoyable.

2.3.2 Early Detection of Disorders

Many research projects on the early detection of developmental delay focus on identifying a single sign or a set of signs that can be compiled into an accurate diagnostic screener, whether they are behavioral, physical, or biological, which can be significant indicators of delay. For example, doctors test babies for unusually large heads, believed to be an early warning sign of autism (Lainhart, et al., 1997). Behavioral consultants use survey instruments that have been shown to detect autism in children as young as 18 months old (Baird, et al., 2000). Researchers have shown the promise of analyzing home movies of infants as a means of predicting Asperger's Syndrome. Another approach to determining early warning signs as early as infancy is through the manual analysis of home videos showing early movements of children later diagnosed with Asperger's Syndrome (Teitelbaum, Teitelbaum, Nye, Fryman, & Maurer, 1998). Researchers in the autism domain have also collected early home movies of children who were later diagnosed with autism to see what these children looked like from birth to when they were diagnosed (Baranek, Barnett, Adams, Wolcott, Watson, & Crais, 2005). The Human Speechome project (Roy, et al., 2006) uses an extensive recording infrastructure throughout a house to gather linguistic data to help researchers ascertain how children acquire language. All of these diagnostic methods rely on some form of data collection, either actual measurements on a child or parent reporting, and can benefit from more effective means of data collection.

Others have used technology as a means for automatically identifying early warning signs of developmental delays. For example, Fell *et al.* examined ways to analyze baby babble as early indicator of speech related disorders, and then used that same technology to reward appropriate language development behaviors (Fell, Cress, MacAuslan, & Ferrier, 2004). Westeyn *et al.* augmented toys with sensors to try to automatically identify developmental milestones in young children (Westeyn, Kientz, Starner, & Abowd, 2008). My work seeks to support early detection using a more holistic

approach, by using many different developmental milestones to help make decisions, rather than focusing on a single set or constrained set of signs.

2.3.3 Technologies to Support the Care of Children Autism

Other researchers have explored technology to assist individuals with autism, but most of this work has been in developing applications for use by the individuals themselves, rather than by their caregivers. These devices include Simone Says, a system using voice recognition technology to teach and analyze language skills (Lehman, 1998) and Hailpern *et al.*'s work on using visualizations to encourage vocalizations for children with autism (Hailpern, Karahalios, Halle, DeThorne, & Coletto, 2008). The Discrete Trial Trainer (The Discrete Trial Trainer (DTT), 2004) is a commercial software product that attempts to replace the therapist in Discrete Trial Training therapy by administering similar therapy and education through the computer. While Simone Says, Hailpern *et al.*'s work, and Discrete Trial Trainer are all used by the individuals themselves, they can ease some of the burden on caregivers by allowing a computer to administer therapy, leaving the caregiver more time to handle other aspects of care.

Other technologies have focused on how to teach individuals with autism social skills and aid in communication. Tartaro has explored storytelling with virtual peers to teach social skills to children with autism in a more comfortable setting (Tartaro, 2005), while researchers at MIT have looked at how images of people can be emphasized to help understand subtle emotional cues (Kaliouby & Robinson, 2005). Recent work by Piper *et al.* has explored how a tabletop, multiplayer game, called SIDES, can be used to encourage children with autism to learn social interactions and turn-taking (Piper,

EO'Brien, Morris, & Winograd, 2006). These types of social applications can be used in conjunction with caregivers to provide a more rich education in social skills, which again leaves the caregivers with more time for other, more demanding care issues. The main difference between this work and the work I have conducted is the focus on the use of technology by individuals with autism, rather than supporting their network of caregivers.

One application supporting caregivers of children of autism CareLog, developed by Hayes *et al.* (Hayes, Gardere, Abowd, & Truong, 2008), is similar in spirit to helping caregivers collect better data for decision-making. CareLog seeks to support teachers in a classroom in diagnosing the causes of children's behavior by allowing retroactive video capture of events (through *selective archiving* (Hayes, Truong, Abowd, & Pering, 2005)) to help support systematic decision-making on the cause of the behavior. My work builds upon this work by using a similar method of capturing video for the purposes of decision-making, but focuses more on the access side of things, by providing more spontaneous opportunities for decision-making and allowing caregivers to make decisions based on more data. Additionally, my work is focused on integrating the aspects of capture and access into existing practices, rather than changing the method altogether.

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CHAPTER 3

EMBEDDED CAPTURE & ACCESS FORMATIVE STUDIES

In this chapter, I present the design of and findings from a set of formative studies exploring the needs for various domains that can benefit from embedded capture and access in the caregiving domain. First, I present results and experiences from an in-depth formative study of Discrete Trial Training therapists working with children with autism involving participant observation. Second, I describe the design of a formative study seeking to understand the record-keeping needs of parents and caregivers of young children, largely comprised of interviews and focus groups with stakeholders involved in the care and record-keeping of young children. Finally, I discuss common themes amongst the two formative studies and describe how the findings from the studies informed the concept of embedded capture and access.

3.1 Therapy for Children with Autism

I undertook an in-depth evaluation to understand the practices of therapists working with children with autism. The goal of this work was to determine how technology might be able to support and improve the practices of caregivers for autism and determine the design requirements. In particular, I chose to study therapists conducting a specific type of therapy called Discrete Trial Training (DTT). This work served as the basis for designing and developing both the Abaris for Homes and Abaris for Schools systems. Below, I describe my methods for studying this domain, provide a detailed description of the therapy process uncovered by the study, and present overall results and implications for technology design.

3.1.1 Methods for Studying Discrete Trial Training Therapy

I began studying the domain of DTT therapy through a larger ethnographic study on caregivers for autism with others from my research group (Hayes, Kientz, Truong, White, Abowd, & Pering, 2004). This study started out with a set of semi-structured interviews with domain experts in autism, and one of the findings was that the field of DTT therapy was very popular for children with autism. It is commonly practiced in school settings (especially in special needs classrooms and schools) or at the home of the child by a team of external therapists. I decided to focus my initial efforts on the home domain, because I believed there to be many potential ways that technology may be able to improve the process. Initial studies of this field involved speaking with a consultant who runs a company that conducts DTT therapy and watching a training video created by this consultant, where she described the general motivation and process for conducting therapy. I also watched videos of therapists conducting therapy with a child, observed meetings of therapists discussing the progress of the child in therapy, and interviewed therapists about their experiences.

Though this initial study gave me some helpful insight about the process, much of what I heard through the interviews with therapists was that, "you just have to try it to know." The therapy tends to be very fast-paced, and thus many things become second nature to the therapists and are thus difficult to observe or articulate. I also discovered that "regular" therapists were typically trained by the consultant through on-the-job

training while working with the lead therapist, who would critique them and make suggestions for how to improve their technique. Because most regular therapists were part time and did not require any specific educational background, I decided to go through the same process as new regular therapists and join the therapy team to gain a better understanding of what it was like to be a therapist (Kientz & Abowd, 2008).

After approximately 1 month of training that involved watching videos, observing therapy sessions, and then hands-on training with the lead therapist, I became a full-fledged member of the therapy team. I conducted 1-2 sessions per week with a given child, with each session lasting approximately 2 hours, including paperwork and playtime with the child. I attended the team meetings that happened every two weeks and were approximately 2 hours long. I worked with the team of therapists for approximately 10 months. This study was a form of contextual inquiry (Holtzblatt & Jones, 1993), as I had intentions on using the findings to inform a technological solution, but was taken beyond just a few sessions of observing alongside real therapists to becoming a real therapist myself. Becoming a therapist helped me gain regular access to therapists, learn the inner workings of the design team, better understand the experiences and difficulties associated with conducting therapy, and gain a very deep insight into the domain. It also helped to better understand the results gathered from other methods (*e.g.*, observations and interviews with therapists) and served as a method of triangulation.

3.1.2 Findings from Study of Domain of Discrete Trial Training

The formative study of DTT helped me to understand the details of the domain, which helped to frame the development of technology to support therapists. I outline the basics of DTT and the therapy team below. Although there is variation between different DTT practices, the description below is representative of standard practice, as implemented in a home setting.

3.1.2.1 <u>The Discrete Trial</u>

Advocates of DTT believe that even children with severe developmental disabilities can learn correct behaviors through controlled and conditioned training. A discrete trial is an example of this learning model. The basic process for DTT therapy is as follows. Once the therapist gains the attention of the child, she makes a direct verbal request to the child that requires a well-defined and correct response. If the child responds correctly, he is immediately rewarded with a reinforcing stimulus, such as a piece of candy, a favorite toy, or verbal praise. If the child responds incorrectly, the therapist prompts the child in such a way as to ensure a correct response, such as by gesturing or helping the child perform the task. The trial is immediately repeated, with the therapist providing whatever prompt is needed to guarantee a correct response. The therapist records the result of the trial (an "I" for an independent or correct response; otherwise, any of seven or eight letters that represent the prompting used by the therapist, though these letters and codes vary between different company's or school's methods). If a "correction" trial follows the initial prompted response, the therapist may also record the result of that correction trial.

3.1.2.2 A DTT Program

The therapy regime for DTT consists of a collection (10 to 20) of programs for which data is collected. For the particular type of therapy I studied, these programs came from a list of skills called the Assessment of Basic Language and Learning Skills (ABLLS) (Sundberg, 1990), which is a comprehensive list of programs and skills typical children can do by the time they enter kindergarten and for which the therapy strives to teach. Each program consists of a basic skill (*e.g.*, Picture Identification), a target (*e.g.*, picture of a dog), a note further explaining the task (*e.g.*, selection from a field of three pictures), and a specific command (*e.g.*, "Give me the <target_name>.").

3.1.2.3 <u>A Therapy Session</u>

Before a session, a therapist reviews the child's therapy materials. She consults a notebook containing the child's past session data sheets, program progress graphs, mastered skills, and narrative notes from other therapists on the child's progress. She reads over the notes written by other therapists and prepares her session materials, which includes pictures, objects, and writing utensils. After she has prepared everything, she begins the session with the child by playing and interacting with him, and then brings him to the table to rehearse mastered skills and work on target skills. Figure 1 shows a therapist engaging with the child during a therapy session.



Figure 1: A therapist engaged in a therapy session with a child (left) and paper notebooks used by therapists to collect and store therapy data (right).

Each program/target combination is performed a number of times, ideally distributed randomly throughout an individual, one-on-one session between a therapist and the child. Therapy sessions happen nearly every day and last 1-2 hours in duration. As the different trials for different programs are conducted, the therapist records all data on a paper score sheet (namely, the success of the child, the prompts used, and any notes the therapist wishes to make). At the end of the session, the therapist spends approximately 30 minutes processing the data sheets, calculating the percentage of correct responses for each program, and then plotting the results on a paper graph. Figure 2 shows an example of a data sheet used by the therapist (upper left) and the hand-drawn graph charted by several therapists over a period of several months' worth of therapy.

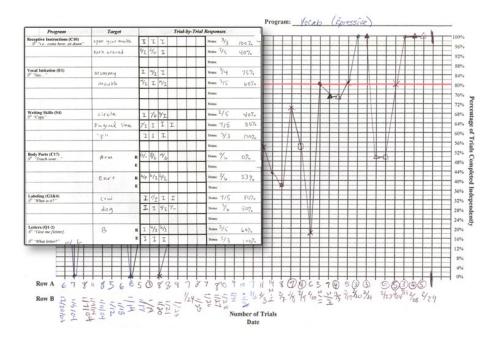


Figure 2: Examples of paper-based forms used by therapists. Left is a therapy data sheet completed during therapy, and right is a graph of the child's progress for a particular skill. A larger version of both images appears in Appendices B.1 and B.2.

3.1.2.4 Evaluating Progress

A given program/target combination is "mastered" when some pre-defined performance level (*e.g.*, 80% correct responses on a given day) is achieved over some interval of time (*e.g.*, three consecutive days). Once a program/target combination is mastered, the target is changed. When a sufficient variety is mastered for a program, the program is mastered overall. Mastered program/target combinations are practiced (without data collection) throughout a therapy session and are then tested less frequently to determine if mastery is maintained over time.

The team I studied consisted of a parent (trained in DTT but not practicing at the time), three regular therapists, one lead therapist, and a consultant, all providing therapy to a seven year-old, low-functioning child diagnosed with Autistic Disorder (mild to moderate) using the DTT procedure described above (see Figure 3). The lead therapist has additional tasks of administrative paperwork, such as determination of which program/target combinations are mastered and scheduling new targets and programs for future sessions. The consultant does no direct therapy with the child, but is an expert in behavior analysis and conducts the team meetings.

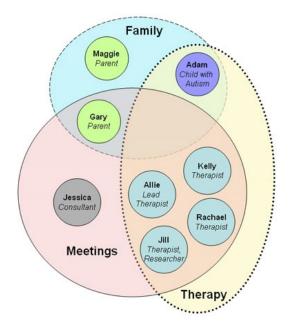


Figure 3: Diagram of interaction amongst people involved in therapy and meetings. Large ovals indicate relationships involving family, therapy, and meetings.

The team typically meets every other week to discuss therapy, analyze data, and make any necessary adjustments to help the child learn the skills more effectively. The consultant leads these meetings and uses the manually recorded data as an agenda to run the meeting (see Figure 4). The consultant looks at the book of graphs and asks the therapists for details from the therapists on how the child is progressing on each skill. If a certain target skill has been on the agenda for a long time with little improvement, the team may choose to remove the target and replace it with another one, or they may discuss why they do not think he is learning it. Therapists try to remember details of what occurred in their sessions and make hypotheses about what is causing the child to perform particularly well or poorly. The consultant will make suggestions on new things to try, and the team generally implements these within the next two weeks of therapy. After making these changes, the team reviews the progress again at the next meeting.



Figure 4: A typical meeting of everyone involved in the therapy team.

3.1.2.5 Artifacts Used in Decision-Making Process

During team meetings and individual therapy sessions, participants often took advantage of a wide variety of artifacts available to them to aid in the decision-making process. Some artifacts were products of the therapy itself, such as samples of the child's handwriting. Others could be presented as a prop for discussion during team meetings, used as key information for individual or group decision-making, or provided a conduit for communication among team members. Team members used different artifacts in therapy sessions to make decisions about the work at hand, directing them to try new skills or change the way they were testing old skills. They also used these artifacts to make determinations about the direction of therapy as a whole outside of individual sessions. These artifacts support decision-making processes surrounding the child's ability to learn a skill at an appropriate rate, the potential additions of new skills to learn, and the determination of success with the current course of action. Below is a description of each of these artifacts and the varied ways in which they were used, as well as the advantages and disadvantages observed for each.

• Graphs showing child's performance over time

- *Description:* Therapists graph data points for each skill which shows the percentage of correct trials for a cumulative set of grades
- Use: Therapists use this to show trends in progress over time
- o Advantages: Shows trends over time, quick to access
- Disadvantages: Does not provide details on specific grades or context, hand drawn, only exists on paper

• Videos of therapy sessions

- *Description:* Therapists use web camera in a fixed location to record 1-2 hour therapy sessions on a nearby computer
- *Use:* Shows events that cannot easily be described in words or remembered by the therapist
- *Advantages:* Very detailed, reliable account of events during therapy, shows others exactly what happened
- Disadvantages: Without indexing, extremely difficult to find moment of interest and thus time-consuming to review

• Data sheets from individual sessions

- *Description:* Individual grades for trials from each therapy session written by the therapist directly after the trial
- Use: Shows which grades therapists give for different skills

- *Advantages:* More detailed information about how a child did on a particular skill than the graph for that skill, may also show notes from therapist written at time of trial
- *Disadvantages:* More difficult to find data of interest than with graphs because there are more of them and they are located in varying places

• Therapy samples from sessions

- *Description:* Physical artifacts from actual therapy sessions, such as handwriting samples or artwork
- Use: Shows examples of what the child is capable of
- Advantages: Provides actual proof of what child is capable of, reasonably quick to access, persistent over time
- *Disadvantages:* Limited in scope since it is only applicable to certain skills with tangible samples, some context of therapy lost if therapists cannot remember it

• Reenactments of child performing a skill

- Description: During meetings, the therapists may have the child try to perform some of the skills from therapy to see if they can repeat incidents from therapy
- *Use:* Used when therapists want to see if a child is capable of doing certain skills before adding them to the therapy program, used to train therapists to conduct trials consistently
- Advantages: Realistic, multi-observer reenactments of what the child is capable of and good therapist training technique

• *Disadvantages:* The child might not be able to perform under pressure, may not explain why some therapists have better results than others

• Memory of those present at a team meeting

- Description: Recount of events during weekly sessions
- *Use:* Used to explain graphs, help clarify differences in grades, make hypotheses about progress
- o Advantages: Very quick to access
- Disadvantages: Can often be very unreliable, includes no details, decays over time, absent therapists cannot contribute

• Observations from External Sources

- *Description:* The parent at the meeting may bring in outside knowledge from the child's school or other therapies, such as if the child had a bad day at school or is not making progress in other areas
- Use: Used to bring in outside knowledge about what may or may not affect the child's progress in therapy
- Advantages: Very quick to access
- Disadvantages: Relies on other people's accurate descriptions, thus can be unreliable or even misleading

• Notes written by therapists after sessions and meetings

 Description: After each therapy session, therapists write general notes about session experiences and any problems they had, also includes minutes from previous meetings

- *Use:* Session notes are typically used when one therapist is absent from the meeting and to convey information from session to session between meetings, previous meeting notes are used to refer to decisions made in past meetings
- Advantages: Thoughts of therapist written within minutes of completion of therapy session
- Disadvantages: Largely qualitative, cannot easily show trends over time, lacks specific details, harder to access

3.1.3 Implications for Design

With a firm understanding of the domain, I was able to distill the findings into several goals for technology. I had three main observations about the potential for technology:

- The therapy sessions, though fairly fast-paced and flexible, have a welldefined structure that can be leveraged naturally by perception technology, potentially providing a suitably indexed recording for later access.
- The team meetings present a high-need example of access, in which the users who are both capturing and accessing the data absolutely require it to perform their jobs.
- Meetings consist of many self-reported reflections on past experience between therapist and child, which is a clear opportunity for improvement with real evidence of what transpired during a therapy session.

Although DTT therapy is a relatively well structured and successful treatment for children with autism, there are some deficiencies in the process that may lead to inaccuracies in the interpretation of the data, making the overall therapy less efficient. Thus, there is potential for technology to address some of these issues and make therapy a better and more useful experience for the therapists and the child.

Discrete Trial Training is particularly well-suited to the use of automatic capture technologies. Therapists and parents alike are highly motivated to use tools that will save time on laborious paperwork yet does not reduce the quality of the intervention. In addition, it is a structured activity, with individuals already trained to be cooperative in the process of manually recording data. Because therapists record, calculate, and graph all of the data by hand, there is a high likelihood that the data may be inaccurate due to simple human error. Furthermore, graphing and calculating all of the data using pen and paper is time consuming, often requiring up to one third of the session and taking time away from the child's instruction. By designing a system that automates much of this hand analysis and calculation, I believed I could reduce the amount of time spent in paperwork, similar to how others have found that automation can save time in paperwork for Activities for Daily Living (ADLs) (Philipose, Fishkin, Perkowitz, & Patterson, 2004).

Despite its well-defined protocol, DTT in practice requires a significant amount of improvisation and thus technology should be designed to be as flexible as possible when capturing data from the therapists. Because pen and paper allows anything to be written anywhere on the page, I felt that keeping the paper for capture is essential. Besides flexibility, I determined that minimal change to existing practice is also of utmost importance, which can increase the likelihood of acceptance, as noted by Mackay *et al.* in their study of air traffic controllers (Mackay, Fayard, Frobert, & Medini, 1998). The challenge is to design capture in a way that maximizes the inherent structure of sessions without violating the process, and to provide a nimble access interface that would encourage exploration of the evidence without requiring too much time, effort, and distraction during team meetings.

At current team meetings, therapists speculate about whether a child is responding to prompts in certain ways, how well the child is focused, whether or not the child exhibits some affect, and whether the therapist is conducting each trial correctly. Much of the grading of each trial is subjective, especially in the grading of word pronunciation or letter formation, thus discrepancies in the grading of the child by multiple therapists tend to interfere with measures of progress. These discrepancies can lead to a mismatch in skills taught and the child's abilities, which can be frustrating both for the child and for the therapist. Capture of rich data, such as video, allows therapists to see what each of the other therapists are doing without being present during therapy sessions and to notice things that the therapist herself may not have, ensuring increased consistency and enabling more accurate decisions and advice. Thus, an overall goal for accessing data is to provide a means of facilitating discussion amongst groups of therapists about trends in the data using easy access to both empirical and rich data to enable data-based decisions for long-term use.

One design goal should be to provide access to those artifacts that are most likely to provide reliable and repeatable forms of evidence. Because analysis of the most reliable data available is an integral part of behavior analysis as a science, technology may serve its users best by providing relatively easy access to salient points within the most reliable data source available, such as video.

3.2 Record-Keeping Needs of Caregivers for Young Children

Ensuring the healthy growth and development of young children presents a different area where caregivers should record data and make decisions. The previous domain I explored, Discrete Trial Training therapy for children with autism, is a well-defined protocol, caregivers are specifically trained, and the time-scale for decision-making is fairly short. Thus, I decided to explore a new domain with caregivers who have much different backgrounds and needs. In particular, I wanted to explore how technology might support record-keeping needs for those caregivers involved in ensuring the healthy development of a child and aid in the early detection of developmental delays. Thus, I undertook a formative study to uncover current practices and design requirements for technology support for this domain. In this section, I describe the methods I used for this formative study, the results of the study, and some implications for design of technology for this domain.

3.2.1 Methods for Studying Caregivers of Young Children

In the summer of 2006, I led a group that interviewed a total 8 of new parents, 8 experienced parents, and 5 secondary caregivers (some of whom were also parents) (Kientz, et al., 2007). I also conducted two focus groups, one with 9 daycare providers and one with 4 medical professionals. Individual and group interviews lasted between one and two hours and were semi-structured in nature. The content of the interviews

consisted of questions regarding current practices for documenting developmental milestones, recording rich media such as pictures or videos, hopes and fears about developmental progress, plans or experiences for care of the children, and then feedback on ideas I had for technology prototypes. The interview guides used in the interviews and focus groups can be found in Appendix A.1. I transcribed all interviews and focus groups and extracted quotes that would be analyzed using two different methods: a more quantitative analysis of the transcripts to test whether participants confirmed or denied preconceived hypotheses and a more qualitative analysis to uncover themes that were unexpected.

3.2.1.1 <u>Target Stakeholders</u>

I identified four sets of stakeholders I believed would provide insight into the problem of record-keeping for young children and used them as the subjects of my interviews and focus groups. With all participants, I prompted discussion of rationales for wanting to keep records and any functions technology would need to provide to enable the process. Additionally, I inquired about willingness and availability to capture and review records, as well as any concerns they may have about the privacy issues associated with video recording and other record types. This section provides an overview of the specific issues I discussed.

• *New or Expecting Parents:* Parents of newborns or expecting parents are the primary users for this type of technology. They can provide a prospective on their plans for keeping records on their new child. Additionally, they can share concerns or ideas they have about being a parent, discuss how much time they plan to dedicate to

documenting their child's development, and the value they place upon the potential of record-keeping.

- *Experienced Parents*: Experienced parents have already been through the process of raising children and can offer valuable insights into the strategies that worked or did not work for their own children. In the interviews, the research team and I focused on what kinds of records and artifacts parents collected for their newborn children, what they did with those records, what records they wish they had collected, and whether or not technology would have had a positive impact in record-keeping for their child. I also asked them about their practices of taking their child to see a medical professional. For experienced parents who had children with special needs, I discussed the diagnosis procedure and any technology needs to support current care or early intervention.
- Secondary Caregivers: Because families often have both parents working outside the home, many children spend time in the care of a secondary caregiver, such as a nanny, a daycare provider, or a family member. Secondary caregivers often take on some of the responsibility for record-keeping and can offer perspectives on caring for children as a profession. In the interviews with secondary caregivers, I discussed their workload and experience with developmental concerns for the children in their care. Additionally, I asked about current practices, if any, in helping parents look for and document milestones or capture video or photographs.
- *Medical Professionals*: The child's pediatrician and the office staff (*e.g.*, nurses) are often the first people to detect developmental delays due to their expertise. Additionally, they will often answer any questions parents may have, can offer advice

on which records to keep in addition to medical records, and make referrals to additional resources for screening if there is a concern about a child's development. For the pediatric professionals, I inquired about the process for assessing developmental progress and their willingness to review records collected by parents.

3.2.1.2 Interview Participant Details

I recruited participants primarily from Atlanta and the surrounding area, but also sought participants from other areas in the United States. Interviewers recruited participants through Craigslist.org, specific mailing lists (*e.g.*, a nanny mailing list), and word-of-mouth. All participants received a \$20 gift card for participating. Although I did not specifically seek women, all but two of the respondents were mothers or female daycare providers. Participants came from a wide variety of backgrounds and socioeconomic statuses Table 1. Most parents were married, but I also interviewed several single mothers, divorcees, and parents in a second or third marriage. Although I did not specifically recruit for this, ten participants had experience raising or caring for children with a variety of developmental concerns.

| Category | New Parents | Experienced Parents | Secondary Caregivers |
|---------------------------|---|--|--|
| Number of Participants | 8 | 8 | 5 |
| Gender | Female (6), Male (2) | Female (8) | Female (5) |
| Marital Status | Married (6), Single (1), Divorced (1) | Married (8) | Single (2), Married (3) |
| Age Groups | 18-24 (2), 25-32 (2), 33-40 (3), 41-50 (2) | 25-32 (3), 33-40 (4), 41-50 (1) | 18-24(2), 25-32(2), 33-40(1) |
| Education | High School(2), Bachelor's(1), Master's(2), Ph.D/J.D.(2) | High School(2), Bachelor's(4), Master's(1), Ph.D/J.D.(1) | High School (2), Some College (2), Bachelor's (1) |
| Household Income | \$25-50K(4), \$50-100K(2), \$100-150K(1), \$150K+(1) | \$25-50K(3), \$50-100K(3), \$100-150K(1), \$150K+(1) | \$0-25K(2), \$25-50K(1), \$50-100K(1) |
| Occupations | social caseworker, graduate student (2), stay at home mom (2), middle school teacher, computing researcher, lawyer | science teacher, job development and real estate worker, church office manager, stay at home mom (2), client services representative, substitute teacher, real estate agent | in-home nanny (2), part time nanny, daycare provider, preschool teacher |

Table 1: Summary of interview participants, including demographic information, socioeconomic status, and occupation.

3.2.1.3 Focus Group Details

Because time with medical professionals and daycare employees is difficult to obtain and schedule, I chose to conduct focus groups to maximize input. I recruited focus group participants through direct contact with the manager for either the pediatrician's office or the daycare center. All focus group participants also received a \$20 gift card.

I conducted a focus group at a university-affiliated daycare center, which is a franchise of a national chain. The focus group included 8 lead teachers (all female) caring for children from infants to pre-kindergarten (around age 5), and one office manager. The teachers also had a wide range of ages and experiences with the company and in teaching, ranging from someone who had been with the company for eight years to someone who had just started that week.

The second focus group included medical professionals from a pediatric practice in a suburban town. The practice was associated with a state-funded children's hospital. Many of the patients at this practice were of lower socioeconomic status and almost 50% of them were Hispanic immigrants. The focus group consisted of two pediatricians (one male, one female), a nurse practitioner, and the office manager.

3.2.2 Findings from Formative Study

I analyzed interview transcripts for specific hypotheses I made about the rationales behind and functions required for technology to support record-keeping. Additionally, my analysis aimed at uncovering additional, unanticipated issues brought up by participants.

3.2.2.1 Analysis Methods

Going into this study, I had intuitions about appropriate designs for helping to track developmental milestones. However, I needed to confirm whether these hypotheses were correct. Therefore, prior to conducting the interviews, I distilled six rationales for why parents would want or need to use technology supports and nine functions I believed technology would need to support (see Table 2).

Table 2: Pre-determined rationales and functions for technology to support caregivers of children that served as interview coding criteria

| Code | Statement | | |
|------|---|--|--|
| R1 | Parents and caregivers often do not have time to track developmental milestones | | |
| R2 | Parents want the best outcome for child | | |
| R3 | Parents need reminders of when to record data | | |
| R4 | Parents may miss events that occur while away | | |
| R5 | Parents and caregivers are already motivated to record data, pictures, videos, or keepsakes | | |
| R6 | Parents want to be able to share information and pictures of their children with others | | |
| F1 | Provide proactive reminders to enter data | | |
| F2 | Monitor child's health and development and alert parents if anything is unordinary | | |
| F3 | Use sensors to automatically collect information about a child so parents don't have to record it | | |
| F4 | Create keepsakes, memorabilia, or photo albums to share with friends and family | | |
| F5 | Allow parents to share information they collect with healthcare providers if there is a concern | | |
| F6 | Provide an all-in-one data repository for child, including both health and sentimental records | | |
| F7 | Allow for multiple caregivers to provide input and use of the system | | |
| F8 | Allow for the capture of pictures and videos for both health and sentimental reasons | | |
| F9 | Give parents the opportunity to share information or experiences with other parents, or read more about parenting from trusted online sources | | |

I also conducted an analysis of the transcripts to look for additional themes that fell outside my hypothesized rationales and functions. The themes examined include additional rationales and functions and any other interesting issues discussed during the interviews and focus groups.

I coded data from the interviews and focus groups to look for the predicted 6 rationales and 9 functional requirements. For the interviews, researchers read the transcripts and marked times a particular rationale or function was mentioned. I coded roughly half of the interviews (11/21) a second time and conducted inter-rater reliability between coders. When coders disagreed on 33% or more of the items on a transcript, a third coder would check the disputed items and decide how to code them. This lead to an inter-rater reliability of 95% agreement.

3.2.2.2 <u>Results – Emergence of Trends</u>

According to my analysis, the average agreement between the participants and the predicted rationales ranged from 61% to 83% (see Table 3) I conducted independent sample T-tests between the 3 groups of caregivers, which indicated that there was no significant difference amongst stakeholder types in their agreement with my predicted rationales and functions, nor was there a difference between the two types of predictions made.

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| | Rationales | Functions |
|-------------|------------|-----------|
| New | 60.42% | 66.67% |
| Experienced | 77.08% | 68.06% |
| Secondary | 83.33% | 66.67% |

Table 3: Percent agreement for different stakeholders with my predicted rationales and functions.

The different stakeholders my research team interviewed agreed with the rationales more often than not, which confirmed my prediction that there is a need for designing technology for record-keeping. Although I had no prior hypothesis on how participant agreement with the rationales and functions might differ amongst the different stakeholders, I did see some interesting differences when looking at particular rationales and functions (see Figure 5). I conducted additional T-tests between experienced parents and secondary caregivers, which showed secondary caregivers more strongly agreed than parents on Rationale 2 ("Parents want the best outcome for their child", t(7) = -2.646, p=.03). Inherent in this rationale is the notion that if caregivers "catch" potential problems, then the child is more likely to have a better outcome. Perhaps secondary caregivers, as professionals, are more likely to notice problems that working parents may overlook. This is supported by comments made by one nanny during the interview and the daycare providers in the focus group. They mentioned that many times, they had been the first to notice problems with a child in their care and not the parent.

This analysis indicates that there may be a better appreciation for the value of computer-assisted record-keeping by experienced parents and professional caregivers than new parents. For example, for Rationale 3 ("Parents need reminders), tests showed

lower agreement between new parents and experienced parents (t(14) = -2.16, p=.05). On Rationale 4 ("Parents may miss developmental milestones") tests also showed lower agreement between new parents and both experienced parents (t(12.36) = -2.26, p=.04) and secondary caregivers (t(7) = -3.42, p=.01).

These results may point to a difference between the optimism of new parents and the practicality of experienced caregivers. New parents often expect to be around for all of their child's milestones and may overestimate the amount of time they will be able to devote to record-keeping. On the other hand, experienced caregivers (both parents and professionals) know that, after a while, it is nearly impossible to keep records of all of their child's development and thus request reminders to document their child's progress. Along the same lines, new parents were less likely than professional caregivers to agree that Function 7 ("Technology should include multiple user input") is a desirable function of computer-supported record-keeping (t(7) = -2.65, p=.03). Again, this may be because new parents believe they will be around for all of their child's milestones, whereas professional caregivers know that keeping track of a child's milestones is one of their responsibilities and thus may be expected to maintain the child's developmental record.

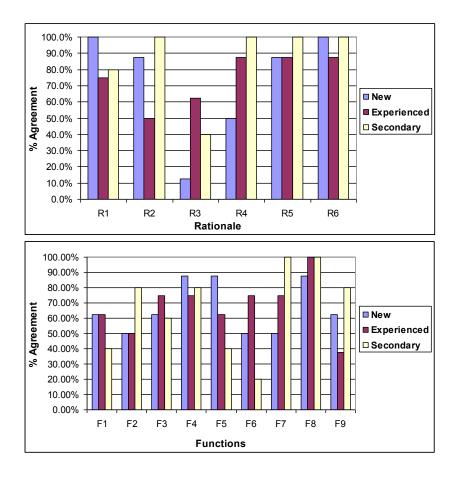


Figure 5: Percent of New Parents, Experienced Parents, and Secondary Caregivers that agreed with the predicted rationales (top) and functions (bottom).

3.2.2.3 <u>Results - Emergence of Themes</u>

After coding for the original rationales and functions I proposed for recordkeeping technology, I analyzed the remaining data to extract relevant themes, considerations, rationales, and functions that fell outside of the predicted needs. To do this analysis, I used a Grounded Theory approach (Glaser & Strauss, 1967). I had the interview coders make notes of other interesting data points during the rationale and function coding. The goal of this analysis was to identify key themes that were important to the stakeholders interviewed. The analysis used axial, inductive coding and resulted in eight extracted themes, which I describe below.

3.2.2.3.1 Customized Records for the Individual Child

Many parents reported that existing lists of developmental milestones were too generic and impersonal and thus did not fit their child's particular needs. For example, they do not even account for differences between boys and girls (*e.g.*, girls tend to develop more quickly in certain aspects). Other reasons for customization include premature births or cultural differences (*e.g.*, a child learning two languages may develop language skills at a different rate). One nanny also said she believed that children with nannies may receive more attention than those in daycare, and thus it could affect how quickly children achieved milestones.

Nanny: "[The child's mother] is always like "oh, he's not doing this... what are we going to do...is this okay??" and I'm like "[child's name] was born 3 weeks early too" and there's gestational age versus actual age ... I think doctors have been saying for the first two years, a lot of children will follow their gestational age in development."

3.2.2.3.2 Supporting Interactions with Pediatricians

Several parents reported that their pediatrician is their most trusted source for information and instructions for caring for their children. However, a pediatrician's time is very limited, and scheduling appointments outside of regular visits takes time and potentially extra money. Pediatrician participants reported that they require all parents to list milestones their child has achieved since their last checkup, but a few parents stated it was sometimes difficult to remember or easily fill out these questionnaires. Mother of 1 year old girl: "as far as when they're new ... all the stuff that you have to keep up with, like when you go to the doctor's office. They want to know how much they're drinking, and how much they use the restroom.... you know, all day is such a blur So something that would make that easier for me would be a godsend."

Pediatricians supported the idea of parents bringing a list of completed milestones to the visit to help them fill out their sheets. This would also help parents keep their own personal records consistent with the ones kept by their pediatrician. Pediatricians stated that young children were sometimes uncooperative or upset during visits, and thus they would ask parents to conduct vision or hearing screening at home prior to their visit. Parents said at the end of their regular pediatrician visits (*i.e.*, "Well Child" visits), they would receive a list of things to look for in the next month, and they found it useful. However, one pediatrician reported these lists were often forgotten or misplaced once they left the office.

Pediatrician from focus group: [referring to sheets sent home with parents] "Some parents will say they're very useful....for most of our parents, it's extremely stressful, the whole situation, so by the time you come to the tip sheet, most of the time the tip sheets are left behind... they had it, but the kids are crying, we've stuck them [with needles]... by then, they really don't want another piece of paper to read, because all they want to do is get their kids in the car."

3.2.2.3.3 Difficulties with Capturing Records

Parents and caregivers mentioned a variety of reasons for not recording as much data as they wanted. I predicted a lack of time as one, but participants spontaneously mentioned many issues that I had not considered. For example, parents often record pictures and some videos of their children, but it is difficult to organize them. The advent of digital cameras means that parents can take as many pictures as they want, but they often end up with so many pictures that it is hard to find the "good" ones. Participants also reported difficulty in recording videos or pictures of their children doing spontaneous things (*e.g.*, events outside of planned photo sessions at birthdays and holidays). Also, once children are walking, they are very mobile and thus difficult to capture. I heard numerous times that parents tend to collect fewer pictures and data on their second, third, or later children. Parents suggested this was because they did not have time, but also suggested that the novelty of a new baby was not as strong for their second child.

Mother of two: "When you have your first child, everything is so new and fresh, and then by the time the second one rolls around...you're just so overwhelmed with having two that you're...it's not that you don't want to do...you just forget. and the time goes fast."

Parents also expressed frustration in the difficulty of recording and sharing videos. They had significant concerns about the privacy of secondary caregivers, and nannies echoed the same concerns over privacy.

Nanny: "A lot of parents will just put up a ceiling camera... and a lot of times nannies will quit over that, because the parents say 'oh, I just want to see what's going on during the day'... it's this great feeling of distrust... and there are times when like [child's name] throws up...and I'll be like "I'm just going to take off my shirt because no one's here" and if there's a nanny cam, it's an invasion of privacy."

3.2.2.3.4 *Record-keeping is Not for Everyone*

Some participants reported that they did not need or want to record information on their children. Others mentioned friends or acquaintances who felt no need for such recording. Some reasons against collecting data were a desire to "let nature take its course" or rely on parental instincts.

Father of two: "Yeah so, I don't document... you wouldn't get from me a diary of daily activities, his improvements, even a social improvement, all of that stuff. No, I don't track that. I just let nature I guess work on him."

Some parents stated that fixating on developmental milestones may cause unnecessary paranoia or worry if children do not meet the milestones spot on.

Father-to-be: "In my case, I do worry and I do think about all this stuff, but ... finding out the details of everything that you can worry about is not a good exercise. There's not enough time, first of all, because of all sorts of pathologies, and second of all, it's not healthy... it can drive you crazy in the end."

Some participants did not like the ideas of videos at all, again stating concerns with privacy and discomfort with being on camera. For example, one nanny did not like how she looked on camera and was concerned if the parents she worked for showed the videos to people she did not know. Lastly, some pediatricians in the focus group expressed a concern that any technology to support data collection may be too costly for lower income parents.

3.2.2.3.5 Knowing What, When, and How to Record

Another emergent theme was that parents confessed to not knowing what data to collect beyond "the basics." They reported receiving much information, but still found it

difficult to decide what was "right." Participants from all stakeholder groups expressed a need for reliable sources for data. Parents also stated that sometimes it is difficult to separate fact from fiction when it comes to raising a healthy child. Pediatricians noted that some patients read false information on the Internet and tried to argue with doctors, especially when it comes to immunizing their children.

Pediatrician from focus group: "I think with middle class families, a lot of times, at least in my experience, is that they have too much information. And they almost don't know how to decide what information is valid and what isn't. For example, in modern middle-income families, they'll say they don't want immunizations... the no immunization part really bothers me. When you ask them where they get the information, it's off the Internet. There are good sources, and there are bad sources."

Newer parents reported a need to have assistance with recording, and experienced parents said they would have liked assistance when they were first starting out. Parents and secondary caregivers reported that they would often use their child's peers in playgroups or daycare to serve as a comparison for their own child's growth, and experienced parents stated they used their older child as a baseline for their subsequent children. Parents and caregivers expressed a need for better descriptions of milestones and a place to get more information if there was confusion. If there was a milestone their child was missing, they would like instruction on how to encourage the child to achieve that milestone. For example, if the milestone required the ability to play with toys in creative ways, there would also be a suggestion for toys that may help the child achieve this goal.

Nanny: "I remember reading one [a listed milestone] once and was like 'what are they talking about?' but...you know, sometimes they have the quotations marks on these, like "helps" around the house...I'm like... 'what do you mean by "helps" around the house?'"

Several participants expressed frustration with milestone lists that only allow for yes or no answers, when they really should have a range of values (*e.g.*, plays "make believe").

3.2.2.3.6 Reflection and Analysis on Childhood Records

Study participants suggested several ideas for reviewing and analyzing collected data beyond what I predicted. Many parents wanted to look over data for sentimental reasons or for curiosity (*e.g.*, compare their children with others). Those concerned about health requested the ability to see trends over time, such as graphs of height, weight, or number of words in their vocabulary. One participant mentioned that she would like to be able to get a quick overview if she was pressed for time, but if she had more time and was curious, that she would like to see more details. One experienced parent mentioned needing to remember data to tell schools.

Experienced mother of three: "Nowadays when they go into school, they want to know when they sat up, when they walked, when they talked, when they rolled over, and I'm sitting here trying to think of things later, and I'm like "oh lord..." and I pretty much end up guessing. Because after 5 years, I can't [remember]..."

Experienced mother of two: "I think that would be great as we get older... you want to look back more on those things...I think now...my husband is 40 and he wants to start looking back at the video tapes. So, I think that as we get older, you want to start going back more."

3.2.2.3.7 Pros and Cons of Computerized Recording

Participants expressed mixed views on using computers to help with recording information about their children. Most acknowledged that computers may have the ability to make their lives and data recording easier, but they had some concerns. Some of the advantages of using a computer that were reported were that it was easier to enter, it was more interactive, it had the ability to back up data, and that it could be very helpful in helping them to organize data. One participant liked the idea of using her computer to track progress so much that she had tried to keep track of her children's records in a spreadsheet, but complained about a lack of a good method for organization.

Father-to-be: "Carrying around all this stuff is just not practical and if it burns down.... you lose it. With digital data, if you have it backed up in a couple of different places, then it still exists."

New mother of twins: "I've had to look stuff up...and probably the most questions I've asked pediatricians about is speech... but it would be nice to have something that... I'd rather punch it up on the computer and not have to do a stupid search or look through a stupid book. It'd be easier."

Several participants noted reservations about using a computer to keep track of their records. A few participants who enjoyed making scrapbooks reported concerns that computers seemed less personal than handmade scrapbooks or photo albums. They also questioned the ability of the computer to track physical keepsakes like baby blankets or toys. Lastly, several participants reported a fear of a computer crash leading to the loss of all their records.

Future mother: "My grandmother has even given me like a grandmother's book that I had no idea this whole time she'd been jotting things down about how she grew up and different things with her and I and, so, that's definitely special.... I would probably do things myself, just because I think it means a little bit more [than on a computer]."

3.2.2.3.8 Diagnosing Disabilities and Disorders

A number of participants had their own children with special needs or had cared for children with special needs, thus, interesting insights into the diagnosis of these disorders also emerged from these interviews. Most parents commented that their child's diagnoses had been surprises. They did not have any family history of delays, and thus they were not looking for the warning signs. However, once the diagnosis was made, parents reported they believed they could have detected something earlier had they known what to look for. Additionally, several parents decided to wait to see if their child was just slower than average development. They had not expected a delay, they were told things such as "boys develop slower than girls," or they were even told by their pediatrician to wait and see if things improve.

Preschool teacher and mother of child with autism: "[my daughter] ... did everything typical, then when my son came around, it was kind of like "well, he's not walking yet..." well, "boys develop slower than girls", everyone always tells me that.... I had a general sense that he was delayed, but I thought it was because he was kind of sheltered because we didn't do much besides our playgroup or home."

In the daycare focus group and also one of the interviews, participants mentioned they had some discomfort in the idea of telling parents that something may be wrong, and oftentimes would go to the director to bring up any problems. One participant mentioned that any computing technology would have to be sensitive when suggesting that their child may have a delay, or perhaps only prompt the parent to consult their doctor.

Mother of a son with speech delays: "... as the mother of a child who has delays, it's hard for me to see that they really should be doing it [a particular milestone]

by this point. ...it's really hard to see that in black in white... to see that first report that your child isn't perfect."

3.2.3 Implications for Design

Based on the validation of my initial hypotheses of rationale and requirements, as well as the new themes I discovered from the interviews and focus groups, I determined several design considerations for this domain.

Take advantage of existing motivations. Keeping useful records on children can be time consuming, but the promise of early diagnosis or better health alone may not be motivating enough to encourage this behavior. Parents are already motivated to keep sentimental records on their children and share that information with friends and family. By building something that tracks both, researchers may be able to use sentimental record-keeping as a persuasive technology to motivate parents to keep better health records.

The computer should not replace the pediatrician. Both parents and pediatricians have expressed how important doctor visits are for new children, and technology should not interfere with that relationship. Instead, computing technology should be used to improve the parent/pediatrician interaction and make the precious time together even more resourceful. Moreover, the computer should not be seen as making any diagnosis, only providing supporting evidence for a parent or professional to consult.

Provide a reliable information source. Parents are naturally curious and want to learn what they can, as evidenced by the amount of reading the participants reported they did. By associating software with reliable experts, such as a national pediatrics

association, designers can increase user confidence in keeping the right records. Additionally, customized lists can be obtained for children, such as using ranges instead of yes/no levels. By providing examples, such as a video or longer description of what "helping" around the house means, a well-designed system could become the *de facto* standard for record-keeping.

Provide for effective communication for the child's caregiver network. Input comes from a range of care providers who have different stakes in the health of the child. Thus, any technology designed for children should allow input from multiple sources and accommodate easy sharing and notification of changes. Furthermore, technology should provide long distance communications channels because parents may be motivated to share important information with distant relatives or friends.

3.3 Overall Implications for Embedded Capture & Access

By executing these two formative studies and analyzing the results, I discovered some common implications for technology for these two caregiving domains. These findings are similar to challenges and opportunities uncovered in other collaborative care domains, such as care for the elderly or chronic condition management (Abowd, Hayes, Kientz, Mamykina, & Mynatt, 2006). However, the emphasis here is how the commonalities of the two domains affect the design choices and features of the concept of embedded capture and access.

Caregivers almost always have the child's best interest in mind. From my interviews and observations with therapists and other caregivers, I almost always heard from people that they would not mind working a little harder or sacrificing their own

comforts if it would benefit the child for whom they cared. For example, several of the therapists mentioned that although they did not necessarily like being videotaped or have their therapy critiqued, they understood that it was to ensure that the best care was being delivered to the child. In addition, parents stated that they wanted to know what was best for their child, and even if it was bad news (such as their child having a developmental disability), they would want to know as soon as possible to ensure that their child would receive the best care. Thus, technology in this domain can assume that caregivers will be dedicated to care and can be focused primarily on the needs of the child rather than their own.

The decision-making process is often a combination of many smaller decisions. In both the domains I explored, I found that big, critical decisions were fairly uncommon. Instead, decision-making was mostly comprised of smaller decisions that happened frequently. In the case of the therapists, they would make 10-13 smaller decisions about different skills at meetings every two weeks or so. More complex decisions, such as adding a new member to the team of therapists, maybe only happened once or twice per year. For parents, there were again many choices that they made that were much simpler and regular, such as whether their child has achieved one of 40 milestones in a list, or which foods their child should be eating. The more complex decisions in this case, such as whether to vaccinate a child, were more common than in the case for therapy, but they still did not happen often. Thus, technology for decision-making in these domains should support making regular, smaller decisions and look for ways of motivating caregivers to think about them. It is often difficult to retrain caregivers. Despite having the child's best interest at heart, many times caregivers go by their own instincts and have to do things quickly. In the case of trained therapists, the way they learned to do therapy was very much ingrained in the habits of the therapists. Parents are often taught concepts of parenting from their friends and family at an early age, and thus may be fairly set in their ways. Any technology designed to support these types of caregivers should take into account the fact that it may be difficult to retrain caregivers to change their habits. Because therapy is fast-paced and becomes a very intuition process, anything that would require therapists to change their habits would be very difficult to use. Additionally, since parents are already busy and likely to forget things, having something that requires a large amount of time and attention would also have a lower likelihood of success.

Providing evidence in decision-making is important. In the two formative studies I conducted, participants reported on many occasions that they valued the use of reliable evidence and the data-based decision-making process. The Discrete Trial Training therapy protocol is based on the notion that taking data is crucial for making decisions about the different skills on which a child works. Also, many parents and medical professionals often expressed disdain with conflicting data and information and the idea of making decisions about care without consulting with professionals or past records. However, caregivers did not necessarily want to expend a significant amount of effort collecting data and reviewing it. As such, having technology support for this domain should support easy, natural data collection that seamlessly integrates into existing practices.

Decision-making is often a collaborative task. Although there is a notion of primary and secondary caregivers, the task of providing care to an individual is typically not a task undertaken alone. In the Discrete Trial Training practice, therapists worked individually with the child, but came together as a team to make decisions about the course that future therapy sessions would follow. In raising young children, parents often consulted with other family members, friends, their pediatricians, and secondary caregivers. Therefore, technology for this domain should be able to support input and access from a large variety of users.

3.4 Summary and Contributions

In this chapter, I described two major formative studies I conducted to gain a better understanding of decision-making for the collaborative care domain. The two domains were supporting the needs and processes of Discrete Trial Training therapists and aiding the record-keeping needs for caring for young children. In studying DTT therapists, I conducted a long-term participant observation and interviews with domain experts. To understand the needs for record-keeping for young children, I conducted interviews and focus groups with various stakeholders who care for children, including new and experienced parents, secondary caregivers, and medical professionals. The results of these studies uncovered some design requirements and themes which I then was able to use to design and prototype different technology ideas.

The main contribution of this work was in determining and defining the needs of caregivers in two of these domains. These domains are both relatively underrepresented in the field of Human-Computer Interaction. They are both caregiving domains with similar goals, but have many differences as well. However, I was able to distill common themes that helped me in shaping the definition of embedded capture and access. In addition, I was able to use these studies to determine specific evaluation metrics for technologies to support decision-making for caregivers.

CHAPTER 4

EMBEDDED CAPTURE & ACCESS PROTOTYPES

In this chapter, I describe the design and development of three prototype applications using embedded capture and access techniques for supporting caregivers in the decision-making process. Two of these prototypes are two versions of Abaris, one for home therapists and one for schools, and the third is the Baby Steps system, including a digitized baby book and the KidCam monitoring and recording device. Each of these technologies went through several design iterations and was aided by input from individuals in each of the domains for which I was designing. For each prototype, I describe design alternatives considered then the design and implementation details for the capture and access portions.

4.1 Abaris for Homes

Abaris for Homes is a fully functioning prototype embedded capture and access system that supports therapists conducting Discrete Trial Training therapy with children with autism. The main goals of the system are to seamlessly capture data during therapy sessions, automatically graph data to reduce burden on therapists, and provide an interface for accessing relevant artifacts from therapy in the decision-making process during meetings. The version described in this section is the one used for the deployment and evaluation described in Chapter 5.

4.1.1 Design Process

This section describes the process I undertook as a trained and practicing therapist and the design process of the Abaris system, including iterative design alternatives and how my experience in being trained as a therapist affected the design. As a therapist with the mind of a technology designer, I paid close attention to aspects of the therapy that could be improved using technology. During team meetings, I expressed difficulties or hardships I had to determine if these were common problems with other therapists or just difficulties I had as an outsider. I also began to ask the therapists for ideas on how to improve the process and probe new aspects that might fit well into their work practices.

Throughout the process, I collected a list of potential improvements and ways the research team might design a system to address the needs of therapists. Some of the requirements collaboratively determined by myself and the therapy team are as follows:

- Calculating percentages and drawing graphs by hand is cumbersome and time consuming.
- Data kept on paper is difficult to share and access during team meetings.
- Therapy is fast-paced, so any interaction with technology during therapy must be quick and unobtrusive.
- Because the therapists work with children that have severe cognitive impairments, any technology design cannot rely on the child's cooperation or input.
- The technology cannot distract the therapist or the child from the therapy itself.
- Therapists have trouble remembering the nuances of what happened during a given therapy session. In addition, it is difficult for therapists to articulate to

others what the child did during their sessions. Though videos of sessions are recorded, it is difficult to find a particular instance in the video that they might want to share during meetings.

• The theory behind the therapy protocol is that therapists must be consistent in the way they test the child and thus therapists must use meeting times to obtain consistency.

I and others began brainstorming ideas for technology designs that might address these issues and fit into the everyday practices. Based on the observations, experiences, and the discussions with the team of therapists, the overall idea was for a system that could eliminate the need for hand-drawing graphs while providing a way to easily access and view all the data that was collected, as described in Section 3.1. In addition, because therapists were already recording videos of their therapy sessions, I incorporated a way to easily access relevant moments in a video stream to share with others during team meetings.

The therapy team agreed with the overall idea for technology, however, there were many aspects of the design to be considered to ensure that it would fit well within the existing practice. One of the most difficult aspects of the technology was how to link parts of the therapy to the relevant moments in the video stream, namely, the beginning and ending of the trial of a skill. An initial idea was to replace the paper data sheet with a Tablet PC version and have users select their grades on a digitized version of their datasheet on the tablet while conducting therapy (see Figure 6). The tablet would then automatically timestamp the data as it was selected on the form. A team of undergraduates initially prototyped this concept, and I modified their prototype to better

suit therapists' needs. I and several other therapists tried it during several therapy sessions. After using it during the sessions, the therapists reported that it felt too heavy, and the tablet was not nearly as flexible as the paper data sheet if they wanted to make additional notes.



Figure 6: Tablet PC version of Abaris

Another idea was to have therapists make a gesture that an overhead camera could recognize, which would indicate the grade for a given trial. This was accomplished by having a sheet of paper with symbols indicating the start of a trial (see Figure 7), which the therapists would cover with their fingers. Then, they covered another set of symbols to indicate the child's grade for a given trial which also indicated the ending time of the trial. I tried this technique during one of my own sessions and quickly realized the idea would not work well in practice. It was very difficult to remember to do the start and stop gestures due to the fast-paced nature of the therapy, and it was an additional task that was not part of the normal workflow. These gestures were even more problematic in that child was distracted by them and tried to mimic them, which interrupted the flow of therapy.

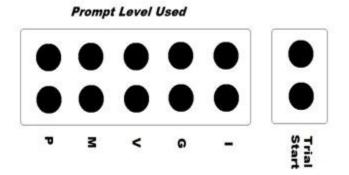


Figure 7: Paper sheet used to indicate to vision system when a trial starts and stops.

With these initial designs quickly tested and dismissed, I settled upon a design that fit well into the therapists' workflow by being completely transparent to them during sessions and only required explicit interaction before and after the therapy sessions and during meetings. The final system designed was named "Abaris", which is a play on ABA, the field from which DTT therapy comes. Abaris contains two major software components—one for capture or recording of data and one for access and analysis of data—which are located on the same computer. This computer acts as a network server to allow remote use for certain tasks, like maintaining the programs and viewing the captured sessions. As shown in Figure 8, additional devices supplement the software on the single PC including a color, laser printer for augmented datasheets, a web cam for capturing video and audio data, a high-quality wireless microphone for voice recognition, and a digital pen for writing the grades on the specially printed paper. The capture and access interfaces are described in detail in the following sections.



Figure 8: The basic system setup to run and interact with Abaris.

4.1.2 Abaris Capture Interface

During therapy sessions, therapists use the Abaris capture interface. The interface is fairly simple and ensures that therapists complete sessions according to a specific workflow, which resembles their actual workflow. The capture interface allows therapists to begin by reviewing notes of previous therapists, preview the datasheet for the day, then print it and start the video recording. The therapist then begins her regular session using the digital pen and paper. After completion of the session, the therapist docks the pen to the USB dock, which downloads all the data and stops the recording. The therapist is then provided with an interface to type in the letters written for each of the trials to eliminate the need for handwriting recognition and any associated error correction (see Figure 9, right). Afterwards, the capture interface displays how the child did that day, then prompts the therapist to write general notes about the session for other therapists to review.

Recorded video from therapy sessions coupled with appropriate indexing allows fast access to particular trials. In current practice, therapists use both a spoken command

to indicate the beginning of the trial to the child and a pen to record data after a trial. I leveraged these practices to explore effective indices into the captured therapy session. Using Nexidia's (Nexidia, Inc., 2008) voice recognition technology (an off-the-shelf, phoneme-based speech recognition system), Abaris retrieves timestamps for a specific stimulus discriminant (*i.e.*, the verbal command), obtaining estimates for trial beginnings. After trials, therapists record grades on the augmented datasheet using a special pen (see Figure 9, left). Replacing traditional pen and paper with Anoto's digital pen technology (Anoto, Inc., 2008) affords collection of positions and time-stamps of every stroke, while preserving the flexibility inherent to writing. The original form the therapists used is found in Appendix B.1 along with the redesigned form in Appendix B.2, which serves as a comparison between the two forms.

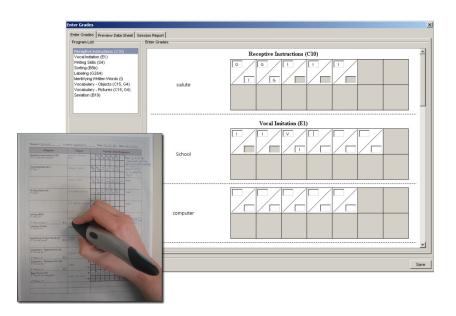


Figure 9: Digital pen and specially designed datasheet (left) and interface to enter grades (right).

While capturing a session, Abaris records an additional audio file, which is monitored and indexed by Nexidia while recording, including a pattern file that can be searched for speech patterns indicating the beginning of a trial. Within the plain-text XML file generated by the digital pen's interaction with a data sheet, each stroke is stored with its coordinates and associated absolute beginning timestamp. A stroke, by definition, contains at least 6 pixels and more than half of its points inside the 31x20-pixel cell the system is analyzing, preventing erroneous marks on the paper made by therapists signaling trial data. Using data stored from the written records and the patterns in the audio, Abaris reconstructs likely beginning and ending times for particular trials.

4.1.3 Abaris Access Interface

The access interface for Abaris provides therapists with the ability to review sessions and correct grades and timestamps for places where technical or human error created incorrect data. Therapists need to perform these tasks both locally at the site of therapy and remotely from their homes or offices in preparation for team meetings and therapy sessions. Furthermore, they must be able to access Abaris both individually and in a group setting during team meetings. Abaris must provide at least the same level of functionality as the traditional pen and paper process, including graphing of empirical data and review interfaces for therapist data-sheets.

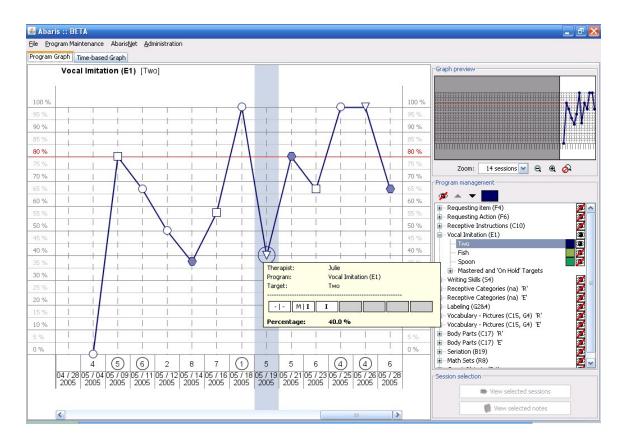


Figure 10: The main access interface displaying a single selected graph on the left with a tool tip indicating information for a specific session. The right shows a view of the entire graph and the list of selectable programs.

Once the access interface is started, the therapist/consultant can choose which programs to view by marking programs and targets to be shown or not. If more than one target is visible, the graphs are overlaid in the same view with a displayed legend. Because multiple graphs might become confusing, other visualization techniques facilitate analysis. A tool tip (describing the target and program) appears each time the cursor is near a target's line. Another tool tip shows the data of a target from a particular session when the user hovers near that data point. Figure 10 shows an example of a typical graph with a therapist-specific tool tip.

Users can select multiple sessions for which they want to view more details by clicking and highlighting the columns associated with those sessions. This functionality allows the user to review between two and five different sessions quickly to compare procedures (see Figure 11). The session browser loads in its own window, with typical video control functions of play, pause, stop, fast forward, and frame seeking functions as well as functions to jump to the next or previous trial of currently visible programs. Along the bottom of the window is a zoomable timeline that shows when trials occurred, using the predictions described above. To the right of the video are the grades for selected programs. Clicking on a grade moves the video to the start time for that trial. If there are several sessions loaded, the user can switch between them by clicking on the timeline of another video or selecting a trial that is not part of the video currently shown. The grades assigned to a trial, as well as the beginning and end times, can be modified. These corrections appear on the graphs immediately after saving the changes. Within the access interface, therapists can also add and edit programs and targets, an activity that happens frequently during the course of a team meeting.

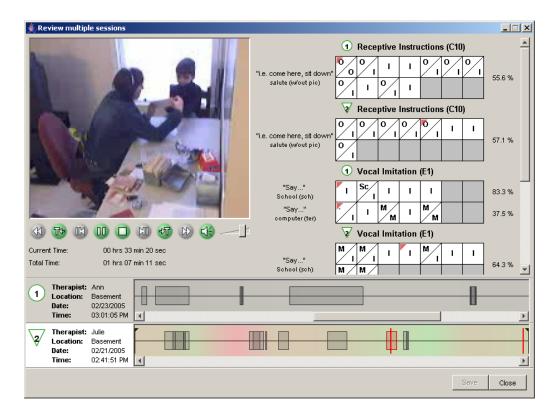


Figure 11: A session browser set up to view two different therapy sessions. On the bottom are two different timelines and on the left are the grades for the different trials.

4.2 Abaris for Schools

While many children receive Discrete Trial Training therapy in the home, many more children receive the therapy in a school setting via teachers in a classroom. Abaris worked well for a close-knit team of therapists all dedicated to one child, but I wanted to explore its ability to improve data collection and support for a team of people who must work with a larger amount of data and multiple children in a less structured environment. Thus, I chose to extend the most useful aspects of Abaris to work in a school setting. This section describes the design of Abaris for Schools and what changed between it and the original version. For more details on Abaris for Schools' features, I refer to the Abaris for Schools User Manual that I provided to the teachers, which can be found in Appendix C.1.

4.2.1 Design Process

To design a version of Abaris for a school setting, I worked with the University of Washington's Experimental Education Unit (EEU). The EEU is an on-campus prekindergarten school that serves a mixture of children with special needs and typically developing children. In this school, researchers can test experimental educational programs with real children and teachers to collect data on its efficacy.

After presenting the work on Abaris to the EEU, they became very interested in adapting the technology for their own uses. The teachers at the school had a practice of doing Discrete Trial Training therapy with students, but it was normally one teacher with two students at a time, which was different from the experiences with the home-based team. Though they do take data, that data is rarely reviewed in a timely manner, as it is a time-consuming process to create graphs for that many children. Thus, the data is visited usually about once per month when the teachers have a meeting with the lead teacher. During that meeting, they make decisions and changes to the skills on which the child works.

Another aspect of the education at the EEU was the attempt to generalize the skills learned in the Discrete Trial Training to those used in less structured settings. They had a specific program called "Free Choice" in which they test children on skills in natural settings while playing with other children or during snack time, as opposed to the standard table-top, structured setting of DTT. They noted difficulty in assessing this skill,

because there was not a good way of comparing the skills tested in their Free Choice sessions with that of the Discrete Trial sessions.

I decided the techniques used in Abaris to automatically record and compile graphs might help these teachers more frequently make decisions about the data they were collecting. Frequent access and review of data may also help the children advance more quickly, as they do not have to keep working on skills well after they have learned them. The initial idea was to adapt the original Abaris technology by using the Anoto pen and paper technology to automatically collect and timestamp data and then create graphs and link it to video.

Although the teachers at the EEU also conducted DTT therapy, they used different grading and review styles and needed to accommodate multiple teachers and children simultaneously. Thus, I made several changes to the existing system to accommodate their style and work environment and to achieve the goal of encouraging more frequent review of data. For several reasons explained later, I decided to completely rebuild the Abaris system using more efficient code and address some of the limitations of the old system.

The Abaris for Schools system kept the basic elements of the original system by allowing therapists to easily print automatically-generated data sheets on Anoto paper and download the data to a computer which generates graphs automatically. I developed video support as well, although this was not a major priority for this team of caregivers, as they likely would not be able to have the time to review videos. Additionally, the working environment at the school was usually not in a fixed location, making sufficient video recording more difficult.

4.2.2 Abaris for Schools Capture Interface

When teachers arrive for their workday, they use Abaris and select "Print Data Sheets" from the main menu. They are then presented with a form (see Figure 12) that allows them to select their name from a list and choose a student with whom they will be working. They then select from a list the skills they will work on for the day with that particular student. The list of skills shows the overall percentage correct for the last day of practice, so teachers can sort skills by those that need the most work. As they scroll through the list of skills, the system displays an up-to-date graph of the child's progress for that skill. The graph shows the percentage correct for each day a skill was practiced, for up to 10 of the previous sessions. Additionally, if teachers click on a point in the graph, they can view the individual prompt levels used for that day (*i.e.*, +, -, P+, and P-) and review videos of the session if they were recorded.

This interface allows teachers to review data about a skill at the time they are making the decision about it, which means that if the child has a good understanding of a certain skill, it may be easily swapped with one that needs more practice. After the teacher chooses which skills she will work on with the child that day, she previews the form to make sure everything is correct and prints the data sheet (see Figure 13). The printed sheet only contains the skills the teacher is working on that day and will automatically add the child, the teacher, and the correct day and time to the top of the sheet. The teachers repeat this process for each child that she will work with in a given day, and the entire process takes approximately 5-10 minutes per child.



Figure 12: Screen shot of form used to select children, select skills, and print data sheets for a given day. Teachers can also review graphs and view videos of sessions before printing.

Once teachers have printed their forms for each child they will be working with for the day, they are ready to begin their Discrete Trial sessions in the classroom. They take an Anoto-enabled digital pen to use for their therapy session for the day. For the study, teachers used the Nokia SU-27W (Nokia, Inc., 2008), and each had his or her own pen so teachers could work simultaneously without having to share pens. The digital pen and paper function as a normal ink pen and paper, with the exception that the pen has a camera built into it and the pattern has a fine pattern of dots that the pen's camera uses to recognize the location of pen strokes on the paper. The original forms that the teachers used for Discrete Trial can be found in Appendix B.3, along with the redesigned form in Appendix B.4 to show how the form was redesigned to accommodate the digital pen technology.

The teachers work on Discrete Trial sessions with typically two children at a time for about 1-2 hours. During that time, they randomly conduct trials with the children for each skill on the data sheet. They take data on the data sheets using their digital pen. For each skill, there is a box on the data sheet with room for up to 10 trials (see Figure 13). Each trial line has a space for writing the stimulus (*e.g.*, "crayons" for a sorting task) and four columns associated with four different prompting levels. The teacher uses the pen to place a checkmark in the appropriate column to indicate the prompt level required for the child to complete the skill. She repeats this process for each trial conducted with the children during her classroom session, and she can complete the skills in any order and alternate between children, taking data as she did before using Abaris. If the teachers choose, they can use a separate interface on a computer in the classroom for recording videos of therapy sessions. The digital pen will record timestamps as the teachers write down skills, and they can then be matched to the video-recorded trials.

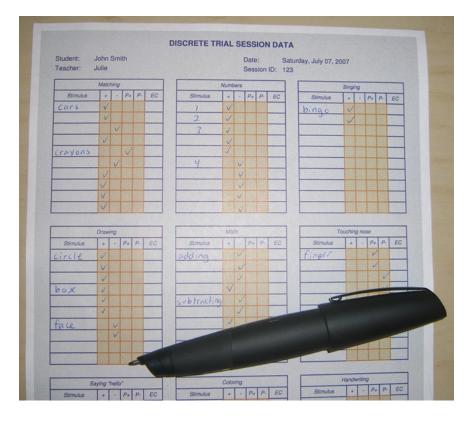


Figure 13: Automatically generated data sheet with data entered by a teacher. The checkmarks appearing in the orange box will be used to generate graphs for each skill.

Finally, I designed the Abaris for Schools system to allow teachers to manually enter data from "Free Choice" sessions and generate graphs for data on those sessions (see Figure 14). I provided a way for teachers to easily compare skills tested in Discrete Trial Training sessions and Free Choice sessions to see if there are similar trends for each child (See Figure 15). Teachers also had the ability to print data sheets and make annotations for their own records and to use during meetings with one another.

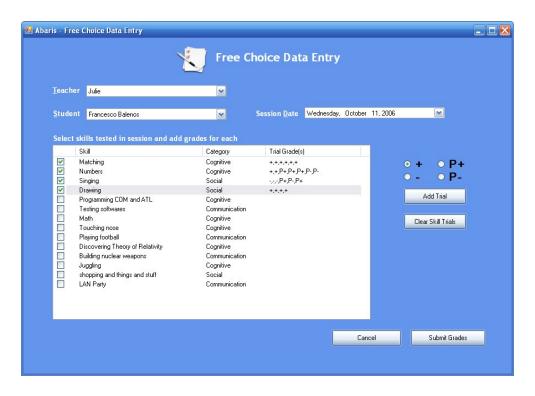


Figure 14: Form for manually entering data from Free Choice sessions. This serves as a comparison between the automatically generated graphs and the hand-entered data.

4.2.3 Abaris for Schools Access Interface

After the teachers complete their Discrete Trial work with their students, they return to the computer which they printed the forms from and dock the digital pen with the USB dock, which downloads the pen strokes they took on the paper during their therapy session. After downloading the data, the teachers then place the paper copy of the data sheet in a binder, to serve as a backup in case anything happens to the digital data stored on the computer. This process was designed to be as quick as possible so that teachers could just dock the pens and leave for the day if they have that need.

After downloading the data, Abaris automatically generates graphs of the last session, which are immediately viewable. To view graphs, teachers can go to a Data Review screen (see Figure 15) of Abaris to compare graphs of various skills quickly. In this screen, the teachers can quickly switch between children and skills to review which skills need more work in Discrete Trial and which can be mastered. Teachers have the ability to print graphs to add to the children's student records or for further annotations. Also in this screen, if data is entered for other tests of skills, such as testing skills in Free Choice, they can be compared side by side. After reviewing the data, if teachers decide to add additional skills or work with different children, there is an interface that allows teachers or other data administrators to add new or edit existing teachers, students, and skills.



Figure 15: Screen shot of the Data Review screen. Teachers can review data for multiple students and print graphs.

The main feature that I changed from the previous Abaris system to the new Abaris for Schools system was the integration of data review into the data sheet generation process, which is essentially embedding the access portion into part of the capture portion. On the screen where they select skills to add to their data sheets, which is something that they have to do before they can conduct therapy that day, Abaris for Schools displays the graph and video preview for those skills so they are encouraged to view the graphs and are reminded to view the videos (see Figure 12).

4.3 Baby Steps and KidCam

Baby Steps and KidCam are two embedded capture and access prototypes I developed to support decision-making for parents of children from birth until age 5, which is based on the formative study results described in Section 3.2. Baby Steps serves as a digital version of a baby book, which encourages parents to enter information on their child's developmental progress and associate pictures and videos with milestones. It also allows them to review and share data with others. KidCam is designed to aid parents in recording videos and pictures of their child's development, which can automatically be downloaded and synchronized with Baby Steps. This section provides a detailed description of the design process for Baby Steps and KidCam, as well as details on the final design and implementation.

4.3.1 Design Process

This section describes the early design process for coming up with the concepts for Baby Steps and KidCam, as well as how I used the findings from the formative evaluation to refine and iterate upon the two ideas.

4.3.1.1 Early Design Concepts

The early idea for creating Baby Steps was the result of me attending a presentation at the 2004 Organization for Autism Research Conference in Washington, D.C., where I saw experts from the Centers for Disease Control and Prevention (CDC) give a presentation on their goals of the ActEarly campaign (Centers for Disease Control and Prevention, 2008) and discuss the success of the materials they had prepared to distribute to new parents at pediatrician's offices across the United States. The ActEarly campaign's goal was to educate parents and medical professionals about the early warning signs of autism. It also aimed to educate them about when children of varying ages should reach certain developmental milestones. During their presentation, they discussed problems they had with engaging parents in the static materials, and that many parents would just leave behind the information without reading it due to the stressful nature of Well Child Visits at the pediatrician's office. Thus, I came up with the concept of making the CDC's materials digital so they could be more interactive and proactive about encouraging parents to more frequently consider their child's development and check for developmental progress more regularly.

To get the idea started, in the spring of 2005, I and others advised a team of undergraduates who needed a topic for a software engineering class project. For their project, they developed a system they called KidCal, which would serve as an initial prototype for getting the ideas of an interactive baby calendar across to parents and the CDC. Throughout the semester, the students arranged meetings with the CDC to discuss ideas and show early prototypes, and they eventually built a web-based system for keeping track of developmental milestones. This project served as a prototype to get my ideas out and refined, but after this experience, I realized that I needed to do a more indepth study on the design requirements for this domain. Thus, I began the formative study described in Section 3.2, which served as the main basis for my design of the Baby Steps and KidCam systems.

4.3.1.2 <u>Refined Design Ideas based on Formative Study</u>

The ideas for Baby Steps and KidCam existed before conducting this study, but I used this process to refine and iterate upon them after confirming with subjects that they would be useful. Thus, I used many of the rationales, functions, and emergent themes from the study to identify important aspects for the design, and at the end of interviews with various stakeholders, I reviewed design ideas to obtain feedback. Below I describe the general ideas that I came up with after conducting the formative study.

For Baby Steps, I proposed the development of an application that allows parents to enter health-related information, pictures, and videos of their child. Figure 16 shows an early mocked-up screenshot of the Baby Steps system. Based on the age of the child, the system can automatically prompt caregivers to enter and check off relevant developmental milestones that their child has achieved. The list of milestones and dates should come from a trusted source, such as a national association of pediatrics. These reminders, either through pop-ups on the screen when they turn on their computer or through email, can prompt them to enter data about their child. Because some participants in the study did not mention the need for reminders (Function 3 from Table 2), these may be optional, or only appear after a long period of inactivity. The system can allow parents to review progress over time at varying levels of details, and if they have any questions, they can view information about various types of childhood disorders or see examples of developmental milestones. Additionally, they can share experiences or upload artifacts for others online (F9). If a child has gone too long without completing a specific milestone, rather than warning the parent about the potential of a disorder, it will alert them and add it to a list of questions they can print and bring to their pediatrician at their next scheduled visit.



Figure 16: Early screen mock-up of a digital repository where parents can enter and review milestones and videos.

Because parents are already motivated to enter pictures and share them with others (R5), the system can encourage uploading of pictures or videos as evidence for milestone completion. Additionally, it can automatically generate keepsakes for parents, such as DVDs of videos captured in relation to their important milestones or an automatically generated newsletter on their son or daughter's development to send to friends and family (F4). To preserve parents' desire for physical artifacts, the system can also help generate photos or decorations for scrapbooks. Secondary caregivers would be able to enter data into the system and send any new information to parents through email. Additionally, if there are any health concerns, the parents can send their child's data, pictures, or videos to their pediatrician to help answer questions or address concerns (F5). Lastly, the computer would provide automatic backups of their child's data onto an external disk or remote server.

In the focus group with medical professionals, one of the doctors stated that many times, a parent cannot easily convey something their child does and agreed that video may help them better convey questions. Additionally, many parents expressed a desire to record more videos of their children (F8). However, the capture of videos for each milestone a child encounters will be a very difficult task. Thus, I proposed the concept of KidCam, which would act as a smart baby monitor that "selectively archives" things it sees (Hayes, Truong, Abowd, & Pering, 2005). The monitor could be built using a handtop computer with an integrated camera that constantly records and saves the last 20 minutes of video data (see Figure 17 for an early prototype design). When parents or caregivers observe important events, they can trigger the baby monitor to save video clips of what just happened by tapping a button on the screen.



Figure 17: Left shows screen shot of smart baby monitor interface. Right shows baby monitor on a portable handtop computer.

Some milestones may occur at times or locations when the parent or caregiver is unable to constantly monitor them (R4), thus, I proposed a system for a set of wireless, sensor-enabled toys (F3). These toys could sense when a child plays with them and trigger recording when events are likely to happen. For example, one of the developmental milestones a child should reach by the time he is 7 months is "picking up and shaking hand toys." A rattle with a wireless accelerometer can sense when a baby shakes it and trigger recording from the monitor nearby. Other toys that can sense developmental milestones include dangling objects that can sense when they are being moved or a bucket that can sense when objects are being added or removed.

This prototype would address several concerns raised by the stakeholders in the formative study. Automatic recording of milestones could help parents who are short on time (R1) or are afraid of missing events (R2). Selective archiving can be an appropriate way to manage privacy expectations and control of recording (Hayes & Abowd, 2006) that many of the participants requested. One major factor would also be to design a

modular system that will work as a stand-alone application or with a subset of toys to help mitigate some cost concerns associated with equipment.

4.3.1.3 <u>Development Process for Deployable Prototypes</u>

I chose to develop the Baby Steps digital baby book and the KidCam baby monitor system as the basis for my testing of an embedded capture and access system. For my dissertation, I chose not to implement the sensor-enabled toys because more research is needed to understand what toys are needed and how to design appropriate toys with appropriate sensors. This research is being carried out by Westeyn *et al.* (Westeyn, Kientz, Starner, & Abowd, 2008). The Baby Steps and KidCam prototypes alone would enable me to test the different features of embedded capture and access to determine if this type of technology is feasible for this domain.

Baby Steps and KidCam were developed simultaneously, initially beginning in January of 2007. I decided to make Baby Steps a stand-alone software application as opposed to a web-based application, largely due to the need for secured medical-related data of the child and the ease of implementation of more advanced features, such as audio/video storage and playback. Thus, Baby Steps was designed to use a database that would reside on the parents' computer. Similarly, KidCam existed as a stand-alone application that would run on a separate, handheld computer, once again to ensure data security. I designed the two devices were designed to that they could synchronize with each other over a wireless internet connection.

Both the Baby Steps and KidCam applications were developed using Microsoft .NET's C# programming language with a MS SQL database server installed locally on the machine. Video playback for Baby Steps uses the Microsoft Direct X libraries, and a custom DirectShow playback feature was implemented to provide the buffering capabilities and playback of video on the KidCam device. Baby Steps runs on a Microsoft Windows XP machine and uses a Windows service for the reminder system for parents. The video buffering for KidCam was originally implemented by another student using Microsoft DirectShow and third party audio/video codecs and filters. One other student and I were responsible for refining the video buffering features for the KidCam application to ensure proper audio/video synchronization and compression.

The general GUI theme for both Baby Steps and KidCam is one that I custom designed using pastel colors and nursery-themed graphics and icons. The interface is designed to be gender neutral and appeal to both parents and children. This theme was modeled after many baby book designs, which use many colors and decorative pictures for aesthetic and sentimental reasons. This also was chosen so that the baby book would seem less like a medical record and more like a keepsake or scrapbook.

KidCam was prototyped as a mobile recording device on a Sony Vaio-UX ultra mobile PC (UMPC) running Windows XP. This was necessary for ease of development, custom interface design, storage space, and sufficient processing for the video buffering. The UMPC also had a built-in touch-screen, camera, microphone, wireless connectivity, and was portable enough that it could be taken anywhere. I also designed it so that KidCam could be used as a baby monitor with remote video and audio monitoring capabilities. The remote monitoring device used a Nokia N800, which used the Remote Desktop Protocol (RDP) to mirror the screen of the UMPC. I also used the Voice-Over IP freely available application Gizmo from SIPphone (SIPphone, 2008) to provide remote monitoring of audio from the KidCam device. Using the metaphor of the baby monitor, the UMPC acted as the camera/microphone that stayed in the room with the child, and the Nokia N800 acted as the remote monitoring device that the parents would keep with them.

The entire development process for the deployable versions of both Baby Steps and KidCam took approximately 1 year, and ended in January of 2008. I conducted most of the development for the Baby Steps application, with small pieces of the development divided up as small projects for undergraduate and master's student projects. While I was designing the interfaces, I would informally ask parents for feedback on the design and usability issues. I and another student also conducted fairly rigorous bug-testing before the final version was deployed to participants.

4.3.2 Baby Steps Digital Baby Book Design Details

This section contains details on all of the features of the Baby Steps digital baby book application. For even more details on the features, I refer to the Baby Steps User Manual that I wrote for parents, which can be found in Appendix C.2.

The main component of the Baby Steps system is a stand-alone software application that acts as a repository for storing all the information about a child or children, using the metaphor of a "digital baby book." To run the application, users click an icon on their desktop. This shows the Main Menu (see Figure 18), which displays a picture of the most recent child viewed and a list of the main options for the application. If the user has more than one child, he/she can easily switch between users using the pulldown menu. Users also have the option of changing their child's picture to make Baby Steps more personalized.

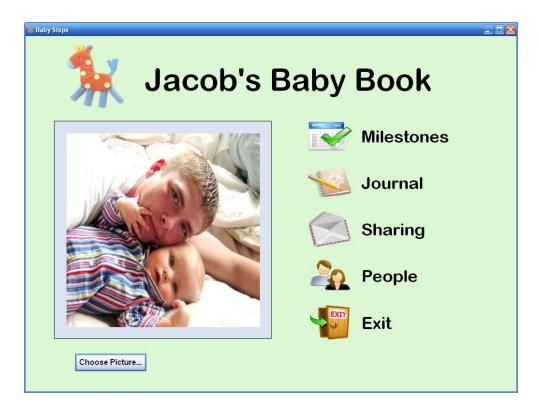


Figure 18: Screen shot of Main Menu of Baby Steps digital baby book.

From the Main Menu, the primary feature is the Milestones link. Clicking on this link opens the main screen for viewing a child's milestone progress (see Figure 19). The Milestones screen always starts by showing the current targets for the selected child based on his/her date of birth, and parents can choose to view different age ranges using the numbered links across the top. For my prototype, I used milestones from a standardized list used in many pediatricians' offices across the United States, called the Ages and Stages Questionnaire (Bricker, Squires, Potter, & Twombly, 1999). These milestones are phrased as questions directed to parents, such as "Does your child catch a large ball with both hands?", to which parents must respond "Yes," "Sometimes," or "Not Yet." The milestones are organized into 6 categories, including Communication, Gross Motor, Fine Motor, Personal-Social, Problem Solving, and Overall. They can view different categories for each age range by selecting the different categories from the selection box.



Figure 19: Main screen for viewing a child's milestone progress. Numbered links across the top are used to access different age ranges. The orange box on the left contains milestone questions, and as the parent enters information, it is displayed on the blue panel on the right.

To add information about a milestone, parents must click the "Add" button, which displays a dialog for entering data about a specific milestone (see Figure 20). Information that can be added about a milestone includes whether it's completed (*e.g.*, "Yes", "Sometimes", "Not Yet"), who observed the child completing it, the date it was completed, the parents' confidence in their decision, and any notes they want to make about the milestone. They can associate any pictures or videos with the milestone as "evidence" for completion. They can then use the main milestone interface to view the data they have entered. The milestones marked as "Yes" have a green checkmark next to them, milestones marked as "Sometimes" will show a yellow circle, and milestones marked as "Not Yet" will have a red X next to them. If parents have associated video or picture evidence with a milestone, gold star icon will be displayed. On this screen, parents can also enter information about their child's height and weight, which show a graph of their height and weight over time when clicked.

| 🐐 Add Milestone | |
|--|---|
| When your child wa | nts something, does she tell you by pointing to it? |
| Completed? | Yes Add Milestone to |
| Date Last Seen: | Question List |
| Recorded By: | Julie |
| Supporting Evidence: (pictures, videos) | C\dev\BabyCal\BabyCal\BabyCal\Media\1\mainphot C\dev\BabyCal\BabyCal\BabyCal\Media\2\mainphot Delete Selected |
| Confidence Level: | ⊙ 5 - Highest ○ 4 - Higher ○ 3 - Average ○ 2 - Lower ○ 1 - Lowest |
| Additional Notes: | Jacob points at his blanket when he wants it. |
| A LA | Cancel Add Milestone |

Figure 20: Screen for entering milestone information into the Baby Steps system.

From the main menu, parents can also choose to write a journal entry about their child's progress (see Figure 21). The journal allows more free form entry of information about their child where users type in text. The baby journal allows parents to enter dates, subjects, and authors, similar to how an online web log, or "blog," works. The information can then be viewed and printed if desired.

| 🕅 Baby Steps | | 🛛 |
|--|--|---|
| 🧐 Jacob's E | Baby Journal | * |
| Select Entry | View Journal Entry | |
| | Date: 1/17/2008 Writer: Julie | |
| 🖌 January, 2008 💽 | Subject: Jacob's Progress | |
| Sun Mon Tue Wed Thu Fri Sat 30 31 1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20 21 22 23 24 25 26 27 28 29 30 31 1 2 3 4 5 6 7 8 9 Today: 1/17/2008 | Jacob is progressing well. He should be walking any dayl | (1) (2) (3) (4) (5) (5) (5) (6) (6) (6) (7) (7) (8) (9) (9) |
| | Edit | Delete |
| TT ST | Write New Entry | Done |

Figure 21: Journal entry and viewer screen shot from Baby Steps

The third option from the Main Menu is to for parents to choose to share information about their child with others. The first option is to save and print information to share with their pediatrician. The parents can print "baby book" data, which will basically print the child's entire record of progress for a given age range, which is identical to the information requested by pediatricians for parents to bring with them to their Well Child Visit (see Figure 22). There is also a "Question List', which parents can use to keep track of questions they have for their pediatrician that they want to remember to ask at their next visit. This question list can also be printed.

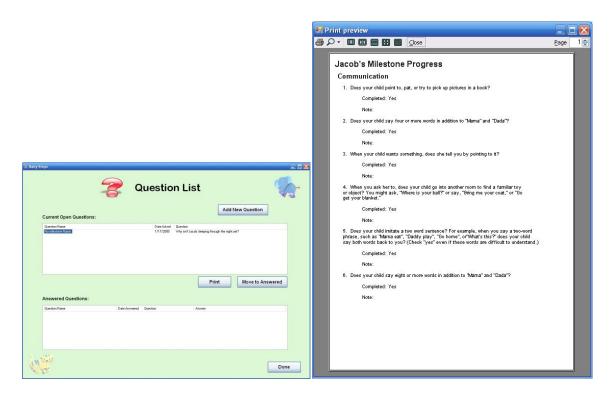


Figure 22: Question List that parents can use to keep track of and print questions for their pediatrician (left) and sample printout of a child's milestone information to share with their pediatrician (right).

Also from the Sharing Menu, parents can choose to automatically generate a newsletter in PDF format to send to friends and family in digital format or to print it share with local friends and family (see Figure 23). To generate the newsletter, parents choose an age range of the child that the newsletter to cover and the items they wish to include (*e.g.*, milestone information, height/weight, journal entries). The system then automatically formats a baby newsletter with pictures and the selected information and will send it to recipients that the parents choose, or automatically send it to their printer for a paper copy to give to others or keep in a child's scrapbook.

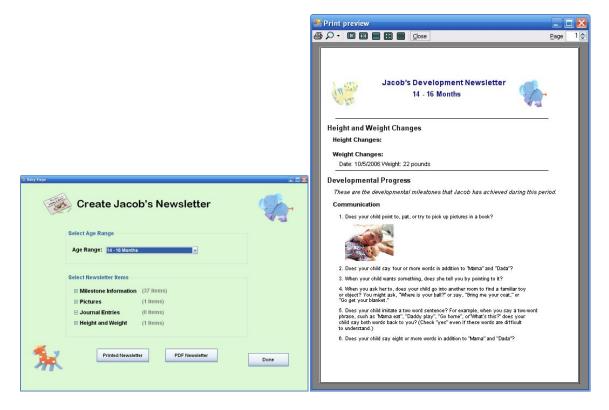


Figure 23: Screen for selecting items to include in a newsletter (left) and print preview screen of an automatically generated newsletter (right).

Another option from the Sharing Menu is the ability for parents to share videos of their child's progress with others (see Figure 24). There are two options for doing this. If the video is small enough (under 4 MB), parents can use the Baby Steps system to send the video via email to selected recipients. For larger videos, Baby Steps also allows parents to directly upload videos from the system to the popular video sharing website, YouTube.com (YouTube, LLC, 2008).

| 🛞 Baby Steps | | | |
|--|--------------------|---|---------------------|
| 🚺 Shar | e Jacob' | s Videos | 4 |
| 1. Select Video | 2. Send via En | nail | |
| Choose Video: | Select Recipients: | Subject: | |
| C:Wideos/Test.wmv C:Wideos/Test.wmv | Julie Shwetak | Jacob at the zoo | |
| | Add New | O Use My Mail ○ Use Baby Steps | |
| | - OR - | | |
| | 2. Share Onlin | e via YouTube | |
| File Size: 0.316 MB | User Name: E | ElegantFire | YouTube |
| Video Preview: | Password: | •••• | Sign Up for YouTube |
| - | Video Title: J | acob at the zoo | |
| | Description: | This is a video of Jacob and his first trip to the zoo | |
| | Category: F | Pets & Animals 🛛 🖌 🔿 Public | Upload Video |
| | | aby zoo family | 9d) |
| | ι <u></u> | | Done |

Figure 24: Interface for sharing videos from Baby Steps via email or uploading to YouTube.com

Parents can choose to synchronize Baby Steps with the KidCam device described in Section 4.3.3. To do the synchronization, both the computer with Baby Steps and the KidCam computer must be connected to the wireless internet. Then, when the parent clicks the synchronize button, all the new videos and pictures captured with the KidCam device will be copied locally so they can be associated with different developmental milestones (see Figure 25). Additionally, Baby Steps will send 3 random milestones that the child has not yet completed to KidCam, which will be shown on the KidCam's capture screen to remind parents of milestones to look out for in the future.

| throws a ball_01-28-2008_09-30-2 throws a ball_01-28-2008_09-30-2 throws a ball_01-28-2008_09-30-2 throws picture_01-27-2008_06-30 new picture_01-27-2008_06-34 new picture_01-27-2008_06-34 threads shoelace put on coat alone threads shoelace put on coat alone threads shoelace th | K | * | Sync With KidCam | | | | |
|--|----|---|--|---|----------------------|-------|--|
| Videos Pictures Target Milestone throws a ball_01-28-2008_09-30-2 new picture_01-27-2008_06-30 new picture_01-27-2008_06-30 new picture_01-27-2008_06-34 new picture_01-27-2008_06-34 new picture_01-27-2008_06-34 kick ball without support threads shoelace put on coat alone | | | | Now | KidCam Ready to Sync | Kid | |
| new picture_01-27-2008_06-30 new picture_01-27-2008_06-32 new picture_01-27-2008_06-34 new picture_01-27-2008_06-34 | es | Target Milestones | 2 | | deos | Video | |
| new picture_01-27-2008_06-34- new picture_01-27-2008_07-57- new picture_01-30-2008_09-29- new picture_01-30-2008_09-31- | es | s shoelace coat alone ist contains three randomly in, uncompleted milestones re sent to KidCam as new | thread put on This chos that d | new picture_01-27-2008_06-30 new picture_01-27-2008_06-32 new picture_01-27-2008_06-34- new picture_01-27-2008_06-34- new picture_01-27-2008_06-34- new picture_01-27-2008_06-34- new picture_01-27-2008_07-57- new picture_01-30-2008_09-29- new picture_01-30-2008_09-31- | | | |

Figure 25: Screen shot of Baby Steps' interface for synchronizing data with the KidCam device.

Baby Steps also has a proactive email reminder system that can keep parents on top of their child's developmental progress and remind them to enter data about their child's milestones. There are two forms of notification (see Figure 26): a popup that shows up at the corner of the parents' computer screen and an email reminder that goes to the specified caregiver(s). Each of these reminders contains three randomly selected target milestones in the child's current or next age range to which a parent has not yet entered information, or to which they have not chosen a "Yes" response. The default is for the popup reminders to appear once per day and for the email reminders to be sent once every three days.

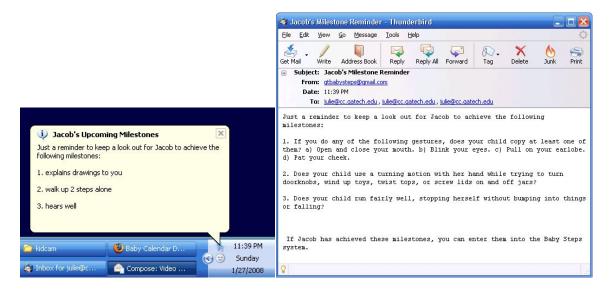


Figure 26: Baby Steps' reminder system, which includes daily popup messages (left) and email messages sent every 3 days (right).

Lastly, parents have the option from the main menu to add and maintain the people associated with their child in the Baby Steps system. This includes adding and editing their child or children's names, genders, and birthdates, adding and editing caregivers associated with the children, and adding and editing contact lists of recipients of the items sent from the "Sharing" menu, such as the automatically generated newsletter or the shared video recordings. Figure 27 shows the interface for maintaining people in the Baby Steps database.

| | Chil | dren | | Caregivers | | | | Sharing Recipients | | |
|--------|----------|---------------------------|---------------------------|--------------------------|---------------------------------|---|------------------|--------------------|--|--|
| lame | Gender | Date of Birth 7/6/2005 | Name | Gender | Relation | Email | Name Julie | Relation | Email | |
| acob | Male | | Shawna Jeremy Carol | Female Male Female | Mother Father Grandmother | julie@cc.gatech.edu julie@cc.gatech.edu julie@cc.gatech.edu | Shwetak | Aunt Uncle | julie@cc.gatech.edu julie@cc.gatech.edu | |
| Add Ch | ild Edit | Child Delete Child | | Add Caregiver | Edit Caregiver | Delete Caregiver | Add Recipient | Edit Recipie | | |

Figure 27: Interface in Baby Steps for adding and editing people associated with the system (children, caregivers, and recipients).

4.3.3 KidCam Child Recording Device Design Details

In this section, I provide details on all of the features of the KidCam child recording and monitoring device. For more details on the features, I refer to the KidCam User Manual that I wrote for parents, which can be found in Appendix C.3.

Rather than building a device from scratch, I decided to implement the KidCam prototype on an existing platform that had many features I could use to my advantage. I used the Sony VAIOTM UX running Windows XP, an ultra-mobile PC (see Figure 28), though any model of UMPC would work. The VAIO has two built-in cameras (one on

the front and one on the back), a touch screen interface, a mini-querty keyboard, Bluetooth and 802.11 wireless communications, and 30 GB of storage space. A user interface themed as a child monitor and recording device is used to control the photo and video recording and playback. The basic functionality of this device enables the recording of video, audio, and still pictures using either the front or the back camera, as well as reviewing multimedia data based on different annotations that are provided either during or after capture. A commercially available mobile RAM© mount stand was added to the system to allow people to situate the device and camera to whichever angle they need in a variety of environments. When attached to the mount, the entire unit stands about 9 inches (23 cm) high. The device can be easily removed from the stand for handheld recording and viewing. The battery life of the device enables it to run for approximately 1.5 to 2 hours while unplugged, thus it is recommended that parents leave the device plugged in while it is situated in the stand. Overall, the device is completely mobile when detached from the base, as it is approximately 6 inches (15 cm) wide, 4 inches (10 cm) high, and 1.5 inches (4 cm) thick, and weighs 1.1 pounds (0.5 kg). When attached to the base, it is slightly less mobile as the base and unit together weigh approximately 3.75 pounds (1.7 kg).



Figure 28: View of KidCam prototype on a Sony VAIO (left) and a screen shot showing the main menu of KidCam's interface (right).

To archive videos, I wanted to allow for continuous recording during an event and have users specifically choose to save videos either during, before, or after an event happens. To accomplish recording prior to an event, the user can set the recorder to save video for a specified number of minutes in the future. For example, a parent may witness their child spontaneously take her first steps and wish to go back and record it, or at the child's first birthday party, the parent may set KidCam to record from the beginning of opening presents until they are finished. To accomplish this, I supervised a student who implemented a video buffering system similar to that which a digital video recorder (DVR) uses. The concept of this design was similar to that of the Experience Buffers work (Hayes, Truong, Abowd, & Pering, 2005), which allows for the selective archiving of different events that have occurred in the past. KidCam uses the DirectX® capture library to save 1 minute video segments to a temporary directory. Up until the set length of the buffer (the default is 20 minutes), the system will continue to save segments and then begin deleting the oldest ones. If the user chooses to save a video file (see Figure 29), he specifies how far back in the past to save the video and how far into the future to

continue saving the video. The device then copies the specified segments and creates an internal file that corresponds to the beginning and ending of the desired video segment. Later, the user can choose to export the file into a different and more widely distributable format using another component of the system. While the device is buffering multimedia data, the interface shows a live preview of the video so it can be easily positioned to the desired angle while in the stand or used in a fashion similar to that of a handheld video camcorder. It also shows parents three random milestones that their child is set to achieve soon, to remind them of what they should be on the lookout for and can try to capture videos of. If the user selects one of the milestones, the video will automatically be associated with that particular milestone.

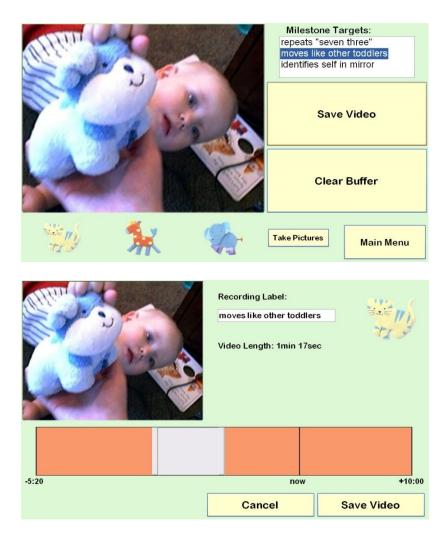


Figure 29: Interface for previewing current capture of KidCam (top) and interface for saving videos using a range slider to indicate the start and stop points of the video to archive (bottom).

Parents can also use KidCam to review videos and pictures they have recorded on the device. This serves the purpose of allowing the KidCam device to be taken to other places to share videos and pictures with others. For example, they might take KidCam with them to the pediatrician's office to show them a video of something they have a concern about or to a grandparent's house to show photos of their child's birthday party. To view videos, there is an option where they can quickly browse all the videos saved on the device, or they can choose to view videos in full screen mode (see Figure 30). There is also an interface for viewing all of the pictures taken with the device.

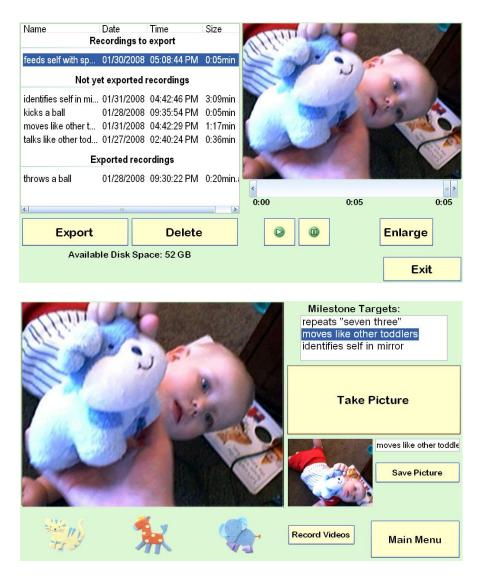


Figure 30: Review video screen for browsing videos (top) and pictures (bottom).

Parents may want to capture video or photographs where they cannot be present or it would be inconvenient to be present. For example, if a child is napping in her crib, the parent may wish to monitor from the kitchen while he is making dinner. Alternatively, a parent may wish to monitor his child at daycare from his desk at work. Because parents may already be using a baby monitor to monitor their child while sleeping, this may also encourage them to have the device near their child more often, which may in turn increase the opportunities to capture spontaneous events. Thus, I developed a way of remotely viewing and triggering the KidCam. For my implementation, I used the Nokia N800 Internet Tablet[™] to create a remote connection over an ad-hoc wireless network between itself and KidCam (see Figure 31). The remote connection copies the screen of the KidCam to the Nokia and provides for remote interaction through the touch screen of the Nokia N800. The live audio-visual feed from the KidCam can be remotely accessed on the Nokia N800, though at a reduced video frame rate.



Figure 31: KidCam shown with remote monitoring device on Nokia 770 shown to the left of it.

4.4 Summary and Contributions

In this chapter, I presented the design and development of three different embedded capture and access applications. The first was Abaris for Homes, a technology to support Discrete Trial Training therapists working with children in a home setting. The second was a redesign of Abaris for a school setting, called Abaris for Schools, which aimed at supporting teachers working with many children in a classroom setting. The final application was a set of tools called Baby Steps and KidCam, which were two technologies aimed to support caregivers of young children in making decisions about developmental progress.

The main contributions of this work were the designs of technologies that aimed to address the design requirements established in the formative studies of the two domains I was supporting and the manifestation of technology ideas into fully functioning prototypes. Each of the applications was developed using a novel combination of off-the-shelf technologies (*e.g.*, Anoto digital pen and paper, selective archiving on a UMPC). In addition, the design process for each of these technologies is novel, especially in the case of Abaris, where my training as a therapist helped in iterating on different design ideas to come up with a final technology design.

CHAPTER 5

ABARIS FOR HOMES EVALUATION

In this chapter, I present the design and results of a deployment and evaluation of Abaris for Homes in a real-world setting. Abaris is a system to support decision-making for teams of therapists working with children with autism. I discuss how it enabled easier data capture, encouraged better collaboration, and increased the frequency of access to various artifacts in the decision-making process. The results of this study are also reported in several external publications (Kientz, Hayes, Abowd, & Grinter, 2006; Kientz, Boring, Abowd, & Hayes, 2005)

5.1 Study Description

This section describes the first study I conducted in testing the effectiveness of an embedded capture and access application to support decision-making for caregivers, Abaris for Homes (described in Section 4.1). This version of Abaris was designed for homes and thus was tested with a home-based therapy team for one child. The main goals of this study were to determine whether Abaris could be effectively embedded into a therapy team, whether it impacted the collaborative nature of the decisions being made, and whether it encouraged therapists to use more reliable evidence to make decisions.

5.1.1 Study Design

To evaluate the impact of Abaris on the team of therapists, I conducted a longterm, real-use study of the use of Abaris over a four month deployment period. Two key goals of Abaris were to support the decision-making abilities and discussions of therapists in team meetings and to increase the use of reliable artifacts in the decision-making process, while reducing the reliance on less reliable, unverifiable artifacts.

In the 18 months prior to deployment and throughout the design process, several members of the research team conducted regular therapy (at least one session per week) as participating observers. During this time, I observed and participated in bi-weekly team meetings and collected artifacts from therapy, videos of a subset of meetings, and notes from observations. For the deployment, the therapy team used Abaris in the home of one child for a four-month period between February and June of 2005. I continued conducting therapy during deployment to help troubleshoot glitches in the software if they occurred and also to serve as a "champion" (Grudin, 1994) for the new technology to encourage its use. This therapy team consisted of a lead therapist and three other therapists, with a fourth starting at the end of the third month. The parents of the child also occasionally used the system, and the child's father regularly participated in team meetings. Overall, the team used Abaris to record 52 therapy sessions, for a total of 45.1 hours of video.

The therapy team conducted six meetings using Abaris, each lasting between one and two hours. The team members, who normally met once every two weeks, succumbed to scheduling difficulties during the study resulting in gaps of one to four weeks between meetings. I observed and participated in meetings both with Abaris during the deployment and without Abaris both before and after the deployment. In the meetings where Abaris was used, the access interface was projected onto a wall from a desktop computer for everyone at the meeting to see (see Figure 32).



Figure 32: a) Team meetings without Abaris. b) Team meetings with Abaris. c) Abaris projected on a wall during meeting.

5.1.2 Participant Selection

I chose to work with the team of therapists with whom I had been trained as a therapist and with whom I had already been working. This was largely due to the fact that the team had been instrumental in helping me to design Abaris and to get a good understanding of the therapy process. I also chose this team because they were familiar with me and already comfortable enough with the researchers to provide honest feedback on the design. This particular therapy team worked with a 7-year-old child with autism spectrum disorder (ASD) in the basement of the child's family's house, the father of whom was also involved in my research at Georgia Tech. At the time of the Abaris deployment, the therapy team consisted of one lead therapist and three regular therapists, with a fourth regular therapist joining the team during the last month. The lead therapist had a Master's degree in behavioral analysis and was employed by the consulting company. She worked as a lead therapist full time and also worked with therapy teams supporting different families around the Atlanta area. The regular therapists consisted of a psychology undergraduate student at Georgia Tech hired by the family, a lead therapist in-training who was also employed by the consulting company, and me. The meetings

were attended by the therapy team, a behavioral consultant who owns the company that the family hired to organize and conduct the therapy, and the father of the child. The consultant held a Ph.D. in behavioral analysis and did not conduct therapy directly with the child, but had a great deal of experience in working with children and therapists.

5.1.3 Data Collected and Analysis Methods

To understand how Abaris was used and its impact on the workflow of the therapists during sessions and within meetings, I collected a variety of both qualitative and quantitative data which I used to evaluate Abaris's effectiveness in supporting decisions. This section outlines the data I collected and the methods I used for analyzing it. The results for each metric follow in Section 5.3, then the implications and discussion of the results follow in Section 5.4.

In the months before Abaris was deployed, I had therapists keep a log of the time that they spent doing various therapy related activities, including therapy time, paperwork, and playtime with the child (usually done during breaks in therapy). I had therapists continue to record this information so I could see whether Abaris had any impact on this distribution of time. Therapists usually were required to work a certain number of hours per day (they would pick up the child from school and stay with them until the parents arrived home from work), thus I was not tracking the total length of time they stayed with the child, but just the proportion of time that certain activities took place during that set amount of time.

The Abaris software had event logging designed into it, which captured fine level details with timestamps regarding use of the system. This would enable me to analyze

which features of Abaris were most used and how frequently and visualize how different aspects of video viewing were utilized. I also logged all data captured to a database, which would enable easy-to-access storage of all the data regarding the therapy and could allow me to search for various details about the therapy sessions.

To analyze how Abaris impacted team meetings, I videotaped meetings before, during, and after Abaris was deployed with the team of therapists. I and another researcher then analyzed the videos by coding a total of six meetings (3 with Abaris, 3 without) for all of the decisions made during the meetings. Decision points consisted of the times when the therapy team would decide what to do about each of the skills they were currently working on with the child, such as whether to continue the current course of action or to change the therapy to accommodate a better style of learning. For each of the decision points, the other researcher and I independently coded two different factors: the different artifacts therapists used in each of the decision points and a qualitative rating for each of the members' level of collaboration. The artifacts coded for are described in Section 3.2, and the level of collaboration rating was assigned on a scale of 1 to 3, with 1 being little or no input on a decision and 3 being someone who was very instrumental in making the decision. I then analyzed these coding results to determine percentages of time the team relied on the different artifacts and an overall comparison on the collaboration of the team with and without the use of Abaris. I analyzed the overall findings using standard statistical tests for significance, namely 2-tailed T-tests (Steel & Torrie, 1960). An example of the coding sheet used by the video coders can be found in Appendix D.1.

Finally, I collected a significant amount of qualitative data throughout the deployment. I collected summary notes produced from all six meetings, notes written by therapists after each session, work samples from the child's therapy sessions, and took field notes from the researchers with observations of both therapy and meeting sessions. I conducted interviews with each member of the therapy team toward the end of the deployment period and in the months after the system was removed. The interview guides for all of the interviews I conducted are found in Appendix D.2. The main purpose of the qualitative feedback was to verify the findings I uncovered using the more quantitative metrics, such as the log analysis and the video coding, which I analyzed using a simple coding technique. This type of long-term, mixed method study provided an opportunity to uncover the best results of actual use without biasing the results by me being a member of the therapy team.

5.2 Deployment Study Results

This section outlines the results I found from the deployment of Abaris in the home setting and the analysis of the data collected during the study. I analyzed the data for Abaris's effects on team dynamics and use of evidence in the decision-making process.

5.2.1 Use of Capture System

The team captured 52 sessions, consisting of 3869 trials and 45.1 hours of recorded data, including every session that had taken place during the study. The capture interface was easy for the therapists to learn, because the digital pen allowed therapists to

perform their work in the exact same way they had done it before. Although the interface appeared to be easy for therapists to use, they initially demonstrated skeptical attitudes about its use. Despite this skepticism, participants used Abaris in all of their sessions for which it was available. The only benefit of use at this stage was removing the need for users to "hand graph." This consistent use is remarkable given that at first, all users were contributing to this groupware system while receiving little benefit (Grudin, 1994). I believe this was due in large part to the conscious effort during design to maintain nearly identical work practices that reduce or maintain the same level of effort. At the first meeting that made use of Abaris, participants were then able to experience the benefits of access.

Therapists reported allocation of session time both before and during the deployment. Overall, work time for these hourly employees decreased slightly, but this may be the result of fewer target skills for the child during the time of the deployment due to the child being sick or having a difficult time in school. The percentage of time that therapists spent in paperwork decreased from 31% of the session to 22% of the session, resulting in more time spent in therapy or playing with the child (see Figure 33). Thus, with Abaris, therapists could devote a greater percentage of their paid time to interaction with the child.

Two therapists reported that the clip-on microphone used for speech recognition was a bit too heavy for some of their typical clothing and could be uncomfortable. Most preferred to use a head-mounted boom microphone. A few incidents occurred in which the child became fascinated by the microphone and would reach out and play with it, a behavior that typically occurs when therapists wear jewelry the child finds interesting. Although this behavior can be common for some children with autism, it may not happen in all cases. I considered using a room level microphone, but the child often vocalizes during therapy sessions, which affects the accuracy of the voice recognition.

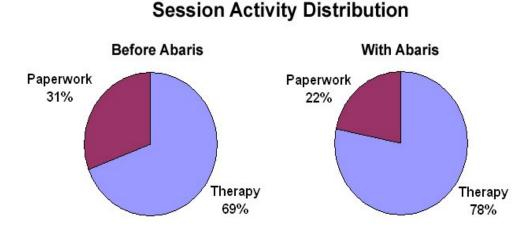


Figure 33: Comparison of the activity makeup of each session before and after deployment.

Simple usage errors sometimes had large impact. One of the therapists forgot to press the record button at the beginning of her session, resulting in no video for the session. In one incident, placement of the Anoto paper in the printer backwards resulted in incorrect detection of the timestamps. These errors can be prevented future versions of Abaris, but because of its improvisational nature, I could not predict all of the exceptions to the therapy. For example, the lead therapist wanted to change the success criteria for one type of program, but she had no way of doing this with the current interface. Basing Abaris on pen and paper input allowed for a significant amount of improvisation, but it was still very difficult to plan and address all cases.

5.2.2 Use of Access System

Therapists used the access interface for discussion during all six meetings, which lasted between 1.5 and 2.5 hours. Each meeting was video recorded and observed, and afterwards I held a "debriefing" session with the therapy team on their experience with the system, in which discussion was similar to that of a focus group. The access interface was instrumented so that I could have logs of its use, providing some empirical evidence of access behaviors. As an example of use, in the second meeting with Abaris, the team used the access interface to view the video six times, and video viewing took up 20.4 percent of the meeting time. Visualizations of interesting data in these logs are presented in Figure 34, Figure 35, and Figure 36. The top graph is a typical example of comparing a program across two therapists viewed by the lead therapist before the meeting. The middle graph shows various artifacts in the interface—the timeline and the trial grades were used to navigate to the desired portion of video. The bottom graph is a detailed version of a portion of the middle graph. That this kind of browsing occurred six times during a single meeting is an indication that the team found the value of viewing video outweighed the cost of finding the appropriate session. For 18 months prior to these two meetings with Abaris, the team had access to digital video recordings of the sessions at the site of the meeting, and not once was a segment viewed during a meeting, reportedly because it took too long to find a relevant clip.

Due to the complexity of the data recorded for DTT, therapists reported the access interface to be complicated at first. They received two hours of training before expressing enough comfort to use it on their own. Although ease of use was not as high as would be ideal, therapists reported that the benefits of the system were worth the time it took to learn the access interface. Additionally, the access interface was intended for expert users (*e.g.*, the lead therapist and the consultant), allowing them to use the system with all of their clients once they are past this initial learning curve.

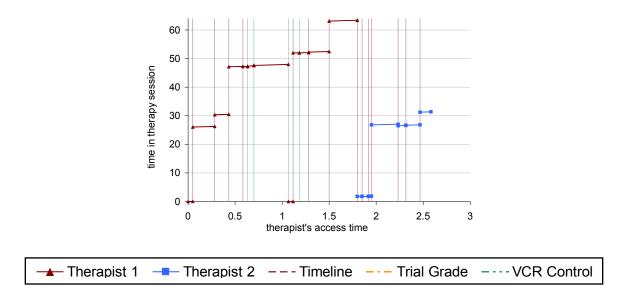


Figure 34: Visualization of access of video from the lead therapist before the meeting. Colors denote two different videos of two different therapists being watched. Vertical lines show which widgets were used to access relevant portions of the video.

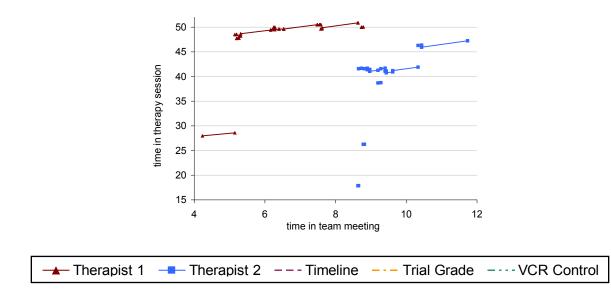


Figure 35: Visualization of access to videos during the meeting. The plot with dark, triangle data points shows access to video of one therapist, while the plot with light, square data points shows viewing a different therapist.

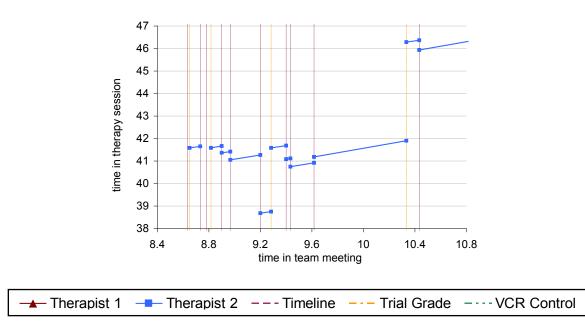


Figure 36: Expanded segment of the Figure 34 (between 8.4-10.4 minutes into the meeting) which shows how different artifacts are used to facilitate navigation.

5.2.3 Impact on Team Dynamics

Prior to the deployment, the consultant ran the meetings and asked for feedback from the therapists or the parents when questions arose. She was the only one with easy visual access to the graphed data and data sheets, which were typically placed in a binder that she held throughout the meetings. Only when others present requested to see a graph or a data sheet were they shared amongst the group. When Abaris was used, however, everyone could see the graphs projected on the wall at all times. Therapists reported that because they could see the data, they felt more engaged in the meetings and participated more. When I asked the consultant, Jessica (all names have been changed to protect anonymity), about this change during her interview, she reported that the quality and the number of the comments were better than before and that the meetings were "much more efficient." When asked, she also reported that she did not feel like her control was lost during meetings, and in fact, appreciated more input from the other members of the team.

Jessica (Consultant): "I didn't feel that any authority or dominance that I wanted was taken away from me in any way shape or form... I loved being able to have a more engaged team."

I designed the access interface for use by one person at a time, mostly for the sake of simplicity. Thus, one person volunteered to "drive" the meeting each time. At the first meeting, a member of the research team drove the interface under the direction of the therapists, to demonstrate its use. During this first meeting, the consultant and others would make requests about what to show on screen. After the first meeting, the lead therapist, Allie, was comfortable enough with the interface that she often became the driver. She also adopted the habit of reviewing data and videos before the meeting to have things in mind that she wanted to discuss during the meeting. Sometimes, at the start of the meetings, Allie would already have videos loaded and ready to play. As decisions were made in the meeting, she would use Abaris to immediately make changes to the therapy program. These changes then became available to the next therapist printing her data sheet - a significant change over the manual production of data sheets that needed to be made by the individual therapists directly before therapy. Because the system was controlled by a single user, other team members made requests when they wanted her to change what was currently being shown. Interestingly, even though the lead therapist felt that she lost a bit of control over the overall therapy (due to the system handling many of the managerial duties), she gained more control during the meetings due to taking on the role of driving the interface.

In this type of team, each of the members has varying degrees of expertise in the therapy. Therapists who are less knowledgeable or experienced about therapy might be reluctant to question decisions made by team members with more experience. However, during the time Abaris was used, there were a few instances in which the less experienced therapists used the video as evidence to question a decision being suggested by more experienced therapists. During these discussions, they noted something they believed they had seen in the video that others did not. The conversation below illustrates one such example, during which the entire group challenged the lead therapist about what she was accepting as a correct response for the child.

[New graph is displayed, showing a very high upward trend, then a sharp drop in progress for Allie's session. If Allie had continued the trend, the skill would have been considered "mastered" or completed.] Jessica (consultant and Allie's boss): "nooooooo....." Allie (lead, extremely experienced therapist): "I want to talk about this one..." Jessica: "Allie, what did you do? I don't think I want to hear this story." [Allie explains what happened and demonstrates what occurred during her session] Jessica: "I want to see... sorry ..." [Group plays video of Allie performing the skill] Kelly (newer therapist): "See, now I was accepting that" [referring to child's response while watching Allie's video] Jessica: "let's clearly talk about what we're accepting and what we're not accepting" [Conversation continues amongst all therapists in which they each demonstrate what they were accepting and note how the video showed Adam doing the same

what they were accepting and note how the video showed Adam doing the same thing in Allie's videos that she was not accepting] Jessica: "Change your data.... She's an outlier, we just won't count [that one]."

[Jessica then ensures that Allie is comfortable with changing the data so that the child masters the skill, and Allie agrees, so the data is changed and the skill is considered mastered]

In another instance, Kelly challenged a hypothesis by Jessica (the consultant) on the objects to which the child is attending during a particular task. Jessica was explaining one possible hypothesis, and Kelly countered with another while referring to the video as evidence. They then continued the conversation based on Kelly's observations as opposed to Jessica's hypothesis, which typically would have been taken as the most likely explanation.

5.2.4 Changes in the Level of Collaboration

To estimate the impact of Abaris on team collaboration, I and another researcher rated the level of participation of each therapist during the meetings and compared this participation when the system was in use against when it was not in use. For this evaluation, the other researcher and I watched videos of three meetings with the system and three meetings without (one prior to deployment and two several months after the end of the deployment). I chose these videos based on what was available and which ones had the most team members in common, since regular therapists changed frequently or certain team members were absent. For each video, the other researcher and I looked at each of the decisions that were made, based on the meeting minutes from that meeting. For each decision, the other researcher and I rated the level of engagement in the conversation for each member of the care team on a scale from 1 to 3, where 1 is little or no input into the decision, and 3 is significant participation in the decision. The other researcher and I reviewed a total of 39 decision points made in meetings without Abaris and 42 decisions made in meetings with Abaris. Based on these ratings, in meetings with Abaris, I determined that the average participation level was 2.49 for all team members across all the decision points across all three meetings, with a standard deviation of 0.67. Without Abaris, the average participation level was 1.96 with a standard deviation of 0.86. A 2-tailed T-test analysis (equal variances assumed) indicates that these averages are statistically significant, with p < .005. Figure 37 shows a graph of these figures.

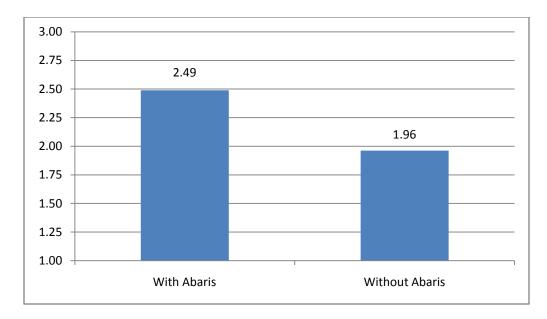


Figure 37: Average meeting participation levels with and without the use of Abaris.

While these figures are an estimate, they are consistent with the reported observations of team members about their participation levels in the meetings in their interviews. In her post deployment interview, the consultant reported that she believed the discussion was better in the meetings with Abaris.

Jessica (Consultant): "I do feel like with the system we certainly did a lot of discussion around things, around programs, because everyone's able to look at that data and make hypotheses and talk about that.... And people were able to visually see that, and I think make better comments. The quality of comments maybe went up and maybe the number too."

In the meetings without Abaris, the discussion was mainly driven by the lead therapist, the consultant, and the parent of the child. With Abaris, I saw higher participation levels among the regular therapists. The lower standard deviation during the deployment condition may indicate that the discussion was more distributed amongst members of the team.

5.2.5 Changes in the Use of Artifacts

During the deployment, I observed a significant change in the artifacts therapists used in the decision-making process. In the same six meetings analyzed above, I also kept track of which artifacts at least one person consulted in the discussion for each decision point. Table 4 lists each of the artifacts described above and the percentage of decision points in which they were used in discussion during meetings with and without Abaris, as well as the results of tests for statistically significant differences.

| | %With Abaris | %Without Abaris | T-Test Value (P Value) |
|-------------------|--------------|-----------------|------------------------|
| Video* | 45.2 | 0.0 | T=5.60 (p < 0.005) |
| Graphs | 81.9 | 56.0 | T=1.91 (p = 0.06) |
| Data sheets* | 45.2 | 20.5 | T=2.41 (p < 0.05) |
| Therapy samples* | 19.0 | 0.0 | T=2.99 (p < 0.005) |
| Reenactment | 4.8 | 0.0 | T=1.38 (p = 0.17) |
| Memory | 83.3 | 92.3 | T=-1.22 (p = 0.22) |
| Ext. Observations | 21.4 | 25.6 | T=-0.44 (p = 0.66) |
| Therapist Notes | 19.0 | 5.1 | T=1.92 (p = 0.058) |

Table 4: Percentage of time each artifact was used by at least one person for each decision point, both with and without the use of Abaris. Findings with statistically significant changes are marked with an asterisk.

These percentages were meant to serve as an estimate in the changes that Abaris had on the use of artifacts, however, an analysis of this data showed that several of these changes were statistically significant. To do this analysis, I used 2-tailed Two-Sample T- Tests with equal variances assumed. In particular, the use of video, data sheets, and therapy samples all had statistically significant changes between the two conditions (p < 0.05). The changes in the use of therapist notes and graphs were just below the significance threshold, with p values of approximately 0.06. The changes of use in the remaining artifacts, reenactment, memory, and external observations, were not statistically significant.

Videos were used in 45.2% of the decision points with the meetings with Abaris, and they were never used in the meetings without the system that I analyzed, although the videos of sessions were available. The videos were likely never used before because it was so difficult to find interesting moments, but the therapists reported that with Abaris, it was much easier to find the moment of interest. Therapists reported the video was useful because they had never seen each other perform therapy before, so now they could see how others do it and make sure they were all consistent. It also gave them the opportunity to reflect upon themselves and their own techniques. Without the video, they would not have had the same opportunity.

Allie (Lead Therapist): "I think the typical use of the video was to compare the responses for the different therapists ... [Video of me] helps me to do a little self-analysis."

Kelly (Therapist): [while watching video of herself] "I just realized he was doing the exact same thing I was doing, and I didn't even catch that [while I was doing therapy].

Graphs were still the most frequently referenced artifact during the discussions at meetings, and with Abaris, their use further increased. Notably, the graphs were also the default display for the system. The use of datasheet information also increased. In this case, datasheet information was available by hovering over a particular data point in the graph as well as in the video viewing window, compared to being placed in a separate area of the paper notebook from the graphs in the traditional method. While therapists still frequently referenced their memories, memory was no longer the only artifact used in the decision-making process. The therapists were referring to other kinds of artifacts to supplement their memories and make the decisions.

The team members reported in interviews afterwards that viewing the video allowed them to see subtleties about the way they were doing therapy that they did not notice while they were conducting it. One therapist in particular noted that she did not realize how small differences could affect how the child reacts.

Kelly (Therapist): "even though we all have the same training, there's a lot of little differences... we're just realizing which of those actually impact [child's name] and which ones don't."

Although there was no notable change in the amount that other artifacts were used, there were some noticeable differences in the way they were used. In the therapy notes, for example, therapists using Abaris would add directions to the team to watch the video from their sessions for a further explanation of their notes. Even though therapy sessions had been video recorded prior to use of the system, these comments were a completely new phenomenon.

Examples of therapy notes for sessions with Abaris:

"I am not sure if I did the seriation [a skill they were working on] correctly, so watch the video to check it out." "Counting at the table today was great, refer to video."

5.2.6 Video as a Substitute for Being There

Team members often used video as a substitute for other activities. For example, video of team members absent from the meetings might replace those members' inputs to the discussions. One of the regular therapists, Rachael, had a regular conflict with meeting times and thus was only present in one of the six meetings at which the therapists used Abaris. In three of these team meetings, there were nine instances of viewing Rachael's session videos. These instances all occurred directly after questions about her techniques. Previously, when a therapist could not make meetings, the input from the missing therapist was non-existent, and afterwards the lead therapist would call that person, explain the results of the discussion, and ask him or her to change the practice to suit what the group had discussed. With Abaris, the other therapists and consultant in the meeting specifically requested to see the videos of the non-present team member in the discussion during which other present team members were adding their own explanations for how the child was progressing. Thus, the video served as a substitute for Rachael being present at the meeting, though the effectiveness of video as a substitute is an open question. In this case, the video allowed them to learn things they would not have learned had the therapist simply been absent. What they learned, however, was that she conducted her sessions significantly differently from other team members, and thus a new requirement of presence at future team meetings was imposed on all of the therapists.

The consistently absent team member reported appreciating having the videos represent her during the team meetings that she could not attend. Rachel also stated in her follow-up interview that she appreciated the specific feedback she received.

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Rachael (Therapist): "it [feedback] only helps [child's name]. I needed to know if I was doing it wrong."

Rachel used the video as a substitute for her being at the meeting in her own way. Before each session, she would view the videos of the lead therapist to see how to perform therapy for skills she in which she was less confident.

Rachael (Therapist): "I looked at the video to see how to do the bears... I always messed that up." [referring to a skill where the child must count a row of small, plastic bears]

The lead therapist also began to use meeting minutes in a different way. After watching an individual's videos that could not be present at team meetings, she would write notes to that therapist with specific directions based on observations from the video.

Example of minutes for a meeting with Abaris:

"Rachael, you are saying "do the trucks" or "do in order" and he is still doing it right, but please give the "do small to big" command so we can focus on generalization"

Previously, the meeting minutes did not have this level of detail and were never directed toward a specific person.

5.3 Discussion

The results of this study have uncovered several interesting results, especially regarding the use of videos influencing team dynamics and how technology can influence the use of artifacts in decision-making. I believe some of these findings can help others in designing similar technology for related domains.

5.3.1 Team Dynamics

By being a part of the therapy team, I was able provide the "champion" of the system to encourage its initial use, something Grudin argues is critical for groupware adoption (Grudin, 1994). In the post deployment interviews, I queried the therapists on how they felt my enthusiasm affected their adoption of the system, and all of them said they were glad I was there and were comfortable enough with me to give me honest feedback. They also reported that since I was there to help them, they were more comfortable with taking risks and exploring the use of the system. Analysis of the use of a capture and access application to support data-based decision-making for a team of caregivers has some implications for other collaborative systems.

Collect data from all caregivers. Individual therapists can be empowered to see critique as part of a group effort towards improvement only when all team members are being scrutinized equally. The reciprocity inherent to sharing videos of everyone's sessions also enables team members to better empathize and trust one another with common concerns and fears.

Use floor control to provide access control and power to an individual or share it among the group. Previously, the consultant led meetings and was the only one who could view most the data. Therapists interjected when appropriate, but rarely, if ever, asked to see the artifacts. Thus, floor control in the initial design of the system always defaulted to a single individual. This individual wielded an enormous amount of control in what to show on screen and whether to yield to requests from the group.

Provide a way of opting out of data collection. Therapists reported in post deployment interviews that they would like the option of stopping video recording.

Therapists commented that there might be times when they did not want their videos viewed by others, such as if anything happened that the therapist would be embarrassed to share with others. Sometimes, these moments can only be detected after the fact. Thus, designers should a way for therapists to remove a subset of the video without deleting the entire record. My findings indicate that video is extremely useful, however, and thus therapists should only be encouraged to "opt out" in rare circumstances.

In collaborative care settings, design for the needs of the individual receiving care first and the individual concerns of the caregivers second. Surprisingly, no therapist reported feeling uncomfortable with sharing videos of their sessions with others within the same care team. Video capture is a relatively common work practice in this domain. However, anecdotal evidence from the consultant and lead therapist suggests no other team has ever reviewed these videos to near the extent of this team while using Abaris. All of this team's therapists commented that they were willing to put aside some of their own reservations to help the child.

5.3.2 Use of Artifacts

The use of shared artifacts is essential to any collaboration effort. The ways certain artifacts were used did change with Abaris. In this section, I highlight several key insights into changes in the use of artifacts for collaborative care teams.

The context of the individual activities captured in videos can be as meaningful as the activities themselves. When Abaris was used, discussions were sometimes initiated as a result of something observed in the video that was not the primary focus of the video segment chosen. Events happening before or after a moment of interest were often useful in understanding the child's ability to perform a particular skill. Thus, individual clips of the skill tests are not as useful as approximate indexing into moments of interest within the entire video. In fact, errors in the indexing scheme sometimes were beneficial because they forced the team to view more of the context of therapy.

Multiple levels of detail are important. Abaris provides access to artifacts with three distinct levels of detail. The graphs show a summary of progress over time. The individual daily data sheets show the subjective assessment of the therapist at the time of therapy for individual tasks. Finally, the video of a session provides very low-level details of a session. Different levels of detail were necessary in the problem-solving process for different discussions. Sometimes, a quick view of the datasheet might clarify a question, but other times, viewing the video of an actual trial during the session was necessary. Caregivers should be able to transition between different levels of detail easily and as necessary. With Abaris, the default view was to see an overview of the graph, see data sheet details about a particular data point using the hover tool, and then view the video if even more detail was needed.

Providing easy access to richer artifacts may lengthen the meeting time, but increase the richness of the discussion. Meetings in which the team used Abaris tended to take longer, despite the commonly reported perception by team members that they were "more efficient" than meetings without. Furthermore, therapists universally reported being more engaged in the meetings. The consultant reported that having everyone see the data helped the other therapists see the importance of collecting the data. I also observed that regular therapists participated in the discussions more, and there was less downtime in waiting for the consultant to ask the therapists a question. Therapists mentioned that the discussion was worth the extra time spent in the meeting, but this may not be the case for every team.

Speed of access to artifacts is important. Even though access to some artifacts was much faster than it had been previously, towards the end of the meeting, participants sometimes expressed reluctance to access more detailed data. Therapists referenced the datasheets using Abaris much more frequently than they had done previously when the individual data sheets were stored in a different part of the notebook from the graph overviews.

5.3.3 Usefulness of Perception Technologies

The fact that Abaris is considered a useful system by its target user group is encouraging, but as a researcher, I wanted to better understand which features contribute to its usefulness and which do not. The integration of trial time predictions and the recorded video are a reasonable first guess at the success of Abaris. As seen in Figure 35, skimming to an appropriate portion of the video was quick enough to encourage use. End times of trials were equated with the time the grade for that trial was written on the Anoto paper. Beginning trials were estimated based on suggested locations of the appropriate verbal command. I selected four separate therapy sessions, one for each therapist, and had another researcher use Abaris to create "ground truth" timestamps for the beginning and ending of each trial by manually noting when trials began. Figure 38 shows the error distribution of prediction versus ground truth. A negative error indicates a time prediction earlier than ground truth, and a positive error indicates a prediction after ground truth.

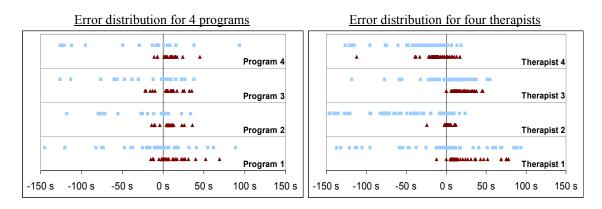


Figure 38: On the left, paired error distributions (in seconds) for Anoto-predicted end of trial (dark triangles) and Nexidia-predicted beginning of trial (light squares) for four of the programs used in the deployment. On the right, error distributions are shown for one session of each of the four therapists (lead and three regulars).

For each of the programs, the error distribution of the Anoto predictions is much narrower than that for Nexidia. The Anoto predictions occurred temporally after the actual end time, as expected, because trials are graded after they occur. The distribution of errors for Nexidia is wider. When viewed grouped by therapist, these error distributions have substantial variation in practice between therapists. Therapist 2's Anoto predictions were very tightly bunched near the actual end of trials. This therapist followed the practice of writing trial grades right after the trial was performed, as opposed to other therapists who ensured delivery of a reinforcing reward first. This is actually considered good practice for DTT, and Abaris benefits from this practice.

The phoneme-detection of Nexidia, and the accompanying algorithm for assigning assumed beginning of trial times, produced a significant amount of error. Errors are not surprising, given the nature of the therapy, with graded and mastered trials often having the same spoken command and occurring in rapid succession. However, because the interface was still usable, as reported based on use during team meetings and the overwhelming positive reaction of the team of therapists in discussions, this error may not be limiting. If this size of error makes no discernable difference, I hypothesize that speech detection may be unnecessary if I can find an alternative approach that introduces no additional errors.

Unfortunately, voice recognition only provides a best guess for the beginning of a particular trial, because many trials for which grades are not recorded use the same spoken command. For example, a therapist may be grading a child's ability to mimic hand clapping, for which the spoken command is "do this" coupled with the therapist modeling hand clapping. Prior to this trial of interest, a therapist may ask the child to perform any number of other activities with the same command of "do this", and then end with the final request "do this" while hand clapping. Thus, I considered a vision-based solution in which therapists used a simple two-finger gesture on a score sheet to indicate the beginning of a graded trial and the actual grades before and after the trial itself. Though the approach was simple to teach and the vision problem was feasible, I found that therapists could not remember to do the gestures at the correct times, resulting in a loss of grading information. Instead, I developed a simple algorithm for determining the most likely beginning of a trial based on a combination of the time that the trial likely ended (from the Anoto data) and the time that different spoken commands were used.

Considering the narrow distribution of the Anoto errors for trial endings in Figure 38, there are several suggestions for potential temporal heuristics that might produce begin trial estimates at least as good as Nexidia. I have anecdotal evidence that for Therapist 2, a fairly reliable heuristic was a function of the program type and whether or not a correction trial was needed. The current results give me confidence that there is an

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upper bound on the error distribution for estimating the start of a trial, and thus I can experiment with a variety of algorithms to find one that is both accurate and precise enough without impinging on the therapy itself.

5.3.4 Study Limitations

Though the findings from the Abaris for Homes study were encouraging in that it promoted collaboration, higher use of more reliable artifacts in decision-making, and a decrease in the amount of overhead in capturing data, the study is not without its limitations. Because the family I studied was so closely involved with the research, there may have been some unintentional bias in the findings. In addition, since I remained an active therapist and still attended meetings throughout the evaluation, there may again be some unintentional skewing of participation levels. I did do a recalculation of the results of the collaboration levels by removing my data and found that there was still a statistically significant difference without my input, but there may still be a bias just because of my presence at team meetings. There may also be some effect in how easy the system was to learn and how much the therapists were willing to accept it because I was involved as well. This study was also only a case study conducted with one family and one company who may not have been "typical" users on the whole. Thus, additional research may be needed to determine whether this particular version of Abaris is as effective for other home-based teams working with different companies. The Abaris for Schools study described in Chapter 6 attempts to remove some of this bias and see if a redesigned version of Abaris deployed with a team I was not personally involved with can help generalize some of the findings for Discrete Trial Training therapy.

5.4 Summary and Contributions

In this chapter, I presented the design, execution, results, and discussion of a study testing the effectiveness of Abaris for Homes to achieve some of the goals described in the thesis statement for embedded capture and access applications. In particular, this study tested the ability of Abaris to support teams of caregivers making decisions and evaluating the effectiveness of their decision-making using the metrics of collaboration and use of reliable artifacts. I also evaluated the technological aspects of Abaris and which features contributed to the success of the application.

The main contribution of this work was a study that showed that the design of Abaris met the needs of in-home therapists administering interventions to a child with autism. The real-world deployment study showed that Abaris was able to increase the level of collaboration amongst caregivers, as measured through subjective rating scale of decisions-made through analysis of meeting videos (Thesis Claim 3). It also determined that Abaris for Homes was able to increase the use of once hard-to-access artifacts in the decision-making process, as measured through analysis of artifacts used in decision points in videos of meetings (Thesis Claim 2).

CHAPTER 6

ABARIS FOR SCHOOLS EVALUATION

The promising results of the Abaris for Homes study lead me to want to explore the usefulness of this technology in settings beyond just the home. Because Discrete Trial Training is often used in schools, I wanted to test its ability to aid teachers working with multiple students in a less constrained environment. Thus, I redesigned Abaris to work for a school setting. This chapter describes the deployment of the redesigned version of Abaris for a school setting. I also present the results of the evaluation and discuss the further implications of this work.

6.1 Study Description

This section describes the study I designed and conducted with researchers at the University of Washington's Experimental Education Unit (EEU) to test the ability of the redesigned version of Abaris to support teachers conducting Discrete Trial Training in a classroom setting. This includes the design of the study, the selection of participants for the study, the methods used, and the data collected during the course of the study.

6.1.1 Study Design

To study the effectiveness of the newly designed Abaris in supporting teachers making decisions about care, I coordinated a deployment study with the EEU at the University of Washington. This study involved the deployment of the Abaris for Schools system for a 5 week period to evaluate its feasibility, usability, acceptability, efficiency, and effectiveness. The class I worked with had a current practice of data recording and analysis for both Discrete Trial Training and Free Choice and consisted of a team of 8 regular teachers and a single lead teacher in a pre-school classroom of 16 students with special needs. This particular classroom had a history of taking daily records for Discrete Trial Training and Free Choice sessions, but many teachers were not in the practice of regularly graphing data for DTT, and they never had the practice of graphing Free Choice data. Thus, the data they collected was rarely analyzed and reflected upon. One of the main goals of this study then became to see if Abaris for Schools would encourage teachers to review data more frequently.

Prior to the deployment, I worked with the researchers at the EEU to collect data on the previous practices of the teachers with regard to data collection and analysis. This involved reviewing the prior month's data sheets and graphs for completeness and a review of the students' progress and the rate at which they achieved their objectives on the various skills for Discrete Trial Training and Free Choice. Additionally, teachers were asked to report the number of times they graphed data within the last month and the frequency at which they refer to them when making decisions about when to make new objectives for the students they work with. Teachers also participated in a focus group on their current practices and completed a survey on their experiences with technology.

During the deployment, the Abaris for Schools application logged and timestamped the interactions of the teachers with the system, including which videos and graphs they accessed and for how long, in order to determine the most frequently used parts of the system. Additionally, my collaborators at the EEU conducted observations twice per week and wrote down notes about the following: the frequency of using the data sheets, any difficulty using the digital pens, if the children noticed or were distracted by any part of the system, and if there were any features of the classroom that inherently prohibit the use of Abaris for Schools.

After the end of the deployment period, teachers participated in interviews about the usability and acceptability of Abaris for Schools and whether or not it fit well into their work practices. I conducted these interviews over the phone while one researcher from UW simultaneously conducted them with the teachers in person. Questions during this interview included topics such as the teachers' perceptions of improved confidence and collaboration. The interview guide from these interviews can be found in Appendix E.1. In addition to the interviews, the research team at UW conducted an analysis of the data sheets from therapy sessions both with and without the use of Abaris for Schools to determine whether teachers changed the child's objectives more quickly with the use of Abaris due to more frequent access to graphs. I also analyzed the data from the system logs to see how often the graphs and videos were accessed.

6.1.2 Participant Selection

I chose to work with the University of Washington's EEU for this work due to their willingness to use Abaris and support the study locally while I coordinated from Atlanta. In particular, I worked with students and teachers in the Developmentally Appropriate Treatment of Autism (DATA) program, which was developed as an early intervention extended program. The DATA classroom served a total of 15 students (13 males, 2 females), with all children having a diagnosis of either autism spectrum disorder (ASD) or pervasive developmental disorder (PDD), which were diagnosed by an external evaluator prior to their admittance to the classroom. Approximately half of the students met for 4 hours in the morning and the other half in the afternoon for an additional eight hours per week of highly structured and supported instructional time. The instructional model was based on intensive, one-on-one Discrete Trial Training (Schwartz, Sandall, McBride, & Boulware, 2004).

In this study, the teachers were the primary users of Abaris and thus the target of the study. In the classroom studied, six teachers regularly worked in the project classroom. Two of the teachers taught in both the morning and afternoon classroom sessions while the remaining four teachers taught only one session each (either in the morning or the afternoon). In the initial interviews, teachers reported an average of 4 years of experience working with children with autism ($\sigma = 1.9$). Two of the teachers in the study were certified and reported 1 and 4 years of classroom teaching experience respectively. One teacher who was not certified reported 7 years of preschool teaching.

6.1.3 Data Collected and Analysis Methods

In this section, I present the types of data collected and the ways the University of Washington research team and I analyzed them. There were three main data collection techniques I used. First was an analysis of the children's data both before and after the deployment of Abaris in the classroom, in which the number of days each child spent in a particular skill was analyzed. Second was a qualitative assessment of the value of the Abaris system through an initial focus group with teachers and then a follow up focus group and individual interviews. Finally, I instrumented Abaris to log various statistics about which features of Abaris were used most often.

6.1.3.1 Child Record Review

One of the main goals of Abaris for Schools was to make it easier for teachers to graph data, since they were not already in the habit of doing so. In particular, teachers would wait until their monthly meetings with the head teacher to review progress of the child. Thus, I aimed to make it easy to graph a child's data so teachers could make more timely decisions about whether it was time for a child to move on to another skill. To determine if Abaris was able to encourage teachers to do this, one researcher at UW conducted a review of the child's Discrete Trial Training records both before and during use of the system. Specifically, the prior month's data sheets and graphs were used to identify the extent to which they were complete. Students' progress was also reviewed to identify the rate at which students were achieving the objectives established for them. To analyze the data, a CHI-Square analysis was conducted to determine statistical significance of the findings.

6.1.3.2 <u>Focus Groups, Observations, and Interviews</u>

In the classroom setting, it is difficult to do measurements of confidence and collaboration. Thus, I chose to use qualitative methods to assess these aspects of decision-making. Prior to implementing Abaris in the classroom, researchers at UW conducted a one hour focus group with all the participating teachers and asked them to reflect on different aspects of their job, such as likes and dislikes about current approaches and how the environment could be improved. Teachers were also asked about how they value data and how it can be used to improve their teaching.

During the deployment of Abaris in the classroom, researchers local to the EEU at UW observed teachers in the classroom as they used the Abaris system and wrote direct observation notes. They looked to see how frequently teachers filled out data sheets, whether they had any difficulty using the digital pens, whether students were distracted by any elements of the Abaris system, and whether there were any classroom dynamics that interfered with teachers' ability to use Abaris.

At the end of the study, I interviewed teachers and staff about the usability and acceptability of Abaris for a classroom setting. Questions asked during the interviews included questions about efficiency, confidence, and collaboration using the software. For more details of the questions asked, see the interview guide found in Appendix E.1. Interviews were semi-structured in nature and took approximately one hour and were conducted with one researcher from UW in person and me calling in over the phone.

To analyze the qualitative data, the UW researcher and I combined our notes taken during the interviews into one master list of comments by teachers. Due to Institutional Review Board (IRB) restrictions, I did not have permission to record the interviews. The other researcher and I then coded the notes from each interview to determine if teachers confirmed or denied predictions about how teachers would use the software using the coding scheme found in Table 5. The coding scheme was based on the questions asked during the interview and the range of answers provided by each of the teachers. To code the interviews, the two of us scanned the notes for each teacher and marked a yes or no for whether they mentioned a given coding point. I also analyzed the codings for inter-rater reliability.

 Table 5: Coding scheme used for post-study interviews with teachers on their experience with Abaris for Schools.

| Question | Торіс | Teacher Response Coding Scheme | |
|----------|----------------------------------|--|--|
| 1a | Abaris likes | Convenience, Better use of time, ease of use, Focus on kids/teaching, Graphing, Other | |
| 1b | Difficulties with Abaris | No phase changes, Problems with sets/stimuli, Other lack of flexibility, Printing, Other software issues | |
| 2 | Changes to routines? | Yes, Changing programs more often, No | |
| 3 | Frequency of data review | Every day, Once per week, Other | |
| 4 | Change in frequency | About the same, More often, No response | |
| 5 | Discrete Trial graph review | Every day, Once per week, Other | |
| 6 | Free Choice graph review | Every day, Once per week, Other | |
| 7 | Change in frequency of decisions | More frequent updates, Less frequent updates, No difference, Other | |
| 8 | Confidence in decisions | More confident, Less confident, No difference, Other | |
| 9a | Discussions with other teachers? | Yes, No | |
| 9b | Nature of discussions | Formal, Informal | |
| 10 | Effect on collaboration | More frequent collaboration, Less frequent collaboration, No difference, Other | |
| 11 | Attitude toward video capture | Bothered me or children, No effect on me or children, Liked it, Other | |
| 12 | Recommended changes to Abaris | Greater flexibility, More information, More guidance for decision-making, Change to hardware, Other | |

6.1.3.3 Logged Software Data

Some of the other data collected about Abaris was how often it was used and which features were used most often. This would help in determining how often teachers had access to a child's data. To do this, I instrumented the Abaris system to log to a text file when the system was used and which features were used at any given time. Each interaction also contained a timestamp. In addition, all data that teachers entered into the Abaris system was stored in a database, which facilitates easy analysis of data entered, users of the system, and total input from all teachers. To analyze this data, I had predetermined uses that I looked at the logs to confirm or deny. I also analyzed the logs by doing a frequency count for each of the different artifacts and determined how long teachers spent on each of the screens.

6.2 Results

In this section, I present findings from the study I conducted with the University of Washington's EEU. In particular, I present the results of the review of child's therapy records, results from interviews and focus groups with the teachers, and findings from the analysis of the log files. A discussion of these findings is in Section 6.3.

6.2.1 Effects on Timeliness of Decisions

To determine the effects of Abaris on the ability for teachers to make more timely decisions, a collaborator at UW analyzed the data sheets completed by teachers before using Abaris and then again during its use. In the original, paper-based system, there were two kinds of data collection sheets. One was for daily use that recorded student performance on each trial and the other one was for graphing purpose to visualize student long term progress. The former collection sheet had two major components, program item names, and level of prompts from the teacher. According to the criteria of the student objectives from the individualized education plan (IEP), the teacher determined

the student performance from the trials in percentage. The latter collection sheet consisted of three rows of continuous blank charts with the program name and the teacher name on the top and a box of phase change description at the right edge of the sheet. The X-axis of each chart represented the date, and the Y-axis of each chart represented the criteria in percentage. The teacher recorded a data point of the student performance for each date based on the former data collection sheet. If one data point reached criteria above 90%, it was suggested to move on to the next phase of the program. However, the teacher may delay to proceed. Due to the busy classroom routine, teachers usually graph the chart once in a while. Therefore, teachers may not be aware of the progress the student made at once. In addition, under certain circumstances (*e.g.*, unstable performance though reach criteria, challenging behavior involved) teachers might not feel it is beneficial to the student to proceed the phases.

The Abaris data collection sheets were of two kinds, similar to the data sheets used in the prior paper-based system. One was exactly the same as the DATA project data collection sheet for recording the student performance for each trial. The other data sheet was a printed version of graphs as produced by Abaris, which teachers would annotate using pen and paper after printing it out.

The data was analyzed to determine the following measures:

- Number of phases per program: each program consisted of several phases for students to reach the IEP objectives step by step.
- Number of days per phase: the total amount of instruction days in each phase.
- Data points per phase: the total data points recorded in each phase. Ideally there should be one data point for each day; however, the teachers might not teach

every program every day depending on the student's condition and tailored activity schedule for every student.

• Points reached criteria per phase: the total data points which reached the criteria above 90% in each phase.

In this study across both phases, there were 11 different sets of teachers, and 19 different sets of skills. Table 6 shows the descriptive statistics of the measures taken for each of the teachers and each of the students.

| Maaaura nama | Pre-Abaris | | With-Abaris | |
|--------------------------|-------------------|-------|-------------------|-------|
| Measure name | Mean ± SD | Range | Mean ± SD | Range |
| Phases/skill | 2.76 ± 1.86 | 1-9 | 1.24 ± 0.56 | 1-3 |
| Days/phase | 38.76 ± 36.76 | 1-274 | 23.43 ± 15.02 | 1-52 |
| Data points/phase | 7.44 ± 6.58 | 1-56 | 5.95 ± 3.31 | 1-16 |
| Points at criteria/phase | 1.61 ± 1.81 | 0-9 | 1.23 ± 1.72 | 0-9 |

Table 6: Descriptive statistics (means and ranges) for each of the measures taken both before and during the use of Abaris.

From the sample of 416 total data points, before intervention, 50 of the 339 (14.75%) points and, after intervention, 16 of the 77 (20.78%) points reached criteria in each phase of the program for one point. The chi-square test revealed that the automated data collection system and data points at criteria were not statistically significantly associated (χ 21df = 1.709, p = 0.19). Table 7 shows the Chi-square analysis results.

| Program | Points at criteria=1 | | | Points at criteria ≠ 1 | |
|------------------------------------|-------------------------|-------|-----|---------------------------|-----|
| | n | % | Ν | % | |
| Pre | 50 | 14.75 | 289 | 85.25 | 339 |
| Post | 16 | 20.78 | 61 | 79.22 | 77 |
| Total | 66 | 15.87 | 350 | 84.13 | 416 |
| $\chi^2 = 1.709, df = 1, p = 0.19$ | | | | | |

Table 7: Chi-square between data points reached criteria in each phase for one point and data points reached criteria in each phase for more than one point (n=416)

Though there were not enough data points to prove statistically that students spent less time on particular skills, the difference in means between the days spent working on a particular skill is promising. The results of the post-study interviews, I asked therapists about whether they perceived that they were making decisions more frequently. From the responses of the teachers, three out of seven (43%) stated they believed they were making more frequent updates than before. Three teachers (43%) did not think they noticed a difference, but one teacher (14%) stated that she had not been teaching in this particular classroom as long so it was difficult to determine. None of the teachers believed that Abaris was a detriment to the frequency of the decisions. One of the teachers explicitly said when asked if Abaris changed her routine at all, that it encouraged her to change programs more often.

During the interviews, I also asked teachers to comment on how often they looked at graphs and whether this frequency changed. Five out of the six (83%) regular teachers interviewed stated that they reviewed graphs every day that they were in the classroom, and two of them (29%) believed this was more often than normal, where another two (29%) of them thought this was the same as before. Three of the teachers (42%) did not have a response to this question, which is because they stated they were not sure. Interestingly, the teachers who believed that Abaris did not have an effect on the frequency of reviewing graphs were the more experienced teachers who stated that they already graphed every day with the paper system.

6.2.2 Effects on Perceived Confidence and Collaboration

In the initial focus group, teachers reported that although they gathered data every day, they graphed and reviewed it quite a bit less (sometimes as infrequently as every two weeks). They stated that "you can either be a good teacher or a good data collector" and mentioned that "sometimes (you're) just scrambling" and "I know I miss stuff." They indicated that although graphing was critical for making data-based decisions, it was also the hardest part of the process. In addition to simplifying the graphing process, they expressed an interest in improved ways of gathering anecdotal data and communicating to parents and other teachers.

Several of the questions in the post-deployment interviews focused on the issue of collaboration. In particular, I asked teachers about their experiences in talking to others about a child's data and whether they thought that this collaboration occurred in informal or formal settings. From the interview coding, I found that five out of the six (71%) classroom teachers interviewed stated that they would discuss a student's data with other people, with the other teacher saying that although she did not discuss her students' data with others, she noticed that other teachers did. Four of the seven teachers interviewed (57%) believed that this collaboration was more frequent than had been previously, because when they were printing the student data sheets in the morning, they would often

make comments about how children were doing to each other. Two of the teachers (29%) did not think there was a difference in the level of collaboration, while the other teacher did not think she could comment about it. All six of the classroom teachers (100%) stated that the types of collaboration that Abaris encouraged were all informal in nature. None of the teachers formally met to discuss a students' data as a result of using Abaris if they were not already doing so (*e.g.*, all classroom teachers would regularly meet with the lead teacher prior to using Abaris). I believe that part of these findings were a result of the school's protocol that one student would typically only work with a single teacher, which was different from the structure of the home-based therapy team.

It was difficult to quantify how Abaris affected the confidence levels of their decisions, thus, I asked teachers whether they could comment about it during their interviews. From the interviews, four of the teachers (57%) stated that they were more confident in their decisions now that they were more frequently graphing their child's data. One teacher stated, "It's great to actually *see* that he's doing better on the graph, rather than just rely on instinct." Two of the teachers (29%) did not think that there was a difference in their confidence because they were already graphing every day anyway. Once again, these two teachers were the most experienced. The lead teacher did not comment on whether she thought that teachers had more confidence in their decisions.

6.2.3 Overall Usage Data

In the interviews conducted at the end of the study, teachers indicated that they liked using the system. In particular, they appreciated the way the system reduced the burden of daily graphing. Several of the teachers felt the system encouraged quicker decisions about instructional modifications and facilitated improved communication between teachers. I also found that teachers who had greater knowledge about data-based decision making were better able to use Abaris than those who had less training. However, newer teachers found Abaris to be more valuable, because they had never before seen graphs so frequently and thus felt that they were now making decisions based on data. The observations during the study indicated that the system was transparent to students and easily used by teachers. Because the system requires no changes in typical practice (*i.e.*, pen and paper data collection), teachers were able to use the system with little training. Because the system was easy to use, teachers reported feeling confident in using the system.

The logged data in Abaris for Schools provided some insight into how teachers used the system. Abaris for Schools was installed on a total of four computers at the UW's EEU: 1 computer in the classroom where the teachers worked with the children, which ran the video recording tool and acted as the database server, 1 computer in the office of the head teacher, and 2 computers in the teacher's lounge/office area, where teachers would go every morning before class to print data sheets and thus were the primary machines where Abaris was used. In addition, all of the data from the database was available to determine how much data teachers entered into the Abaris for Schools System. Unfortunately, the hard drive on one of the machines in the teacher's office crashed before the log files could be copied, thus there were only logs from the remaining three machines.

Analysis of the database files provided a good sense for how much data teachers entered into the database. There were a total of 9 teachers and 16 students registered to use the system, and the teachers covered a total of 51 unique skills (*e.g.*, "Independent Play," "Peer Imitation," "Imitation – Drawing") across 3 skill categories (Cognitive, Social, and Communication). Teachers recorded data over a three month period going from October 16, 2006 to January 18, 2007. However, due to the holiday break and several snow days, data was only recorded across approximately 5 weeks. In addition, teachers only collected data on Mondays, Wednesdays, and Fridays. Thus, there is only data for a total of 32 days. Teachers conducted a total of 262 sessions using Abaris for Schools. In general, students worked with only one teacher during the phase of the study in which they used Abaris, but there was one child who worked with two teachers and three children who worked with three teachers. Students participated in an average of 16.38 sessions ($\sigma = 2.92$) covering 10.38 skills ($\sigma = 3.03$) for a total of 757.38 trials of the different skills per child. Table 8 provides a summary of the quantitative data regarding the data captured with Abaris.

| Student | Teacher | # of | # of | # of |
|---------|-----------|----------|--------|--------|
| ID | ID(s) | Sessions | Skills | Trials |
| 1 | 1 | 17 | 10 | 679 |
| 2 | 4, 1 | 16 | 9 | 877 |
| 3 | 3, 6, 8 | 15 | 10 | 506 |
| 4 | 3, 6, 8 | 15 | 6 | 434 |
| 5 | 2 | 15 | 12 | 822 |
| 6 | 2 | 19 | 17 | 894 |
| 7 | 1 | 18 | 8 | 786 |
| 8 | 4 | 19 | 8 | 1,034 |
| 9 | 2 | 16 | 16 | 490 |
| 10 | 2 | 18 | 14 | 800 |
| 11 | 9 | 8 | 8 | 367 |
| 12 | 5 | 16 | 9 | 881 |
| 13 | 5, 6, 8 | 21 | 11 | 1,164 |
| 14 | 6 | 15 | 10 | 752 |
| 15 | 6 | 19 | 10 | 933 |
| 16 | 7 | 15 | 8 | 699 |
| | Total | 262 | 166 | 12,118 |
| | Average | 16.38 | 10.38 | 757.38 |
| | Std. Dev. | 2.92 | 3.03 | 220.45 |

 Table 8: Descriptive data showing how much each input was provided for each student, including the number of sessions, the number of skills, and the number of trials conducted.

Through logs of Abaris, I was able to determine which features were used most often. Obviously, the printing of the Discrete Trial Training data sheets was the most frequently used aspect of Abaris, since teachers could not conduct therapy without it. Thus, because teachers were frequently printing data sheets, they were also reviewing graphs of students' progress. Teachers rarely used the manual Free Choice data entry screen, but during interviews, they said it was because they had not been collecting Free Choice data during the study. Lastly, the log files showed that the video recording feature was rarely used at all. When I asked teachers about this during the interviews, several stated that it was difficult to remember to use the video and that the setup of the classroom made it difficult for them to stay in one place to record videos. However, when we asked the teachers to speculate on whether video would be useful, all of the teachers (100%) stated that they would have liked having video and that it would not have had a negative effect on either them or the children in the classroom. The lead teacher and some of the more experienced teachers stated that they believed using video would help in the training of newer teachers.

6.3 Discussion

The deployment of Abaris in a school setting uncovered some additional considerations that I believe are important for designing and developing embedded capture and access applications. The nature of integrating the technology into a more complex environment with more users and a less defined decision-making process allowed me to reflect on the different aspects of embedded capture and access.

There is much difficulty in creating opportunities for collaboration if they don't exist already. The teachers in the study did not already have a practice of collaborating over student data, mostly because there was no requirement other than individual meetings with the head teacher. Although Abaris made it easier to produce graphs and look at data individual, the results showed that teachers did not collaborate as much as I predicted they would. I believe that because the nature of the classroom protocol was that one student worked with a single teacher, that there was not as much of a need to have discussions about children because the other teachers may not have had much experience with that child. Additionally, it is also difficult to reliably measure informal collaboration, as the teachers reported was the most common format of their interactions with others.

The biggest gains can be achieved for the newest members of a care team. From the interview data, I found that the teachers who found Abaris the most useful and used it for collaboration and decision-making were those who were newest to the team. The teachers who had been working in the classroom and were already practicing good habits found Abaris to be the least useful. Despite the fact that Abaris made graphing easier, it was not complete enough in its ability to annotate graphs that teachers still had to go through the effort of printing graphs and manually annotating them, which did not necessarily save much time over the paper-based methods. Thus, embedded capture and access technology has a better chance of success in aiding less experienced caregivers when the process of embedding is not as seamlessly integrated as it could be.

If making changes to work practices, it is better to start with smaller changes. Because there were so many teachers and students working together, big changes to practices were difficult. For example, prior to using Abaris, teachers would just grab a new data sheet from a stack of printouts to begin their sessions with students in the morning, whereas now they had to go to a computer to print a datasheet. Sometimes, teachers would have to wait on others to finish, which may have had an impact in how long they were able to spend reviewing graphs. Because I already added this step to their process, it was very easy for the teachers to forget about turning on the video or decide to not bother with it. Thus, technologies designed for larger groups working simultaneously need to ensure that they are as simple as possible at first. Then, once initial changes are well-integrated, more complicated technologies can be added.

Each of these findings iterates the importance of understanding the domain fully and looking for good strategies for embedding technology within the existing practices. Using the digital pens and allowing for easy graphing seemed to be successful with this group of teachers, but introducing the concept of recording and watching video was very unsuccessful. This was largely because the teachers did things out of habit and even if the process for recording videos was made simple, just remembering to turn on the recording was difficult. However, anything that was not necessarily in their regular habit but required their attention to do their normal jobs (*e.g.*, printing data sheets) was successful. I believe the design of Abaris for Schools could have been more successful if I had spent as much time working with the teachers and understanding the particularities of their method of conducting therapy and analyzing data as I had with the home-based team.

6.4 Summary and Contributions

In this chapter, I presented a study I conducted with the University of Washington to test the ability of an embedded capture and access system to support decision-making in a school setting. In particular, I tested the capability of a new version of Abaris to improve the current, paper-based technique for Discrete Trial Training therapy. I used an analysis of the student records before and during the use of Abaris to determine if teachers made decisions more often. I also analyzed qualitative interview, focus group, and observation data to determine whether teachers perceived that their confidence was improved and that collaboration was improved. I also reported on usage statistics for Abaris to show which features were used most often and how often Abaris was used generally.

The main contribution of this study is that I showed that an embedded capture and access system shows promise in increasing the timeliness of decisions made about skills (Thesis Claim 5), increase reported confidence in the teachers (Thesis Claim 4), and an increase in perceived collaboration amongst teams of teachers working together in a classroom (Thesis Claim 3). In addition, an analysis of log data shows that teachers were exposed to graphs of the child's data more often (Thesis Claim 2).

CHAPTER 7

BABY STEPS AND KIDCAM EVALUATION

Using embedded capture and access to help make decisions about interventions for children who are already diagnosed with autism is a large problem already, but I wanted to explore the problem on a much broader scale for a less structured setting and for a wider, more diverse audience. Thus, I wanted to explore a new area for embedded capture and access to assist in making decisions about care with respect to young children, and with the implicit goal of detecting developmental delay, such as autism, much earlier than it is currently diagnosed. This chapter describes the study I undertook for evaluating the embedded capture and access applications developed for this domain, called Baby Steps and KidCam, presents the findings from this study, and provides a discussion for broader implications of this work.

7.1 Study Description

In this section, I describe the study I designed to test the various aspects of the embedded capture and access features of the Baby Steps and KidCam prototypes and their ability to support the goals outlined in the thesis statement. I also describe the participants selected and recruited for the study.

7.1.1 Study Design

To determine if Baby Steps and KidCam met the goals for embedded capture and access applications, I conducted a 3-month deployment study of the combination of both

Baby Steps and KidCam. In this study, families used Baby Steps and KidCam to record real data on their child's developmental progress. I devised a study that allowed me to test whether the embedded capture and access features of Baby Steps and KidCam would encourage parents to record more data and make better decisions about their child's progress as outlined in the thesis statement. In particular, I tested whether Baby Steps and KidCam would enable parents to collect more data about their child's progress, review data more often, communicate better with other caregivers about data, have more confidence in their decisions about their child's progress, and make more timely decisions.

To test the embedded capture and access features, I developed two different versions of the Baby Steps system: an experimental version that had all of the embedded capture and access features I predicted would have an impact on parents' ability to record better data and a control version which only had the basic features of the Baby Steps system. In particular, the experimental Baby Steps version had the ability to generate newsletters, share videos with others, capture videos and pictures with KidCam, and had the proactive email and popup reminder system.

The test of the experimental versus control systems was conducted using a between-subjects study design, where 4 families received the experimental version of Baby Steps and KidCam, and 4 families received the control version of Baby Steps. I also conducted some within-subjects tests for each family by administering surveys, interviews, and observations at both the beginning and ending of the study to see whether there were any changes before and after the deployment of either the control or experimental versions. The specifics on data collected are described in Section 7.1.3.

The basic protocol for the study was to meet with each participant for a total of 5 times. The first visit was an observation of the Well Child Visit between the pediatrician, parent, and child (Well Child Visit #1). During the Well Child visit, I distributed initial surveys and consent forms and instructed parents about the study. The next visit was shortly after the Well Child Visit and consisted of me going to the house of the participant to install whichever version of Baby Steps the family was using on their own computers (*i.e.*, the experimental version or the control version). For all but family E-1, the software was installed on the family's own computer. However, there was a problem with installing the SQL Server on E-1's laptop because it was fairly old, so I provided them with a second laptop to use for the Baby Steps application rather than having them withdraw from the study. If the family was in the experimental group, I also gave them the KidCam device. All parents were instructed on how to use the software and given user manuals. However, they were told that they could use the software however they wanted, and that there was no obligation to do anything with it. During Home Visit #1, I also conducted an initial interview, collected surveys distributed during Well Child Visit #1, and then instructed the families to use the Baby Steps and KidCam applications however they wished.

The parents then used the application uninterrupted for approximately 1-2 months, after which I scheduled a second home visit, Home Visit #2, where I downloaded log files, installed any bug fixes that had been identified, and conducted a mid-study interview on their thoughts on Baby Steps and/or KidCam to date. During this time, I also reminded parents to schedule their child's next Well Child Visit and remind me of the time. Finally, after the family had been using the software for approximately 3

months total, I observed the child's second Well Child Visit (Well Child Visit #2) and distributed the same surveys as during the first part of the study. Shortly after Well Child Visit #2, I scheduled a third home visit, Home Visit #3, where I visited each family, collected the surveys distributed during Well Child Visit #2, downloaded log files, collected the loaned equipment for KidCam, and installed the full, most recent version of Baby Steps (including for all the control group participants so they could get all of the features). During this final visit, I also conducted a final interview with parents on their experiences using Baby Steps and their thoughts on improvements and new features.

These studies took place between January and May of 2008, depending on when each family's Well Child Visits were scheduled. Table 9 shows the actual dates that each participant completed each phase of the study, whereas Figure 39 shows an approximate timeline for the study. More details on each of the participants are described in Section 7.1.2.

| Participant ID | Well Child Visit #1 | Home Visit #1 | Home Visit #2 | Well Child Visit #2 | Home Visit #3 |
|-------------------|------------------------|------------------|------------------|------------------------|------------------|
| C-1 | 1-28-08 | 1-29-08 | 3-27-08 | 4-24-08 | 5-2-08 |
| C-2 | 1-14-08 | 1-17-08 | 2-28-08 | 4-21-08 | 4-28-08 |
| C-3 | 1-22-08 | 1-22-08 | 4-2-08 | 4-14-08 | 4-30-08 |
| C-4 | 1-22-08 | 1-28-08 | 3-4-08 | 5-2-08 | 5-5-08 |
| E-1 | 1-31-08 | 2-9-08 | 3-27-08 | 5-1-08 | 5-1-08 |
| E-2 | 2-6-08 | 2-8-08 | 4-2-08 | 4-23-08 | 5-9-08 |
| E-3 | 1-28-08 | 2-4-08 | 3-31-08 | 4-28-08 | 5-5-08 |
| E-4 | 2-1-08 | 2-6-08 | 3-29-08 | 5-9-08 | 5-11-08 |

Table 9: List of participants and the dates that each phase of the Baby Steps study was completed.

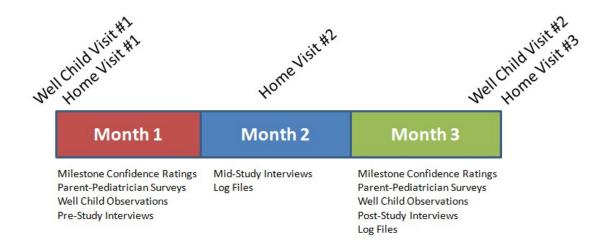


Figure 39: Approximate timeline and data collected during the Baby Steps and KidCam deployment study.

7.1.2 Participant Selection

To recruit participants for this study, I first aimed to find a single pediatrician's office that would be willing to let me recruit several of their patents to use the Baby Steps system. To find this pediatrician's office, I used connections at Children's Healthcare of Atlanta (CHOA), who sent out information on the study to several pediatricians' offices in the greater Atlanta area. Several offices were interested in participating in the study, but in the end I selected Johns Creek Pediatrics (JCP) located in Suwanee, Georgia, United States (a suburban community about 45 minutes from Atlanta) for several reasons. First, they were already using the Ages and Stages Questionnaire, the basis for which I designed Baby Steps, which ensured that the pediatricians and patients I recruited would be familiar with the milestones. Second, they had a recommended Well Child Visit schedule of 9 months, 12 months, 15 months, and 18 months, which meant that I would be able to find a number of patients in the target 9 to 18 month range. Lastly, they served

a large, diverse population of middle class residents, which means I would have a better chance of recruiting a homogeneous set of families for the study. From Johns Creek Pediatrics, I recruited two different pediatricians as participants in my study, whose participant numbers are P-1 and P-2. There are a total of 3 pediatricians serving at Johns Creek, but one pediatrician was being replaced at the time of the study, which is why I only went with the two current pediatricians.

After recruiting the pediatrician's office, the next step was to recruit 8 families to participate in the study: 4 for the experimental group and 4 for the control group. To recruit families, I went to Johns Creek Pediatrics and asked their office staff to look up the names and mailing addresses of patients who would be scheduling their child's 9 month, 12 month, or 15 month checkup in the next 1-2 months. Using the list provided by the office, I came up with 90 potential families who could participate in the study. I then mailed a packet of information to the 90 families, which included a letter jointly written by Johns Creek Pediatrics and Georgia Tech describing the study, a basic description of the study, and a screener survey. The screener survey asked basic information about the composition of the family, demographic information, computing equipment at home, and experience with computers. The complete screener survey can be found in Appendix F.1. Parents were asked to complete the survey if they were interested and mail it back in the envelope provided in the packet. The letter also offered participants \$500 for completing the whole 3 month study.

I received back 28 screener surveys via mail, fax, and email. I had originally planned to recruit a very homogenous set of families that had a single child, two working parents, the same pediatrician, and all children being the same age and gender. The intent was to control for as many confounding factors as possible. However, this proved to be a difficult task because there were so many different families who had responded and there were very few that matched my original criteria. Thus, I instead opted to select pairs of families that matched on various family and demographic criteria and randomly assign one of each pair to the control group and one to the experimental group. I was able to find 4 matching pairs Table 10 shows the composition of the two groups used in the study based on the following criteria: doctor, child's age, gender, number of siblings, and whether both parents were working. The only non-matching pair was E-2 and C-2, which had a difference in gender of the child. However, at such a young age, gender was likely to be less of a confounding factor than the other criteria. These matching pairs ensured that I would have a counterbalanced experimental design.

Table 10: Participant families and demographics selected for the two groups for the deployment study of Baby Steps and KidCam. Participants were randomly assigned to either the control or experimental group.

| ID | Group | Doctor | Child's Initial Age | Gender | # Siblings | Both Parents Working? |
|-----|------------|--------|------------------------|--------|---------------|-----------------------------|
| E-1 | Experiment | 1 | 12 months | М | 1 | No |
| C-1 | Control | 1 | 12 months | М | 1 | No |
| E-2 | Experiment | 2 | 9 months | М | 0 | Yes |
| C-2 | Control | 2 | 9 months | F | 0 | Yes |
| E-3 | Experiment | 1 | 9 months | М | 1 | No |
| C-3 | Control | 1 | 9 months | М | 1 | No |
| E-4 | Experiment | 2 | 15 months | М | 1 | Yes |
| C-4 | Control | 2 | 15 months | М | 1 | Yes |

I also ensured that families did not have drastically different socio-economic statuses, based on the education level of the parents and the annual household income. For this study, most participants were college educated (or currently in college) and fell into middle or upper middle class categories. I also made certain that each of the parents had the minimum computing equipment required to run the applications on their own computers, which included at least 1 Windows computer at home, high speed internet (*e.g.*, cable modem, DSL), a digital camera, and a working printer. One family did not have a working wireless internet network; however, I was able to easily replace their defective wireless router to accommodate that need.

7.1.3 Data Collected and Analysis Methods

This section describes the data collected during each phase of the study and the analysis I conducted to determine the effectiveness of Baby Steps and KidCam in encouraging better decision-making. The results of each of the analyses are reported in Section 7.2.

7.1.3.1 <u>Milestone Confidence Ratings</u>

One of the aspects of decision-making that I predict that embedded capture and access can improve is making decisions with increased confidence. In caring for a child, parents make many assessments about whether their child has completed various developmental milestones. For each of these milestones on which a parent makes a decision, I wanted to have them rate their confidence in that decision. Thus, at the beginning of the study, I gave parents a printed version of the Ages and Stages Questionnaire (Bricker, Squires, Potter, & Twombly, 1999) that was age-appropriate for

their child and had them choose "Yes," "Sometimes," or "Not Yet" for each milestone listed on the questionnaire (there were approximately 36 milestones per questionnaire). For each milestone, I also had parents rate their confidence on a scale from 1 to 5 (1 = Lowest Confidence, 2 = Lower Confidence, 3 = Average Confidence, 4 = Higher Confidence, 5 = Highest Confidence). I repeated this process at the end of the study and gave the parents another questionnaire that was for the child's next age level. In addition to the questionnaires administered both before and after the study, I also had parents rate their confidence on milestones as they entered them into the Baby Steps system (see Figure 20 for an example of the interface for rating confidence). To analyze these confidence ratings, I created a master list for each family both before and after the study and analyzed the average confidence rating to see if confidence improved after completing the study. I analyzed these averages for statistical significance using independent sample 2-tailed T-Tests.

7.1.3.2 <u>Well Child Visit Observations</u>

In the United States, one of the most important aspects of assessing a child's developmental progress is the regular Well Child Visit with his or her pediatrician. At these visits, parents bring their children to the doctor's office for measurement of height and weight, head circumference, vital signs, and receive vaccinations based on the age of the child. In addition, the parent meets with the pediatrician to discuss things such as general health, nutrition, sleeping schedules, urinary and bowel movements, a physical exam by the doctor, and assessment of developmental milestones. Throughout the discussion with the pediatricians, parents are encouraged to ask questions. Often,

pediatricians will administer developmental screener surveys to assess where children stand with respect to national averages, such as the Ages and Stages Questionnaire. These visits usually take approximately 1 hour in total, with visits with the pediatrician taking approximately 10-30 minutes depending on how many questions the parents have or if there are any concerns. At Johns Creek Pediatrics, pediatricians recommend Well Child Visits immediately after birth, then at 1 week, 1 month, 2 months, 4 months, 6 months, 9 months, 12 months, 15 months, 18 months, 2 years, and then once per year after that.

These visits are typically the main venue where collaboration between parents and their pediatrician takes place, and thus were a good opportunity for me to observe the collaboration that takes place. Thus, for every family, I observed two Well Child Visits that were spaced over the 3-month period. I audio recorded the Well Child Visit to keep track of the conversation that parents and pediatricians had, as well as took notes on the topics discussed, questions parents asked, and activities performed by the doctors and nurses (see Appendix F.5 for the observation form I filled out for each observation). I then had all of the Well Child Visits transcribed for easy analysis.

7.1.3.3 Parent-Pediatrician Surveys

Because it is often difficult to assess the relationship of a pediatrician and a patient via just observation, I also wanted to get a sense for how the pediatrician and patient would independently assess their relationship. Thus, I administered a survey that was a modified version of a statistically valid assessment tool called the Patient-Doctor Interaction Scale (PDIS) (Bowman, Herndon, Sharp, & Dignan, 1992) to parents to have them assess their relationship with their pediatrician. For this survey, parents rate their

Well Child Visit experience with their pediatrician on a Likert scale from 1 to 5 and agree or disagree (ranging from Strongly Disagree to Strongly Agree, with a Neutral option as well) with statements such as "The doctor treated my child and me with respect." The modifications I did to the survey were change the phrasing so it made sense from a pediatric standpoint, since in these cases the patient is the child and not the one filling out the survey (for example, I changed "The doctor treated me with respect" to "The doctor treated my child and me with respect."). I administered this survey at the end of each Well Child Visit to determine if there was any change between the first and second visits that may be a result of the Baby Steps software. I also created a similar survey to administer to pediatricians to rate their interactions with the parents, however, this survey was of my own design and was not statistically validated. To analyze the survey results, I averaged each of the survey responses per participant and compared the beginning survey with the end survey using 2-tailed T-Tests to determine if there was a statistically significant difference between the two phases of the study. To see the two different surveys administered to the parents and the pediatricians, see Appendix F.3 and F.4.

7.1.3.4 <u>Software Logging and Database Information</u>

I instrumented both Baby Steps and KidCam with logging capabilities which would write various time stamped usage information to a text file. I logged different usage aspects of the interface, such as when the application was started, which features were used, and how often. I also wrote data entered by the parents to a database file, and when parents changed milestone information, I saved the previous version of each file to a second database table. Thus, I collected a history of all of the information that a parent entered about their child, along with timestamps. I analyzed this data to determine frequency of use, which features were used most often, and to look at the confidence and timeliness of the milestones entered into the system.

7.1.3.5 Qualitative Interviews and Focus Group

I conducted interviews with each of the families in the study a total of three times: once at the beginning of the study, once halfway through the study, and then once after the study was completed. These interviews were semi-structured in nature and served the purpose of clarifying quantitative data collected before, during, and after the study took place. Questions asked during the interview included questions about current practices for recording, thoughts on using Baby Steps or KidCam, relationships with their pediatrician and other caregivers, and notions of awareness and confidence about their child's milestones. For a complete list of questions asked during the interviews at all three stages of the study, see the interview guides in Appendix F.2.

I also conducted individual interviews with the two pediatricians in the study soon after all of the first rounds of Well Child Visits were completed. In addition, I conducted an interview with the pediatrician at Johns Creek who was soon leaving the practice and did not participate in the study otherwise. Finally, I conducted a focus group with the pediatricians and the office staff at Johns Creek Pediatrics where I asked for their feedback on Baby Steps and KidCam and how the technology might fit into their practice. For a list of questions I asked during the interviews and the focus group, see the full interview guides in Appendix F.2.

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7.2 Results

This section presents findings from the analysis of data collected during the deployment study of Baby Steps and KidCam. In particular, I present findings of how Baby Steps and KidCam affected the amount of data collected, confidence in decision-making, changes in the level of collaboration, and timeliness of decisions. In addition, I also present results of the analysis of log files which show statistics on which aspects of Baby Steps and KidCam were used.

7.2.1 Amount of Data Captured

One of the aspects of decision-making is to make decisions based on data and evidence, rather than just opinion or "gut instinct." Thus, I wanted to assess whether the added embedded capture and access features encouraged the addition of more evidence to the system. I also wanted to see whether the extra features enabled parents to make more decisions overall. Thus, I analyzed the logs and database files for each parent to determine how many decisions were made (as judged by the number of entries for milestone information in the system), as well as the percentage of those decisions that had evidence. On average, I found that parents in the experimental group made a higher number of decisions (averages 90.5 vs. 48.5). However, due to the smaller numbers of participants, an independent sample T-Test was unable to show statistical significance for these averages (p = 0.16). The totals for milestones decisions entered and the percentage of those decisions that had evidence are shown in Table 11.

| Participant ID | Number of Decisions | % with Photo Evidence | % with Video Evidence | Total Pictures & Videos |
|-------------------|------------------------|-----------------------------|-----------------------------|-------------------------------|
| C-1 | 64 | 12.5% | 0.0% | 8 |
| C-2 | 12 | 0.0% | 0.0% | 0 |
| C-3 | 5 | 0.0% | 0.0% | 0 |
| C-4 | 113 | 1.00% | 0.0% | 3 |
| E-1 | 74 | 1.35% | 28.4% | 22 |
| E-2 | 79 | 2.53% | 2.53% | 4 |
| E-3 | 101 | 0.0% | 0.0% | 0 |
| E-4 | 108 | 0.0% | 12.96% | 16 |
| Control | 45.8 | 3.13% | 0.00% | 2.75 |
| Group | $(\sigma = 50.41)$ | $(\sigma = 6.25\%)$ | $(\sigma = 0.00\%)$ | $(\sigma = 3.77)$ |
| Experimental | 90.5 | 0.97% | 10.97% | 10.5 |
| Group | $(\sigma = 16.54)$ | $(\sigma = 1.22\%)$ | $(\sigma = 12.9\%)$ | $(\sigma = 10.24)$ |

Table 11: Total number of decisions and evidence captured using Baby Steps by the individuals, plus averages for each group.

Besides decisions about milestones, parents also had the opportunity to enter freeform journal entries about their child's development or sentimental records. These journal entries were available for printing and for the experimental group, they were able to print them as part of their child's newsletter. An analysis of the log files and database records that show the number of journal entries entered by parents using the Baby Steps system is shown in Table 12. Overall, the average use of the journal was higher for the experimental group, but this average was not statistically significant (p = 0.40).

| Participant ID | Number of Entries | Average Length (in words) |
|--------------------|------------------------|------------------------------|
| C-1 | 0 | N/A |
| C-2 | 8 | 6.38 |
| C-3 | 0 | N/A |
| C-4 | 3 | 120.33 |
| E-1 | 6 | 61.0 |
| E-2 | 3 | 40.33 |
| E-3 | 18 | 123.6 |
| E-4 | 0 | N/A |
| Control Group | $2.75 (\sigma = 3.77)$ | $63.36 (\sigma = 80.57)$ |
| Experimental Group | 6.75 (σ = 7.89) | 74.98 (σ = 43.36) |

Table 12: Number of journal entries written by each participant using the Baby Steps system.

The types of journal entries that parents wrote varied widely. I did not tell parents what to write for this section and told them they could use it for "anything they wanted to record about their child." Some parents used it to keep track of sentimental events, such as the celebration of the child's first birthday or his first Easter egg hunt. The mother of family C-4 used the journal on a monthly basis to give a "status update" on her son, which included things like concerns about vocabulary, which she asked her pediatrician during the second Well Child Visit of the study then later wrote about. The mother of family E-3 also used the journal as a monthly status update (and even went back and copied in journal entries she had previously written in a paper-based baby calendar). Each of her entries took on the same format (*e.g.*, favorite foods, likes, dislikes, words her son was saying), which she got the idea of from her calendar. She thus thought that Baby Steps should have pre-determined questions to fill in addition to a free-form text entry box.

Interestingly, almost every parent stated during the post-study interviews that he/she wanted to be able to add pictures to the journal entry, especially those in the experimental group who wanted to make a "more interesting newsletter" or because they thought they might be more inspired to write something about a cute picture they took. The three families that did not use the journal at all mentioned that they either did not have time to update them, forgot about it, or could not think of things to write.

Another aspect of Baby Steps that parents could use to capture data about their child's progress was through the use of the "Question List," which was intended to have parents record questions about their child to remind them to ask their doctor later. This feature was not used at all by the control group, and was used only slightly by 3 of the 4 experimental group participants (2 families had 1 question, 1 family had 3 questions). Despite only having one question, the mother in family E-1 stated that she thought having the question list was one of the most useful aspect of the system because she was always keeping a list of questions on a piece of paper that she often lost track of, and now with Baby Steps, it was always in one place.

Another interesting aspect about data capture was how often parents' changed their minds or edited information about their child. One of the goals of Baby Steps was to encourage parents to not only check off milestones, but update them as necessary. Thus, I had Baby Steps save all previous data entered by parents to a separate table whenever they entered the information about their child. Overall, families from the experimental group edited their entries more on average than the control group family. Despite the small numbers of participants, this average difference was statistically significant according to an independent sample 2-tailed T-Test (p < 0.05). Table 13 shows an analysis of the times that participants edited existing information in the Baby Steps system.

| Participant | Milestones | Evidence | Avg. Edits | Range of Time |
|--------------|-------------------|-------------------|-------------------|----------------------|
| ID | Edited | Edited | Per Entry | Between Edits |
| C-1 | 15 | 1 | 1.60 | 1 - 45 min. |
| C-2 | 0 | 0 | N/A | N/A |
| C-3 | 0 | 0 | N/A | N/A |
| C-4 | 3 | 3 | 1.67 | 1 min. to 6 days |
| E-1 | 28 | 10 | 1.89 | 1 min. to 1.5 months |
| E-2 | 10 | 4 | 1.40 | 1 min. to 1 month |
| E-3 | 16 | 0 | 1.22 | 1 min. to 5 days |
| E-4 | 22 | 3 | 1.14 | 2 min. to 10 days |
| Control | 4.5 | 1.00 | 1.64 | |
| Group | $(\sigma = 7.14)$ | $(\sigma = 1.41)$ | $(\sigma = 0.05)$ | |
| Experimental | 19.0 | 4.25 | 1.41 | |
| Group | $(\sigma = 7.75)$ | $(\sigma = 4.19)$ | $(\sigma = 0.34)$ | |

Table 13: Analysis of results showing how often parents editing existing data using the Baby Steps system.

7.2.2 Confidence in Decisions

Another of the aspects of decision-making that I aimed to support was whether parents were making decisions with increased confidence. To measure confidence, I had parents report the confidence in decisions made about milestones in two different ways. First, I had parents fill out a paper-based survey on the age of their child's milestones using the same survey they previously completed for their pediatrician. At the end of the three month study, I had the parents fill out another survey that was appropriate for their child's current age. For each of the milestones, parents were also asked to rate them on a scale from 1 to 5. To analyze the results from these surveys, I averaged the total number of responses for both within-subjects and between-subjects conditions. In the withinsubjects comparison, there was an increase in confidence for all of the 8 participants between the first stage of the study and the second stage of the study, 5 of which were statistically significant (p < .05). The within-subjects results of the survey are found in Table 14.

| Dertieinent | Pre-Study | Post-Study | |
|--------------|--------------------------|------------------------|---------|
| Participant | Average | Average | p-Value |
| C-1 | $4.57 (\sigma = 0.96)$ | $4.89 (\sigma = 0.45)$ | 0.062 |
| C-2 | $3.76 (\sigma = 1.21)$ | $5.00 (\sigma = 0.00)$ | 0.001 |
| C-3 | $4.94 (\sigma = 0.34)$ | $4.95 (\sigma = 0.33)$ | 0.96 |
| C-4 | $4.11 (\sigma = 0.81)$ | $4.62 (\sigma = 0.67)$ | 0.004 |
| E-1 | 4.41 ($\sigma = 0.90$) | $4.76 (\sigma = 0.54)$ | 0.03 |
| E-2 | $4.64 (\sigma = 0.90)$ | $4.76 (\sigma = 0.60)$ | 0.51 |
| E-3 | $3.73 (\sigma = 1.12)$ | $4.38 (\sigma = 0.68)$ | 0.003 |
| E-4 | $3.62 (\sigma = 1.08)$ | $4.65 (\sigma = 0.71)$ | 0.0001 |
| Control | $4.34 (\sigma = 0.99)$ | $4.87 (\sigma = 0.45)$ | |
| Group | 4.54 (0 - 0.99) | +.07(0-0.43) | |
| Experimental | $4.09 (\sigma = 1.08)$ | $4.64 (\sigma = 0.65)$ | |
| Group | 4.07(0 - 1.08) | 4.04 (0 - 0.03) | |

Table 14: Within-subjects analysis of average confidence ratings as rated on paper-based surveys before and after the deployment of Baby Steps. Statistically significant differences are highlighted in bold (p < .05).

For the between-subjects comparison, it made more sense to compare the average differences between the beginning of the study and the end of the study, since each of the participants may not have rated their confidence consistently due to individual differences. For the control group, the average difference for each of the members was 0.52 ($\sigma = 0.53$). For the experimental group, the average difference each of the members

was 0.56 ($\sigma = 0.39$). The average difference between the two groups was fairly small and thus not statistically significant when analyzed with an independent sample T-Test (p = 0.96). The overall findings from the paper-based surveys thus show that although there was a difference for almost all of the participants in terms of the within-subjects gains, there was not a statistical difference between the experimental and control groups.

I also conducted an analysis of reported confidence for milestones entered using the Baby Steps system for both the experimental and the control groups. I found that in general, there was not a big difference between the two groups in terms of average confidence. However, I did find that when milestones entered with the system also had photo or video evidence, there was a bigger increase in confidence (almost always rated as a 5/5). The results of the confidence levels for the decisions about milestones made using Baby Steps are found in Table 15.

| Participant | Number of | Average | Average Confidence |
|--------------------|---------------------------|------------------------|------------------------|
| ID | Decisions | Confidence | w/ Evidence |
| C-1 | 64 | $4.69 (\sigma = 0.79)$ | $5.00 (\sigma = 0.00)$ |
| C-2 | 12 | $5.00 (\sigma = 0.00)$ | N/A |
| C-3 | 5 | $4.60 (\sigma = 0.89)$ | N/A |
| C-4 | 113 | $4.79 (\sigma = 0.89)$ | $5.00 (\sigma = 0.00)$ |
| E-1 | 74 | $4.81 (\sigma = 0.89)$ | $5.00 (\sigma = 0.00)$ |
| E-2 | 79 | $4.89 (\sigma = 0.36)$ | $5.00 (\sigma = 0.00)$ |
| E-3 | 101 | $3.88 (\sigma = 0.95)$ | N/A |
| E-4 | 108 | $3.79 (\sigma = 0.96)$ | $4.75 (\sigma = 0.45)$ |
| Control Group | $45.8 (\sigma = 50.41)$ | $4.77 (\sigma = 0.17)$ | $5.00 (\sigma = 0.00)$ |
| Experimental Group | 90.5 ($\sigma = 16.54$) | $4.34 (\sigma = 0.59)$ | $4.92 (\sigma = 0.14)$ |

 Table 15: Average confidence levels for milestone information entered with either the experimental or control version of Baby Steps.

Thus, overall it appears that the act of recording milestones in general has an effect on increased confidence across both conditions, but the additional embedded capture and access features did not have a particular effect on increasing or decreasing confidence. However, as shown in Section 7.2.1, the experimental version of Baby Steps increased the amount of records parents entered in general, as well as the amount of photo and video evidence per milestone, which had a positive effect on the confidence parents made in decisions.

To follow up with the quantitative confidence assessments, I asked each of the participants during the final interviews to comment on how using the system affected their confidence in their child's developmental progress. Many of the parents stated that they felt that they were more aware of how their child was progressing. I also asked them whether there were any negative impacts on knowing so much about how their child was progressing, such as feelings of anxiety or paranoia about unfinished milestones. One parent stated that she would want to know how her child compares to the average, not just whether or not he was meeting specific milestones. The other parents reported feeling that since the pediatrician had assured them that their child was on track or ahead developmentally, they did not feel worried. Several did mention that maybe things would be different if their child was not performing at or above average, and they could see how tracking data rigorously might make parents paranoid.

7.2.3 Collaboration on Decisions

Another of my thesis claims is that embedded capture and access technology can support collaboration on decisions and improve perceptions of the level of collaboration with other caregivers. In assessing developmental progress in young children, this collaboration is largely between parents and their pediatrician. To analyze the perceived collaboration levels from the parents' perspective, I used a standardize survey instrument that had parents rate their pediatrician on a scale from 1 to 5 (5 always being a positive answer) along a variety of areas. I also had pediatricians fill out a similar survey rating the parents' collaboration level before and after the survey.

Analysis of the surveys completed by the parents shows that in general, there was a net decrease in the average ratings for the pediatrician for the control group (-0.11, σ = 0.31) and a net increase in the ratings for the pediatrician for the experimental group (+ 0.14, σ = 0.36) between the two phases of the study. An independent sample 2-tailed T-Test shows that the average difference between the two groups is significant (p = 0.05). The results of this analysis are found in Table 16.

| Participant ID | Pre-Study | Post-Study | Difference |
|----------------|-----------------------|----------------|------------|
| Participant ID | Average | Average | Difference |
| C-1 | 4.60 (σ= 0.94) | 4.05 (σ= 0.82) | - 0.55 |
| C-2 | 4.00 (σ= 0.00) | 4.00 (σ= 0.00) | + 0.00 |
| C-3 | 5.00 (σ= 0.00) | 4.90 (σ= 0.44) | - 0.10 |
| C-4 | 4.57 (σ= 0.68) | 4.76 (σ= 0.44) | + 0.19 |
| E-1 | 4.61 (σ= 0.50) | 4.81 (σ= 0.68) | + 0.19 |
| E-2 | 4.33 (σ= 0.91) | 4.09 (σ= 0.77) | - 0.24 |
| E-3 | 4.52 (σ= 0.60) | 4.52 (σ= 0.68) | + 0.00 |
| E-4 | 3.90 (σ= 0.70) | 4.52 (σ= 0.74) | + 0.62 |
| Control | 4.54 | 4.43 | - 0.11 |
| Group | (o= 0.67) | (s=0.65) | (σ=0.31) |
| Experimental | 4.35 | 4.49 | + 0.14 |
| Group | (σ=0.74) | (σ=0.75) | (o= 0.36) |

Table 16: Average scores that parents rated pediatricians after Well Child Visits both before and after the deployment of the software.

An analysis of the survey data where the pediatrician rated their interaction with the parents showed an increase for both groups between the two phases of the study. However, there was a bigger increase for the experimental group (+ 0.51, σ = 0.34) than for the control group (+ 0.18, σ = 0.31). Once again, an independent sample 2-tailed T-Test shows that this change in average differences is significant (p = .01). The results of this analysis are found in Table 17.

| Participant ID | Pre-Study | Post-Study | Difference |
|----------------|-----------------------|----------------|------------|
| | Average | Average | |
| C-1 | 4.06 (σ= 1.06) | 4.67 (σ= 0.59) | +0.61 |
| C-2 | 4.72 (σ= 0.46) | 4.89 (σ= 0.32) | +0.17 |
| C-3 | 4.89 (σ= 0.32) | 4.94 (σ= 0.24) | + 0.06 |
| C-4 | 4.94 (σ= 0.24) | 4.83 (σ= 0.51) | - 0.11 |
| E-1 | 4.72 (σ= 0.46) | 4.94 (σ= 0.24) | + 0.22 |
| E-2 | 4.00 (σ= 1.50) | 5.00 (σ= 0.00) | + 1.00 |
| E-3 | 4.67 (σ= 0.48) | 5.00 (σ= 0.00) | + 0.33 |
| E-4 | 4.11 (σ= 1.08) | 4.61 (σ= 0.97) | + 0.50 |
| Control | 4.65 | 4.83 | + 0.18 |
| Group | (s=0.70) | (s=0.44) | (σ=0.31) |
| Experimental | 4.38 | 4.89 | + 0.51 |
| Group | (σ= 1.01) | (s=0.52) | (o=0.34) |

Table 17: Average scores that pediatricians rated parents after Well Child Visits both before and after deployment of the software.

One other interesting finding for this survey data is that the perceptions of collaboration were not necessarily reciprocal. For example, for C-1, the difference between the pre-study and post-study ratings by the parent showed the biggest decrease between the two phases (-0.55), whereas the rating by the pediatrician for this parent showed the biggest increase (+0.61). A similar trend is shown for participant E-2, where the difference between the two phases from the parent's perspective showed a decrease of

0.24, whereas from the pediatrician's perspective, it showed an increase of 1.00. One possible explanation for this may be that as parents become more aware of their child's developmental progress, it looks very good from the pediatrician's perspective. However, from the parents' perspective, because they are more knowledgeable about what their child is doing, they believe that the pediatrician may not be doing as much as they could. I believe that this calls for more research into a deeper understanding the nature of the parent/pediatrician relationship.

One other aspect on collaboration to note is that for six out of the eight families in the study, one parent primarily took on the role of entering data or deciding on the child's developmental progress. That parent was often the mother, and she was often the only one who attended the Well Child Visits. The exceptions to this were family C-1, where both parents attended both WCVs in the study, and E-4, where the mother attended the first visit and the father attended the second visit due to work schedules. In both of these families, both parents used the system collaboratively. However, in other families, the other parent would help take pictures and videos and otherwise be involved in the capture of the child's life, but not the after-the-fact recording and reviewing of data. This observation means that there is potentially future research that can go into encouraging the parent in the secondary caregiver role more active in the caregiving process.

7.2.4 Timeliness of Decisions

One of the final aspects of decision-making that I aimed to support in this thesis was whether embedded capture and access technology could help caregivers make more timely decisions. To measure this, I had the Baby Steps system record the dates that parents entered information into the system. With these dates, I could determine how often parents entered data and how long they took between decision points. Ideally, parents would make decisions more frequently and more spaced out over the course of the three months between pediatrician visits, rather than all bunched up on one date. In general, I found that the experimental group made decisions on more unique days on average, but due to the small number of samples, an independent sample 2-tailed T-Test did not show statistical significance (p = 0.22). Parents in the experimental group also averaged a shorter amount of time between days that the decisions were made, but again, the small number of samples indicates that there is not enough data to show statistical significance (p = 0.34). In addition, I looked at the longest gap between entries than the experimental condition (p = 0.21). Table 18 shows the results of the analysis for the timeliness of decisions.

| Participant | Number of Days | Average Time | Longest |
|-----------------------|------------------|---------------------------------|------------------|
| ID | Data was Entered | Between Entries | Gap |
| C-1 | 10 | 11.44 days ($\sigma = 11.82$) | 33 days |
| C-2 | 1 | N/A | N/A |
| C-3 | 2 | 31.0 days ($\sigma = 31$) | 31 days |
| C-4 | 12 | 10.18 days ($\sigma = 18.76$) | 64 days |
| E-1 | 7 | 13.0 days ($\sigma = 14.4$) | 35 days |
| E-2 | 6 | 17.7 days ($\sigma = 17.57$) | 37 days |
| E-3 | 16 | 7.27 days ($\sigma = 5.52$) | 21 days |
| E-4 | 20 | 4.53 days ($\sigma = 5.52$) | 14 days |
| Control Group | 6.25 (σ= 5.56) | 17.54 (σ= 11.67) | 42.67 (σ= 18.5) |
| Experimental Group | 12.25 (σ= 6.85) | 10.62 (σ= 5.89) | 26.75 (σ= 11.09) |

Table 18: Analysis of the dates showing how often decisions were made and how long parents took between decisions.

7.2.5 General Usage of Baby Steps and KidCam

Because there were some significant effects on how the use of Baby Steps and KidCam affected different aspects of decision-making, I examined the use of the log files and analyzed the interview data to determine specifics about how families used the Baby Steps and KidCam systems. Table 19 shows a summary of how frequently the Baby Steps application was used by participants in the study.

| Participant ID | Number of Days Baby Steps was Used |
|--------------------|---------------------------------------|
| C-1 | 11 |
| C-2 | 10 |
| C-3 | 4 |
| C-4 | 12 |
| E-1 | 19 |
| E-2 | 12 |
| E-3 | 18 |
| E-4 | 21 |
| Control Group | 9.25 (σ= 3.59) |
| Experimental Group | 17.5 (σ= 3.87) |

Table 19: Frequency of use of the Baby Steps application for each of the participants in the study.

Overall, parents in the experimental group did not use KidCam nearly as much as expected. Due to the cumbersome nature of the baby monitor feature, parents reported not finding the difficulty of getting it set up worth the effort and thus continued to use their existing, commercially available baby monitors. Family E-3 already owned a video baby monitor, and thus the mother said she preferred her existing one because it had infrared cameras that enabled her to see her child in the dark, which was a feature that KidCam did not have. Thus, they only used it as a camcorder or a digital camera. In general, parents did not take many pictures with KidCam. Because the onboard camera was a web cam and did not have a built-in flash, the digital pictures were not nearly as high of quality as that of their own digital cameras and thus parents did not feel they were high enough quality for sharing.

7.3 Discussion

The deployment of Baby Steps and KidCam uncovered some very valuable insights into how embedded capture and access applications can succeed or fail. I also believe that these can serve as guidelines for the design of future embedded capture and access applications. In this section, I discuss various lessons learned and aspects of the design I believe had an impact on the results presented below.

Provide explicit guidance for busy parents to enter information. Although some parents enjoy coming up with their own information to enter about their child, many do not think to write specific ideas without some sort of guidance. Many parents requested ideas for data and topics to record about their child and appreciated the fact that milestones were pre-entered and thus they could just mark "yes" or "no" rather than having to write long descriptions. Thus, I believe Baby Steps could be more embedded into everyday practices by being even closer to existing baby books by asking more sentimental questions. However, I think still leaving room for some free-form entry will make the system flexible enough that parents can use it for a variety of tasks.

Provide examples to spark interest in completing a task. Similarly to not requiring parents to come up with their own data to enter, having specific examples would be helpful in sparking interest or ideas for what a parent might enter. Despite having the Question List explained to them, there was still some misunderstanding of its purpose and several parents mentioned that they did not know what kinds of questions they should put there. In addition, many parents did not use the "Note" field for entering milestone information, because they were not sure what would be appropriate to write in that space. Similarly, parents did not necessarily know what the Newsletter was capable of until they

had data entered into the system, so it is possible that they did not fully appreciate the extent to which it could be used without having an existing example. Thus, having examples for what a parent might want to ask would be helpful in getting them to enter more data or use additional features.

Capturing rich media of children is still a very difficult task. Despite my best efforts to design a functioning system that would support more informal video and photo capture of children, parents still found it very difficult to record interesting, unplanned moments of their child. Children take up a lot of a parent's time, are very mobile once they walk, and still require a lot of attention and help, which makes traditional recording difficult. The type of recording used by KidCam was inspired by the notion of selective archiving, but it was actually more "selective, selective archiving" in that parents had to choose to move the recording device and turn it on whenever they were going to capture videos of their children. Thus, it was still difficult for them to remember to turn on the recording device if it was not always on. When I asked parents during post-deployment interviews whether selectively archiving cameras recording everywhere all the time would be a good solution, several said it would be okay if they still had control over what got saved and stored, because it was in the privacy of their own homes.

Quality of artifacts used for sentimental purposes is important. Because Baby Steps and KidCam were research prototypes developed primarily by me and other students, the time and resources available meant that the design and development of the system was not as high of quality as a commercial system would be. For example, the pictures captured by the Sony Vaio UMPC were low quality, and thus parents were reluctant to use it. The method used to make KidCam into a functional baby monitor was

also cumbersome to use and thus parents quickly dismissed it. Lastly, the newsletter generated by the system was listed as questions rather than statements, so parents were less likely to want to share it for fear of confusing others. Thus, it is very important that when trying to make a system that is creating long-lasting artifacts, the quality should be as high as one would expect in existing commercial products. The importance of visually appealing and good quality aesthetics should not be underestimated.

Perception of collaboration is not reciprocal. As seen in the results of the analysis of ratings of collaboration amongst between the parents and the pediatricians, there can be a difference between how collaboration is perceived amongst different members of the care team. Thus, it may be considered that having more information may actually make caregivers perceive others as not doing as much as they could. Technologies to support caregivers should take the differing roles into consideration and make advancements to help all members of the care team help each other understand the roles of others and help one another be on the same page about how care is progressing.

7.4 Summary and Contributions

In this chapter, I described the design of a deployment study that tested the ability for two embedded capture and access applications, Baby Steps and KidCam, to support caregivers making decisions about a child's developmental progress. The deployment study lasted 3 months and involved 8 sets of families. Four sets of families used a fullyfeatured version of Baby Steps and KidCam, while the other four served as a control group and only used a simplified version of Baby Steps. I presented the results of the test for the ability of Baby Steps and KidCam to support confidence in decision-making, improve collaboration between parents and pediatricians, and increase the timeliness of decisions about developmental milestones. I then present a discussion on what factors I believe contributed to the overall success of the application and present implications for embedded capture and access.

The overall contributions of this chapter are the methods used to test for collaborative decision-making and the verification of an embedded capture and access system that was able to increase the amount of data that parents are able to collect, (Thesis Claim 1), make it easier for parents and pediatricians to access, review, and analyze data (Thesis Claim 2), improve perceptions about collaboration between parents and other caregivers (Thesis Claim 3), improve confidence levels of parents about their child's development (Thesis Claim 4), and improve the timeliness of decisions made about developmental progress (Thesis Claim 5).

CHAPTER 8

CONCLUSIONS AND FUTURE WORK

Through the research explored for this dissertation, I have found that embedded capture and access shows much promise in enabling caregivers in the decision-making process. Though I believe that this work has only scratched the surface of possibilities in this area, the evidence provided in how embedded capture and access was able to support two very different caregiving domains gives me confidence that this work will succeed in domains and areas beyond caregivers of young children and beyond caregivers in general. In this final chapter, I summarize and synthesize the overall findings of this dissertation, as well as describe areas for future directions.

8.1 Summary of Dissertation Results

The main purpose of this thesis work was to explore the nature of how a new type of ubiquitous computing technology could support caregivers in making decisions about those for whom they care. In particular, I aimed to improve decision making along several key dimensions, including the amount of data caregivers can collect and analyze, collaboration with other caregivers on decisions, confidence in decisions, and the timeliness of decisions. The deployment studies I conducted were designed to test three embedded capture and access applications designed for two domains along these dimensions. This section aims to summarize the overall findings of the embedded capture and access applications I uncovered through the three studies. The first claim of my thesis was whether or not embedded capture and access technology could encourage caregivers to more easily capture more data than they could with previous methods. In the Abaris for Homes study, the therapists were able to capture all of the same artifacts that they were able to do with the traditional paper-based method. However, due to the fact that many of the artifacts were automatically generated for the therapists, the data capture became less time-consuming as shown by the percentage of time therapists spent doing paperwork. In the Abaris for Schools study, again the therapists were able to capture all of the same data they were able to before, but also generate graphs more frequently, which several teachers did not have access to before. Finally, in the Baby Steps and KidCam study, the group of families using the embedded capture and access version of Baby Steps captured more milestone information and evidence of children achieving milestones than the control group. Thus, for Thesis Claim 1, I was able to show that embedded capture and access applications can encourage more data capture.

The second claim of the thesis was whether caregivers using embedded capture and access applications could access more data than they could with previous methods. For the Abaris for Homes study, I conducted the analysis determining whether therapists accessed more reliable artifacts during the meetings than they did previously. I found that they accessed the videos, data sheets, and graphs more frequently, which indicates that access was easier and more frequent. In the Abaris for Schools study, it was difficult to assess whether teachers were actually accessing videos because there was no set time for review and teachers shared computers. Thus, that study did not assess whether the embedded capture and access technology increased access. However, for the Baby Steps and KidCam study, I showed that the experimental group showed a trend of more frequently accessing data about their child as shown by the number of days the Baby Steps system was used. Thus, two of the three studies showed that embedded capture and access systems can encourage caregivers to access data collected more often.

The third thesis claim predicted that embedded capture and access applications would encourage more frequent collaboration or perceptions of better collaboration by the caregivers. All three of the studies I conducted tested this thesis claim. For the Abaris for Homes study, I showed that through the video coding analysis of the collaboration ratings for each of the members of the therapy team, in the meetings where Abaris was used, there was a higher level of collaboration which was statistically significant. For the Abaris for Schools study, most of the teachers reported during their final interviews that they felt that Abaris encouraged more informal collaboration. Finally, for the Baby Steps and KidCam study, the analysis of the survey ratings for the parents and pediatricians showed statistically significant increases in ratings between the beginning and end for the families in the experimental group, but did not increase for the control group.

The fourth thesis claim was whether embedded capture and access applications could increase confidence in decisions that caregivers made about various aspects of their responsibilities. The Abaris for Homes study did not test this particular aspect of decision-making, mostly because that study took place before the formalization of which aspects of decision-making I wanted embedded capture and access applications to support. However, the Abaris for Schools study probed teachers about their confidence levels during the post-deployment interviews. Teachers reported that they felt more confident about their students' progress because they were reviewing data more often than they had previously. Finally, for the study exploring the use of Baby Steps and KidCam, I showed that both groups of participants showed a statistically significant increase in the confidence ratings both before and after the deployment of the different applications. I also showed that families using the embedded capture and access version of Baby Steps captured more evidence than those families using the control version, and those milestones with evidence had higher confidence ratings.

The fifth and final thesis claim predicted that embedded capture and access applications could encourage more timely decisions. For the three studies I conducted, only the Abaris for Schools and the Baby Steps and KidCam study tested this claim. In the Abaris for Schools study, an analysis of the records teachers collected before and during the time that Abaris was deployed in the classroom showed a trend that teachers were more likely to spend fewer days working on a particular skill, meaning that students mastered skills more often. Interviews after the deployment confirmed that teachers felt like they were making more timely decisions about which skills on which their students were working. For the Baby Steps and KidCam study, trends indicate that families in the experimental group made decisions more regularly, with fewer gaps in between times that they entered data.

Table 20 shows a summary of the findings for each of the three studies and whether or not the study supported each of the five claims. For each of the claims and each of the studies, I list whether the study showed a strong positive confirmation of the claim, a positive of the claim, or a negative result for that particular claim. A strong positive confirmation for a claim indicates that the evidence from the study showed a statistically significant result or was verified using multiple methods. A positive confirmation shows that trends indicate a positive result, but they are not particularly strong (*e.g.*, not statistically significant or not supported by multiple methods). Finally, a negative result indicates that the findings were opposite of what was predicted for that claim or not supported by any methods. The table shows that for each of the five claims, I was able to at least show trends indicating that the embedded capture and access applications I developed were able to support the various aspects of decision-making.

Table 20: Summary of results for each of the thesis claims as supported by each of the studies described in Chapters 5, 6, and 7. An "X" in a column indicates that the study did not explicitly test for that claim.

| Thesis Claim | Abaris for Homes (Chapter 5) | Abaris for Schools (Chapter 6) | Baby Steps & KidCam (Chapter 7) |
|------------------|---------------------------------|-----------------------------------|------------------------------------|
| 1. Data capture | ÷ | | ÷ |
| 2. Data access | ╺╬╸╬╸ | Х | ╺╋╺╋ |
| 3. Collaboration | ╺╬╸╬╸ | ╺┨╸ | |
| 4. Confidence | Х | - <mark></mark> - | - |
| 5. Timeliness | Х | | ł |



8.2 Overall Dissertation Discussion Points

The discussion in the individual chapters for each of the studies presented in this dissertation focused primarily on how the findings from the study reflected upon the different design choices made in the different embedded capture and access applications I developed. However, there are broader implications for the findings from these studies that were common across several or all of the findings in the studies. In this section, I describe more of these general findings and implications on how embedded capture and access and the research presented in this dissertation might affect both researchers working in this domain and those who work in the particular fields studied.

The importance of truly understanding the domain. Throughout all of this work, it became clear that in order to be successful in designing technology for caregiving domains, it is extremely important to have a good understanding of the goals, practices, and expectations of the different domains. This is not a new claim, as many who have worked in developing technology for use in the real world have called for an extensive understanding of the users before designing technology. However, this is particularly relevant to developing embedded capture and access applications in that a good understanding of existing work practices was needed to figure out how technology would be best embedded into the working environments I was studying. As an example, I believe that for the Abaris for Homes study, the design of the application better suited the needs of the therapists because I was so engaged with the team. However, the Abaris for Schools application was missing some fundamental features (*e.g.*, the ability to annotate graphs) because as the designer, I was not as engaged with the school teachers due to their remote location. There still remains an open question of how much is "enough"

understanding of a domain. For example, it is possible that Abaris for Homes could have still been successful without me spending so much time working directly with the therapists.

What does it mean to be embedded? One of the main aspects of the technology I developed as part of this thesis was the ability for capture and access applications to be seamlessly embedded into the existing work practices of caregivers. There are many ways that technology could be embedded into an environment. The main definition of embedded I use is to take advantage of existing motivations and work technology ubiquitously into the environment, making it as unobtrusive as possible. To make the capture portion of technology embedded, this may include using unobtrusive sensors, digital pens, or automated video recording. For embedded access, technology designs can incorporate the use of ambient or peripheral displays, proactive notifications such as daily email summaries of results, or displays shown while the caregiver is doing another task. One of the most useful times to embedded access is during the points where a caregiver is making a decision, which is the most likely time that the data may have a more likely impact. In addition, access should be embedded at times when the caregiver has time to look over the data, rather than at times when they are rushed. There is also a question of how to determine what should be seamlessly integrated and what should be made more visible. For example, one of the aspects of access is making data more visible, which may inherently disrupt existing practices, but may be instrumental to improving care. There is still more research that can be done into determining which aspects of embedded capture and access technology can be the most effective at improving the user experience.

The difficulty of capturing rich media of children across diverse spaces. One of the incidental findings of my research has shown that rich media of children for the purposes of caregiving still remains a major challenge. Despite the fact that video, audio, and photos can be can very beneficial, it remains difficult to design and implement. I believe children are harder to capture than other caregiving subjects. Children are often non-cooperative subjects, especially those that are young or who have cognitive disabilities, and are often highly mobile and reside in many different locations. This problem is exacerbated when multiple children are involved. The video capture for the Abaris for Homes was successful, because therapy only occurred with one child in a fixed location. With Abaris for Schools, video capture became more difficult because many teachers were working simultaneously with multiple children across a large classroom space, and thus the video recording feature was not used often. With the Baby Steps and KidCam project, the informal nature of childcare and the desire to capture quality video made it even more difficult to capture rich media of children.

The social impacts on caregiving. One of the goals of this dissertation work was the focus on teams of caregivers collaborating. The impact of technology can have some interesting effects on the social impacts related to teams of caregivers, such as impacting the balance of power between different care team members or reducing the concept of plausible deniability. For the Abaris for Homes study, there were various social dynamics that changed within the team of caregivers, such as the how the control of the individual artifacts during meetings and how video was used as a substitute for someone not being able to make meetings. In the Abaris for Schools study, having the technology encouraged more informal collaboration and also helped less experienced therapists

realize the importance of graphing data regularly. Finally, the Baby Steps and KidCam studies showed that the technology can have an impact on parents' knowledge and their attitudes toward their pediatrician. Thus, there is evidence to show that technology has an impact on the social dynamics between groups of caregivers.

The effects of the caregiving domain on decision-making. The use of caregivers as the subjects of my dissertation research had some implications for how decision-making could be supported. For example, the nature of caregiving, especially that of young children, is effectively a more nurturing environment than other decision-making domains. For example, in the care of young children, caregivers are often working toward a common goal of wanting what is best for the child. Oftentimes, caregivers may be willing to sacrifice their own personal privacy or comfort for the benefit of the child. In the case of Abaris for Homes, while therapists were at first uncomfortable with others watching videos of their therapy sessions, they often would sacrifice that comfort as long as they felt it was benefiting the child. In other domains, this may not be the case. Workers in nursing homes or mental hospitals are notoriously underpaid and overworked and thus may be less likely to make such sacrifices. Outside of the caregiving domain, there may be even more problems with supporting decision-making in that many stakeholders may have differing goals and opinions, and the environment may not be at all collegial. Some ideas for how technology might support non-collegial decisionmaking could be to develop technology where everyone can choose from a set of goals and try to come to a consensus on mutual goals or a compromise. Also, making decisions over a neutral, asynchronous medium rather than face-to-face may eliminate some of the difficulties with face-to-face discussions where people can say things out of emotion rather than thinking them through first. Because I did not have to encounter these issues in my work, there are some limitations on this work in that it focused on only caregiving domains. Whether or not the findings can generalize to other domains remains an open area of research.

What does it mean to be confident in decision-making? One of the metrics I used for how decision-making could be improved was how caregivers could increase their confidence levels. This was typically measured either through more qualitative measures, such as interviews or surveys, and through a subjective rating on a scale from 1 to 5 for the Baby Steps study. Neither of these measures was particularly strong. Qualitative data reports more holistically and does not typically uncover the more nuanced aspects of decisions with respect to confidence. The qualitative rating scale is difficult because it is again subjective, and also because parents rarely used anything less than a 3 on a scale from 1 to 5 for their decisions. In addition, there were some instances where increased confidence could not necessarily be a positive result. If a parent is very confident about a milestone but is not correct in their assessment, then it is possible that they would not bring up an issue to the doctor. Likewise, if a therapist or teacher is overly confident about a child's ability in a certain skill, they may decide that they do not have to review the data. Thus, there is some question about whether high confidence is a positive attribute of decision-making for the care domain. There is some potential for future research to determine how confidence can be accurately measured and its overall impact on the decision-making process.

The impact of my relationship with study participants. As both a technology designer and evaluator, I cannot help but play a role in the studies that I conducted. The

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relationships I developed during the formative studies I conducted likely had an impact on the results of my studies. This is particularly relevant in the Abaris for Homes studies, because I had worked so long with the team of therapists and also knew the family of the child well. Also, the fact that I remained a therapist in my own evaluation study may have also had some impact on the findings from those results. The Abaris for Schools study and the Baby Steps and KidCam study were less affected by this, as the participants I recruited were not nearly as involved with me as the Abaris for Homes study. Thus, it may be good to conduct a second in home study to remove some of the bias from being so closely involved with the team of therapists. One other point on this aspect is that despite my involvement with participants being a potential influencing factor on the results of the study, being as close as I was to the participants during the formative stages of the work was very beneficial to gaining their trust and having them provide good feedback on design and development ideas. Additionally, having a good knowledge of and experience with the area can help in understanding more about the process. Also, showing a sense of genuine care or concern about the livelihood of the participants and addressing their real problems as opposed to just using them as the proverbial "guinea pigs" can be helpful in getting the participants to be more engaged. There is one other caveat of this approach, is that once you develop a good relationship with your participants, it is difficult to move on from that relationship once the study has completed. One of the participants in the Baby Steps study said, "it's almost as if you're an aunt to [child's name]," meaning she felt that she had revealed many things about the child's growth to me, and I had regular contact with him over the course of the study. Severing that relationship can often be difficult. Lastly, it is often the case that study

participants want to see the work continue and be able to use it later, so there is much pressure to look for ways for research projects to be transitioned to actual products.

The advantages and disadvantages of real-world deployments. The main method for evaluation of the embedded capture and access applications I used was through deployment of the technologies in real world settings. I believe that for decision-making in caregiving domains, it is very difficult to obtain ecologically valid results without testing them in real situations with real data. Despite the advantages of doing real world deployments, they are certainly not without their drawbacks. For one, to do a long term deployment to determine real use, a fully implemented, robust prototype is needed. This includes having a prototype that has undergone extensive usability and bug testing, which can take a significant amount of time and resources. This makes it more difficult to test the feasibility of cutting-edge technology, as many new technologies cannot be fully implemented. Another disadvantage of this technique is that there is not much existing guidance on the best practices of how to conduct real world deployments, such as how long to deploy, how many participants, etc. Some work has started in this direction (Rogers, et al., 2007; Scholtz & Consolvo, 2004), but there is still much more to explore. Thus, I believe more research is needed to determine the best practices and provide guidance to researchers conducting real world deployments.

Aspects of this work for those with limited financial means. Though the technology I developed as part of this dissertation has been shown to be effective for the populations I studied, it should be taken into consideration how the technology would apply for the non-typical user. Access to computing technology is still difficult for those of limited financial means, and some of the more advanced technology could be too

expensive to be accessible for those of lower incomes. For the Abaris work, the technology needed for that system could be provided by the company or school administering the therapy for use in the home or school. For the home setting, the parents would need to have at least a computer, a printer, a web cam, and the digital pen and paper. The therapy in the home setting is already fairly expensive, so this equipment would not be that much beyond the cost of the in-home therapy. The projector could be owned by the consulting company, which the consultant could bring to each meeting. Again, for schools, the overall cost of the equipment is minimal compared to the potential time savings for teachers. However, budgets in schools tend to be limited, so it is still a consideration.

For the Baby Steps work, there is a much bigger burden on the part of the family. If Baby Steps were converted to a web interface, it would alleviate some of the need for owning a computer, as public libraries and workplaces often offer free Internet access. However, the system still relies on digital pictures and videos, which usually require at least a digital camera if not a camcorder. Although the price of these has gone down significantly in recent years, there is still some barrier to purchasing this typically non-essential technology. One potential solution may be to make a mobile-phone based system that relies on SMS technology and uses the camera phone, which may be more economically feasible than a computer with an internet connection. Other potential solutions may be to provide public services, such as kiosks in the grocery store where parents could enter information, use a nearby camera, and print out newsletters. These areas remain open areas for future exploration.

Ethical and privacy issues in the healthcare domain. Though the goals of my study focus on supporting the decision-making process along the lines of data collected, confidence, collaboration, and timeliness, there are other more tangential aspects to take into consideration when designing for these populations. Though none of the families who participated in the Baby Steps and KidCam study personally experienced this, there was some concern about whether parents of children who were not developing at the average or above-average level would have increased feelings of anxiety and whether this could lead to an increased burden on public services. Likewise, parents of over-achieving children may have a growing sense of competitiveness with other parents. A potential solution for this may be to only ask parents yes or no questions and show an overall trajectory for their growth, rather than having a checklist of things that a child should be doing at a certain age. Other considerations are whether information should be made available to parents or family members. The design of Baby Steps was that everything was entered by the parents on a single machine and only they would determine who had access to their information. However, if parents decided to share this information with their pediatricians beyond just bringing in printed data or post information online beyond just video sharing, there should be some more sophisticated privacy control features to comply with both HIPAA regulations (United States Department of Health and Human Services, 1996) and the safety of child's and family's privacy. These features may include password protected web-access for pediatricians and family members or encrypted emails to the pediatrician's office.

How to determine long-term success? Each of the studies I conducted with this work had the larger goal of improving the practice itself, such as making students learn

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skills more effectively or the early detection of developmental delay. However, the studies I conducted here were more limited in scope. Despite being several months long, they were still only just a small snapshot of the day-to-day lives of the caregivers and the patients. This remains a difficult issue to address in the field of preventative healthcare, because there is often no single "cure" that once it is administered, care is no longer needed. Thus, in this field, I believe that longer-term and follow-up studies should be conducted that are similar to those conducted in the medical fields. It is sufficient to do shorter-term deployment studies to determine usability of the application or see if some short-term components of a long-term success are achieved, but to really get into the usefulness feature, the studies should be much longer. This is particularly difficult in technology, because often the technology advances outpace the length of the study and modifications must be made to accommodate these changes, which may disrupt the scientific protocol. This type of long-term success is still a challenge in this area and should be explored along with the best practices for real-world deployments.

Reflection on the methods used for design and evaluation. The bulk of this dissertation work has been a variety of different methods and approaches to conducting work in interesting and important domains. Because of the nature of real world deployment studies, it is often the case that no one single method or metric will enable the researcher to uncover more meaningful results. This work has shown that a triangulation of multiple sets of methods can be crucial in having results that tell a reasonable story about what is going on when people are exposed to technology. It is also important to be flexible with the methods used, as many off-the-shelf methods may not work in all situations. Both qualitative and quantitative methods have a place in real

world deployment studies, and using one to explain the other and vice versa can typically provide more coherent and more scientifically valid results.

8.3 Future Directions

Though I have explored much with regard to decision support for caregivers across two different caregiving domains, I believe that there are many more areas of research to pursue along these lines. In particular, decision-making is a fairly complex task with many more dimensions than I explored in this thesis. The two domains I have explored are also much richer and have many other open issues, and the issues themselves have the potential to touch on many other domains. Thus, in this section, I outline future areas for research that can continue from this work beyond some of the open research questions discussed in Section 8.2.

The results of the Abaris for Schools study shows that automatically creating graphs for teachers and showing them at the time that teachers make decisions about skills has some promising trends for enabling students to master skills more quickly. However, due to the short duration of the study, I was unable to show statistically significant trends. In addition, some of the design decisions about the interface made it less useful for more experienced teachers, such as the lack of a graph annotation tool. Thus, one of the main areas for future exploration will be to address some of the design decisions and repeat the study for a longer period of time. This will help to determine whether the embedded capture and access technology can truly make a difference in the classroom. For the Abaris for Homes work, there were some interesting findings that I plan to pursue further. For example, there were some interesting effects in using

recognition technology as timestamp information. Therapists would look for a particular skill in a video, but the timestamp would not be precise. The therapists would then look at other skills and have a better sense of what the child was doing before and after a skill while waiting for the video to move to the right location. Thus, I am interested in exploring how the accuracy of the timestamps can affect the viewing of videos.

For the Baby Steps work, there is more data I collected during the studies that did not necessarily address the claims of the thesis but will be subjected to further analysis. In particular, I am interested in doing further analysis of the Well Child Visit observations and interviews with parents and pediatricians. I would like to do in-depth analysis of the transcripts of each to uncover deeper issues such as patient/doctor interaction and parents' perceptions of how better tracking of their child's data might impact their levels of anxiety. There is also more qualitative data that can be used to reinforce the more quantitative findings described in Chapter 7 and additional logging information that can be used to determine the most frequently used features of Baby Steps and KidCam. Finally, I plan to explore how more elements of Persuasive Technology might be used to encourage parents to record more data about their child's developmental progress.

For the three studies I conducted to test the various applications of embedded capture and access technology, I was able to show that these types of technology were effective at supporting caregivers. However, it remains to be seen whether the applications as a whole were responsible for the success, or whether individual aspects of embedded capture and access were responsible. For example, there were four main embedded capture and access features for the experimental version of the Baby Steps application: the proactive reminders, the newsletter generation, the online sharing, and the KidCam device. At this point, it is difficult to tell which features had an impact and which did not. Thus, further studies are needed to individually test embedded capture and access features and determine which ones have an effect and which do not.

Finally, the findings from the use of embedded capture and access technology to support decision-making for caregivers of young children showed promising results. However, there are many other domains which can benefit from this approach. Within the field of caregiving, there are other domains that can be explored with respect to early childhood development, such as other caregiver requirements for children with special needs or tracking developmental progress for specific at-risk children. There are also other aspects of typical childcare, such as tracking nutrition or childcare that can be explored. Other caregiving domains with similar goals and challenges for decision-making include eldercare, care for the terminally ill, and care for people with chronic conditions such as HIV/AIDS, diabetes, or asthma.

APPENDIX A: STUDY MATERIALS FOR FORMATIVE STUDIES

A.1 Baby Calendar Interview Guides

Interview Guide - New/Future parents

- 1. What have you done (did you do) to prepare for the birth of your new baby?
- 2. What advice have friends or relatives given you about taking care of a new baby?
- 3. What kinds of books or materials have you purchased or borrowed to help you prepare for the new baby?
- 4. What steps are you planning on taking that will ensure the healthy development of your child?
- 5. What kinds of recording do you plan to do to document your child's growing stages? photos? videos? baby books? Who do you think you will share these with?
- 6. How comfortable are you with computers? What kinds of things do you use them for?
- 7. Besides you and your spouse, whom will you get to help with the care of your child?
- 8. How do you anticipate you will communicate with these people?
- 9. What kinds of things do you think you will communicate?
- 10. What are your thoughts about your child's future? What hopes or fears do you have? (Prepare to follow this up with specific questions about developmental delay)
- 11. Have you thought about how you would handle things if your child were to have a disability?
- 12. Have you discussed this possibility with your spouse/teacher/friend/family/etc.?
- 13. Do you know the risk factors associated with developmental delay?
- 14. Can you think of any specific behaviors parents should look for in a child that may be an indicator of abnormal development?
- 15. What kinds of things do you anticipate purchasing to encourage healthy development in your child? Specialized books, games, toys, videos?
- 16. (Follow up with example scenarios for use of the system. For example, using "smart toys" to trigger recording of specific events.)

Interview Guide – Experienced Parents

- 1. Tell me about your children. How many children do you have, how old are they, and what are their genders?
- 2. How many people are in your household? And were in your household during certain periods in your child's life?
- 3. Who do you consider your child(ren)'s primary caregiver(s)? secondary?

- 4. What things did you record about your child? Pictures? Videos? Records? Scrapbooks?
- 5. What are things you wish you collected but didn't?
- 6. How closely did you track your child's developmental milestones?
- 7. What were the milestones you felt most important to look for?
- 8. If you have more than one child, what do you think was different about keeping records for your younger child(ren)?
- 9. What kinds of hopes or fears did you have about your child as he/she was growing up? (Follow up with more specific questions about developmental delay)
- 10. How did you know what signs to look for to determine how your child was developing? (Did you ask your doctor/friends/relatives/consult books/the internet?)
- 11. How often do your take your child(ren) to see a pediatrician? Do you take them to see any other medical care provider or specialist? How did that change from birth until now?
- 12. What would have made it easier to collect the data and records?
- 13. How do you share your child's records with others?
- 14. What are your thoughts on using a computer to keep track of your child's developmental progress?
- 15. What are some specific features you can think of that would assist you in organizing and maintaining your child's records?
- 16. Did you use baby monitors when your children were growing up? What kinds? What was useful about them?
- 17. What kinds of toys or educational supplies did you use with your child while they were growing up?
- 18. (Follow up with example scenarios for use of the system. For example, using "smart toys" to trigger recording of specific events.)

Interview Guide – Medical Professionals

- 1. Describe a typical "well baby" visit.
- 2. What is your source for what questions to ask during meetings with parents? (*e.g.*, American Pediatrics, guide to new parents, CDC, etc)
- 3. Does this source also include data to be collected or tests you do with a child at each visit to determine the health of a child?
- 4. Do you ever do any pre or post analysis of data collected about a child, or does all of the analysis occur during the child's visit? Who generally does this analysis?
- 5. Besides vaccination and parents making an appointment to see you—what factors determine when you schedule more visits for a particular child?
- 6. What do you feel are the roadblocks in early diagnosis of developmental delay? What factors negatively impact parents ability to report accurately on their child's development?

- 7. What advice do you give new parents with respect to ensuring that they can detect if their child is NOT developing normally?
- 8. Would having a list of milestones completed by the child and when they occurred be helpful during visits?
- 9. Given concern about a child's development, would supporting video of these milestones be useful?
- 10. What are some "red flags" you look for in newborns or infants, to determine if there may be any sort of developmental delay later on?
- 11. What are 2 "red flags" in the first 5 years that you are vigilant about checking or make parents aware of?
- 12. Do you ever check for skills a child once had, but no longer has?
- 13. If you feel the child is exhibiting behavior that is not normal, how do you address this topic with the parents?
- 14. Do parents ever bring you videos or photos of their child exhibiting abnormal behavior? Do you ever recommend parents to record this sort of behavior?
- 15. What do you think would make this process easier? More effective?

Interview Guide – Secondary Caregivers

- 1. As a care provider, what are your responsibilities?
- 2. How often do you engage in activities aimed at encouraging development or education?
- 3. What kinds of records do you keep of the children in your care? Does it differ from age to age, parent to parent? Can we see examples?
- 4. What kinds of media do you record of the children in your care? Pictures? Videos? Keepsakes?
- 5. What concerns, if any, do you have about privacy when it comes to recording?
- 6. Who determines which records to keep? parents? daycare owner?
- 7. How are the records shared amongst the other caregivers and the parents?
- 8. Have you ever been in a situation where you observed something for the first time in a child? How did you know it was the first? How did you communicate that finding with the parents?
- 9. Can you think of any ways to make the data collection progress easier?
- 10. How comfortable are you with computers? What kinds of things do you use them for?
- 11. Have you ever had any children under your care where you were concerned about their growth and development?
- 12. If so, what were the factors you noticed that were problematic?
- 13. How did you deal with the child? How did you bring up the problem with the child's parents?

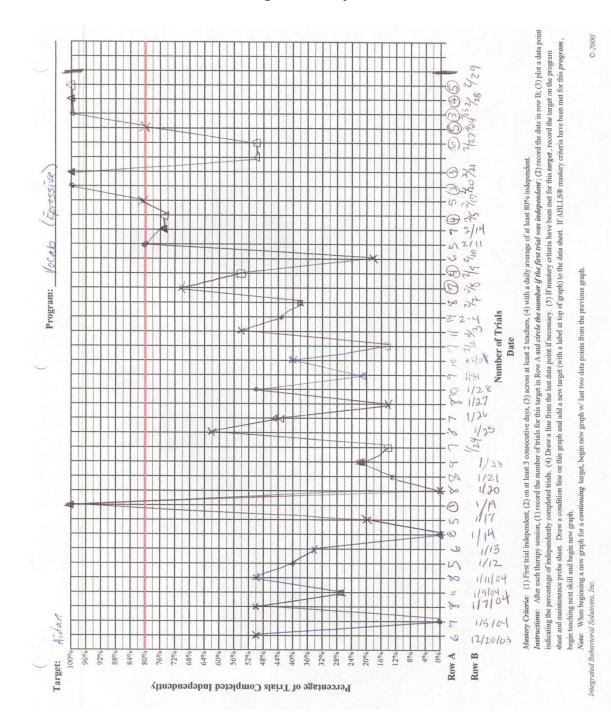
Interview Guide – Day Care Center

- 1. Tell us a bit about the center. What ages do you cover? How long throughout the day do you watch the children? What is the pick up / drop off policy?
- 2. As care providers, what are your responsibilities?
- 3. What kinds of records do you keep of the children in your center? Does it differ from age to age, parent to parent?
- 4. What kinds of things do you record about the children in your care? Pictures? Videos? Keepsakes? Artwork projects?
- 5. What concerns, if any, do you have about privacy when it comes to recording?
- 6. Who determines which records to keep? parents? Center policy?
- 7. How are the records shared amongst the other caregivers and the parents?
- 8. Can you think of any ways to make the data collection progress easier?
- 9. What kinds of technology do you usually use at the daycare center? Does it differ from person to person? How comfortable in general are people with technology?
- 10. Have you ever been in a situation where you observed something for the first time in a child? How did you know it was the first? How did you communicate that finding with the parents?
- 11. Have you ever had any children under your care where you were concerned about their growth and development? If so, what were the factors you noticed that were problematic? How did you deal with the child? How did you bring up the problem with the child's parents?
- 12. How often do you engage in activities aimed at encouraging development or education?

APPENDIX B: ORIGINAL AND REDESIGNED THERAPY FORMS

B.1 Abaris for Homes Original Data Sheet

| Program | Target | | | | | 1 | rial-b | y-Tria | l Responses | |
|--|-----------------|-----|----------------|--------------|------|----|--------|--------|-------------|-------|
| Receptive Instructions (C10) S ^D "i.e., come here, sit down" | open your mouth | ſ | I | I | I | | | | Notes: 3/3 | 1007. |
| | turn around | G | /I | 96 | I | | | | Notes: 2/5 | 40% |
| | | | | | | | | | Notes: | |
| Vocal Imitation (E1) S ^D "Say" | Mommy | - | L | MI | I | | | | Notes: 3/4 | 75% |
| | mouth | N | YI | I | MI | | | | Notes: 3/5 | 602 |
| | | | Referenciacion | elouitopoorp | | | | | Notes: | |
| | | | | | | | | | Notes: | |
| Writing Skills (S4) S ^D "Copy" | circle | | I | 76 | 9/I | | | | Notes: 2/5 | 40% |
| | Diagonal line | 7 | I | I | I | I | | | Notes: 4/5 | 807 |
| | "F" | | I | Ţ | I | | | | Notes: 3/3 | 1007. |
| | | | | | | | | | Notes: | |
| Body Parts (C17) S ^D "Touch vour…" | Arm | RG | 1- | P/G | M.G | | | | Notes: % | 0% |
| | | E | | | | | | | Notes: | |
| | Ears | R G | 10 | 6/I | 6/I | | - | | Notes: 2/6 | 33% |
| | a good and | E | | | / | | | | Notes: | |
| Labeling (G2&4) S^{D} "What is it?" | Cow | | I | VIT | I | I | | | Notes: 415 | 8070 |
| į | dog | | I | I | VI. | 7_ | | | Notes: 3/6 | 50% |
| | | | | | | | | | Notes: | |
| Letters (Q1-2) 5 ⁰ "Give me [letter]. | B | R | r ^e | 54I | Sc/1 | | - | | Notes: 3/5 | 60% |
| 5 ⁰ "What letter?" w/ L | | E | Ŧ | 1 | I | | | | Notes: 3/3 | (00%) |
| | | R | | | | | | | Notes: | |
| | | E | | | | | | | Notes: | |
| | | | T | | | | | | Notes: | |



| $ \frac{g^{0} "Copy"}{g^{0}} = \frac{g^{0} (Copy"}{g^{0}} = \frac{g^{0} (Copy"}{g^$ | Program | | Target | | | Tr | ial-l | by-Ti | ial F | Resp | onses |
|--|---|-------------|---|-------|-----|-----|-------|-------|-------|------|--------|
| $\begin{array}{c c c c c c c c c c c c c c c c c c c $ | Receptive Instructions (C10) ¹⁰ "I.e. come here, sit down" | | salute (w/out pic) | 元 | % | H | %E | H | 7e | H | Notes: |
| Writing Skills (S4)e (trace first) $I = 7/4 I I I I$ Notes: S^{0} "Copy"short words $I = 7/4 I I I I$ Notes:short words $I = 7/4 I I I I$ Notes: S^{0} "Show me"animals (w/ obvious distractors) $I = 7/4 I I I I$ Notes: S^{0} "What are they?"F:3 $I = 7/4 I I I I$ Notes: S^{0} "What are they?"F:3 $I = 1 I I I I I I I I I I I I I I I I I $ | ocal Imitation (E1) | | Pack | m | H | Ħ | H | | | | Notes: |
| S" Copy"short words I I Notes:Receptive Categories (na) S" "Show me"animals (w/ obvious distractors) I I Notes:S" "What are they?"F:3 I I I I Notes:Labeling (G2&4) S" "What is it?"Computer I I I I Notes:Identifying Written Words (I) S" "Give me fword]"F:4Aidan (cursive, w/o/Po) I I I I I S" "What is it?"School bus (Show pic w' Sd) I I I I I I I Vocabulary - Objects (C15, G4) S" "Give me fhe"F:3School bus (Show pic w' Sd) I | | | neck | min | I | 1 | t | | | | Notes; |
| Receptive Categories (na) animals (w/ obvious distractors) animal | Vriting Skills (S4) ^D "Copy" | | e (trace first) | I | Z | Ŧ | F | | | | Notes: |
| S ⁹ "Show me" animals (w/ obvious distractors) Image: constraint of the state of the s | | | short words | T | - | | | | | | Notes: |
| S ⁰ "What are they?" F:3 E Notes: Notes: Labeling (G2&4) Computer Y <td>Receptive Categories (na)</td> <td></td> <td>animals (w/ obvious</td> <td></td> <td>9/2</td> <td>6/</td> <td>H</td> <td></td> <td></td> <td></td> <td>Notes:</td> | Receptive Categories (na) | | animals (w/ obvious | | 9/2 | 6/ | H | | | | Notes: |
| Labering (GSC47) S ⁰ "What is it?"computer $1/2 - 2/4 - 4$ | ^D "What are they?" | F: 3 | E | | | | | | | | Notes: |
| S ^D "Give me [word]" F:4 Interview of the state | abeling (G2&4) ⁰ "What is it?" | | computer | 12 | ¥/= | 17 | 1/2 | 1/2 | 14 | H | Notes: |
| S^0 "What is it?"F:3w/ Sd)EIINotes:Vocabulary - Pictures (C15, G4) S ⁰ "Give me the" R I amp (w/out 1->2)RIIINotes:S ⁰ "What is it?"F:3F:3EIIINotes:S ⁰ "What is it?"F:3F:3EIINotes:S ⁰ "What is it?"F:3F:3EIINotes:S ⁰ "What is it?"F:4PoFIIIS ⁰ "What is it?"Small to big (Trucks w/ Po)IIIINotes:Seriation (B19) | dentifying Written Words (I) "Give me [word]" | F:4 | Aidan (cursive, w/o/Po) | Ĩ | T | H | | | | | Notes: |
| S ⁰ "What is it?" F:3 E I I Notes: Vocabulary - Pictures (C15, G4) R I I I I Notes: S ⁰ "What is it?" F:3 R I I I Notes: Notes: S ⁰ "What is it?" F:3 E I I I Notes: Notes: S ⁰ "What is it?" F:3 E I I Notes: Notes: S ⁰ "Touch your [body part]" neck (w/out pic) R I I I Notes: S ⁰ "What is it?" Small to big (Trucks w/ Po) I I I Notes: Math Sets (R8) 1 (w/object sets on I I I I I I I I I Notes: | /ocabulary - Objects (C15, G4) ^p "Give me the" | | school bus (Show pic | H | 11 | 11 | | | | | Notes: |
| S ⁰ "Give me the" Iamp (w/out 1->2) Imp (w/out 1->2) S ⁰ "What is it?" F:3 E Notes: Body Parts (C17) R Imp (w/out pic) R Imp (w/out pic) Notes: S ⁰ "What is it?" Small to big (Trucks w/ Po) Imp (w/out pic) Imp (w/out pic) </td <td>^D"What is it?"</td> <td>F:3</td> <td></td> <td>F</td> <td>F</td> <td>T</td> <td></td> <td></td> <td></td> <td></td> <td>Notes:</td> | ^D "What is it?" | F:3 | | F | F | T | | | | | Notes: |
| S ³ "What is it?" F:3 Body Parts (C17) neck (w/out pic) S ⁰ "Touch your [body part]" neck (w/out pic) S ⁰ "What is it?" E Seriation (B19) Small to big (Trucks w/ Po) S ⁰ "do" F:4 Notes: I Math Sets (R8) 1 (w/object sets on I) | /ocabulary - Pictures (C15, G4) ^D "Give me the" |) | A state of the state of the state of the state of the state | H | 1/2 | I | I | | | | Notes: |
| S ^D "Touch your [body part]" neck (w/out pic) Image: Constraint of the second | P "What is it?" | F: 3 | E | | | | | | | | Notes: |
| Seriation (B19) Small to big (Trucks w/ Po) I I Notes: Math Sets (R8) 1 (w/object sets on 1 (w/object sets on I I I | Body Parts (C17) ^D "Touch your [body part]" | | Printing and the second state of the second states | 7/r | T | 5/2 | I | | Ŧ | | Notes: |
| S ^D "do" F:4 PO PO Math Sets (R8) 1 (w/object sets on PO PO | ^p "What is it?" | | | | | | FF | T | F | | Notes; |
| Math Sets (R8) 1 (w/object sets on | Seriation (B19) | F:4 | | I | I | T | | | | | Notes: |
| S ^b "Put with same" F:1 table) | Math Sets (R8) | F: 1 | 1 (w/object sets on table) | saya" | T | I | T | | | | Notes: |

B.3 Abaris for Homes Redesigned Data Sheet

DAILY DATA SHEET - Project DATA

Child: Adam

| Date: | 6- | 08 | - | 07 | |
|-------|----|----|---|----|--|
| | | | | | |

| Program <u>M</u> Controlling P | rompt | |
|-----------------------------------|---------------------|-----|
| Stimulus | Child's Response | EC |
| blocks | + | |
| | <u> +</u> | |
| | P+ | 1 |
| | + | 1./ |
| Shapes | + | |
| ur or | + | |
| | P+ | |
| | | |
| | | |

Program Eye

| Stimulus | Child's Response | EC |
|----------|---------------------|----|
| 1 | - | V |
| | P- | |
| | p+ | |
| | + | |
| 2 | + | |
| | + | |
| 3 | - | V |
| | - | |

| Program | |
|-----------------------|---------|
| Controlling Pr | rompt |
| Stimulus | Child's |
| | D |

| Controlling P Stimulus | Child's Response | EC |
|---------------------------|---------------------|----|
| Billy | + | |
| , | + | |
| | + | |
| Sam | + | |
| | + | |
| | + | |
| | | |
| | | |
| | | |
| | | |

contact

| Stimulus | Child's Response | EC |
|----------|---------------------|----|
| | | |
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Data Key: $\mathbf{P} = \text{prompt}$

 $\mathbf{G} = \text{gesture}$

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| |
| |

Program_

EC

Response

| Controlling P | | |
|---------------|---------------------|----|
| Stimulus | Child's Response | EC |
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Program_

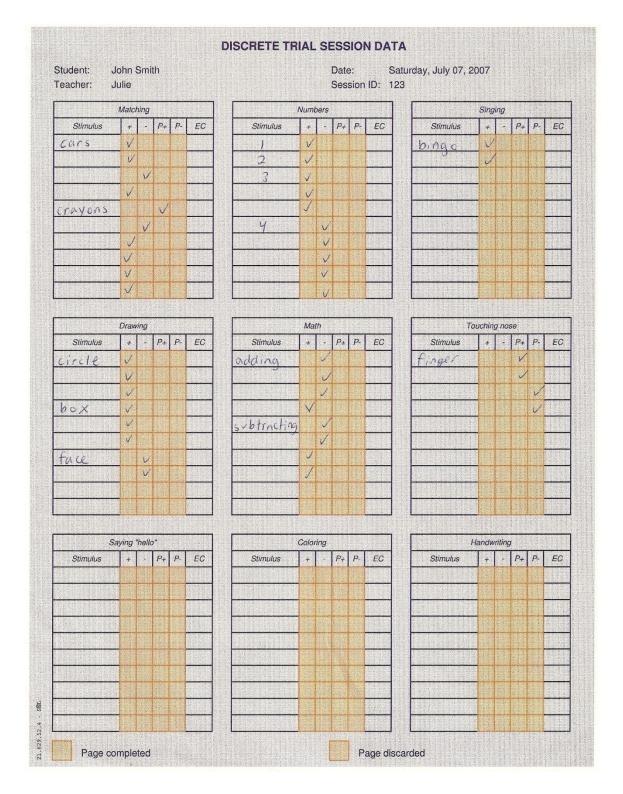
| Controlling P | rompt | 2 |
|----------------------|---------------------|----|
| Stimulus | Child's Response | EC |
| | | |
| | | |
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+ = independent correct -- = incorrect

Program

| Controlling Prompt | | |
|--------------------|---------------------|----|
| Stimulus | Child's Response | EC |
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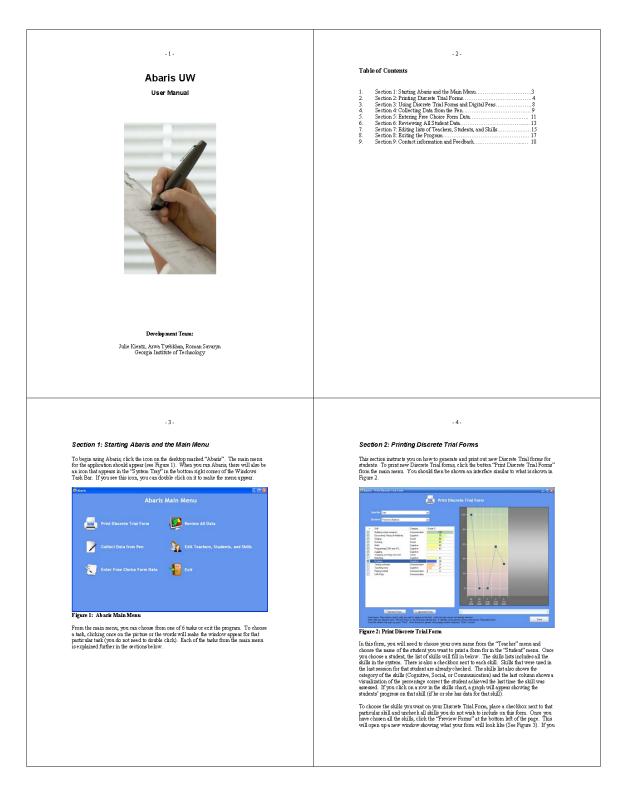
B.5 Abaris for Schools Redesigned Data Sheet

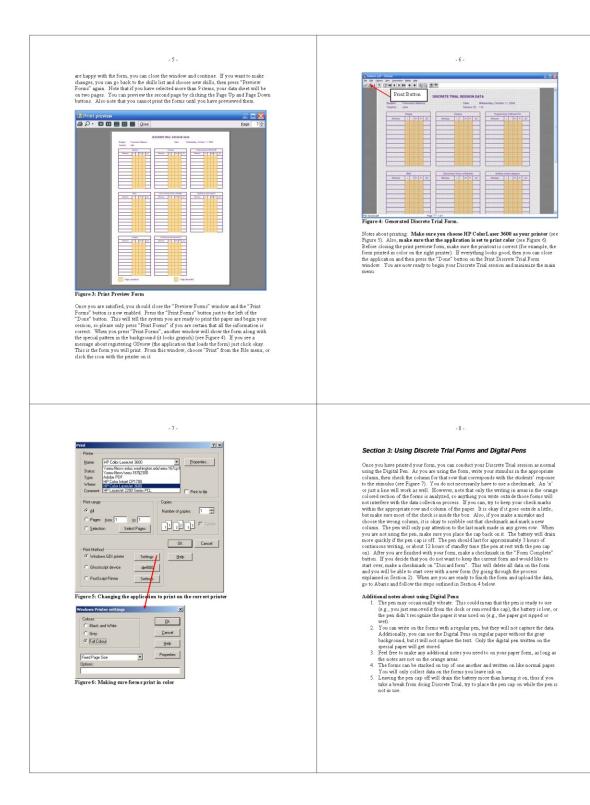


APPENDIX C: USER MANUALS

C.1 Abaris for Schools

In this appendix section is the User Manual for the Abaris for Schools application that I wrote for the teachers working in the Experimental Education system. The manual provided information on how to print relevant data sheets for their students, use the digital pen and paper to capture their therapy sessions, how to review data using the interface, and how to maintain users and student skills in the system.



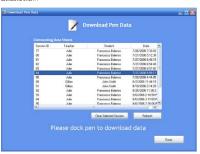


Section 4: Collecting Data from the Pen

To download data from the pen, go to the computer from which you printed your form before you started. This is very important, because if you dock you pen at another computer, it will automatically download the data, and you will have to recreate your session by going all the checkmarks on the same page with your pen.

- 9.

Before downloading, make sure Abaris is running, and click on "Download Data from Pan". This will make a window appear that shows all sessions that are waiting for pendata (see Figure 7). "You can click the box that says "enached" to sort the laby by teacher name and find any of your own sessions that are waiting for data. Then, dock the pen as described below.



To dock the pen, remove the cap and place it in the cradle with the gold metal lines pointed down. To ensure that it is properly docked, check for the lights on the top of the pen to turn on (they should be green or red depending on how charged the pen battery is). Wait a couple of seconds, and you should see a popular parts in the bottom right corner. You will then see another popup appear that ays, "download complete". After this appears, click the button marked "Refresh" to make sure your session has disappeared from the list.

- 11 -

Section 5: Entering Free Choice Form Data

Councily, Johnson S. Lincking, response to the Council Advance of Pree Choice data using the digital press. However, we do provide a way for entering Pree Choice data so that they can be graphed and congrate of Datarete Thial data. In cater Distrets Find data, click. "Eather Free Choice Form Data" from the mean. This will make a form appear for entering data (see Figure 8).



Free choice data needs to be entered individually for each student. To start entering data, choose the teacher name (if there were multiple teachers, you can just choose your own name) and the student you want to easier the data for. Then, choose the data from the pult down mean nambe d'Session date". This will bring up a httle calendar to select the data from (see Figure 9).

- 10 -

If you accidentally created sessions that you don't actually want to collect data from (for example, you clicked "Pinth Forms" and dicht" actually pint a form because you needed to make changes), then you can delute the sessions and publiching that dist ession and clicking "Clear selected ession". This will permanently delete this session, so be very sure you choose the right session to force delting". There will be a confirmation window that pope up before delting data to confirm that you actually want to delete.

Once your sessions disappear from the list you should be all done and can click the "Done" button or press the X to close the window. If you want to wright the grades, you can go back to the Main Menu and choose "Review all data" described in Section 6 below.

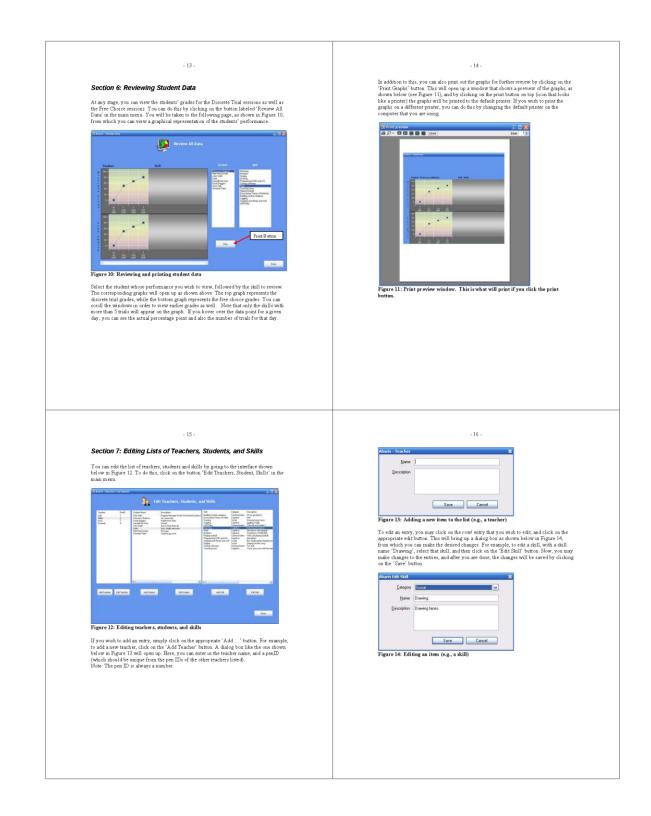
- 12 -



Figure 9: Choosing a date for a Free Choice session.

F gure >: Canosing a state for a free Canoce session. After choosing the teacher, the student, and the date, you are ready to enter the skills for each student. All the skills in the system are shown in the table. When you are ready to enter the skills, highlight the row you with to enter the grades for and then you can enter all of the grades. Choose the grade from the buttons of (from +, p, P, 2) then clock "Add Grade". This will add it itsent to the skill. You can add as many grades as you want for each skill in grades for that row, and you can not determine the skills for a star will clear all the grades for that row, and you can re-stret them. After you are satisfied with that tabling grades for that row, and you can re-stret them. After you are satisfied with that tabling reades, you can highligh it another row by clicking on 11 and add the grades for that tabli. Once you have entered all the grades glace a clackmark next to all the skills for that teasion and click. To show if you show to say "Yes" when the confirmation dalog asks if you are ready to submit.

Known bug: If you change grades, it will clear all of the checkmarks again. Thus, make sume making clicking the checkmarks next to the grades is the last thing you do before submitting the grades.

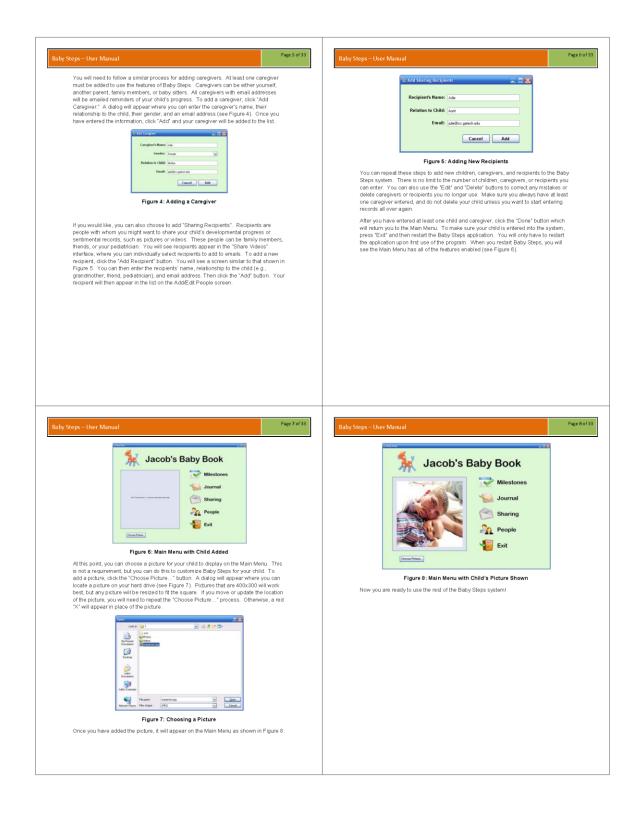


| - 17 - | - 18 - |
|--|---|
| Section 8: Exiting the Program | Section 9: Contact Information and Feedback |
| To enit the program, go to the main menu (if if 's not open, double cluck the Abaris icon in the bottom right comer of the Windows task bar, near the clock) and click the Exit button, or just close the main menu. The icon will disappear from the bottom right corner after Abaris exits. | If you have problems or questions about using the software, you can contact Julie Kientz at <u>ulieRige patch edg</u> or 404-383-0257 or via ACL instant messanger (login: uliekienst). We will do our best to try to help you as quickly and efficiently as we can. EXEAUX a problems Sometimes the data does not go to the application and you will get a message. To fix this problem, try restraining Abari, try do ching the pen again, then try rebooting the computer. Putting you pen in the dock will immediately download the data. Thus, please make sure that you are at the computer at which you printed the form. If you accidentally download the data to the wrong computer, you change at tuden's grader of advance's grader. There is no currently a way to change a tudewil' grader with about. However, we can make changes if you need us to. Please let us know if you need us to change at tudewil' grade. |
| | If you have inggets on it of now we can inprove the intervance, we have an alcomposition from set up for you to leave whatever commenti you with. Too may access this form here, <i>here, here, e.e., aatech, edu/withm 132</i> . You may also enter this form by dicking on the "Adon's UW Feedback Form" on the desktop of a computer that has Adon's installed. |

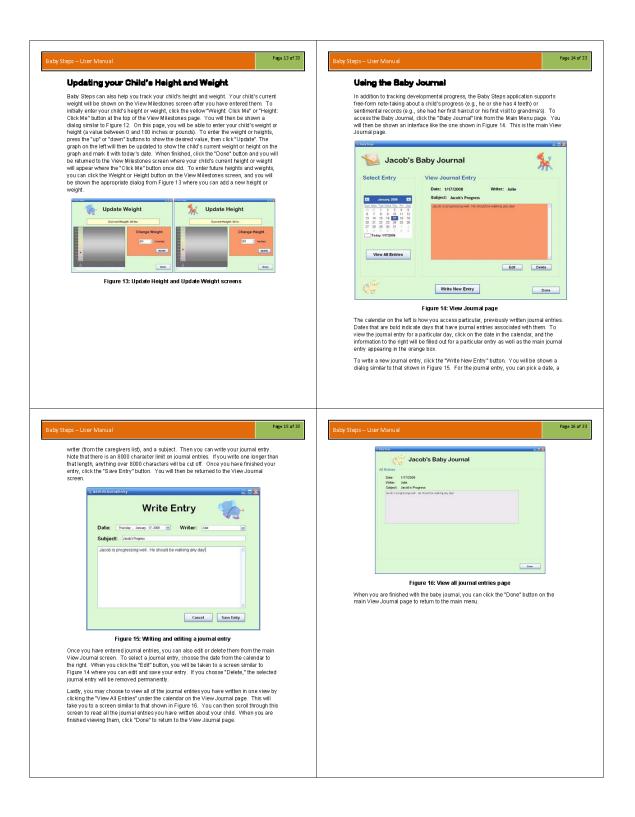
C.2 Baby Steps

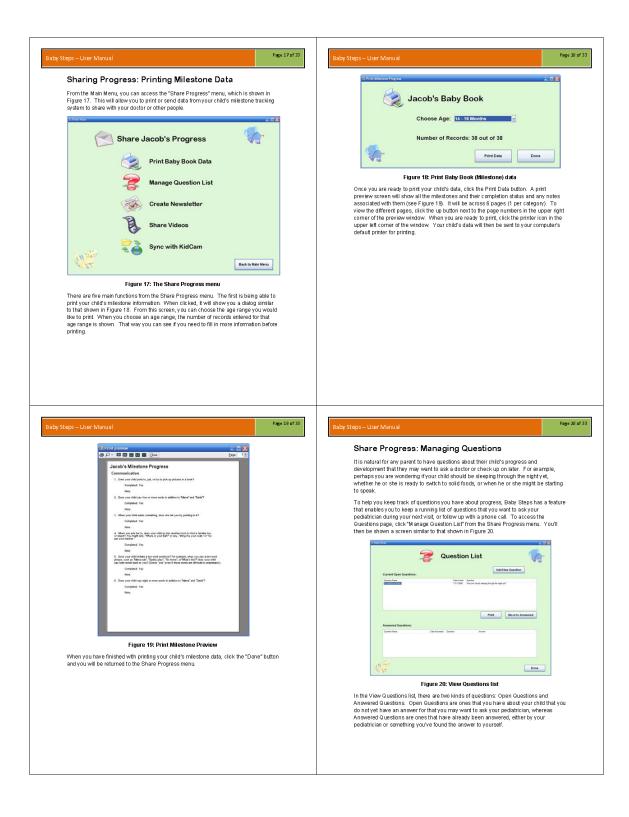
This appendix section contains is the User Manual for Baby Steps that I wrote and provided for parents in the Experimental group for the Baby Steps and KidCam study. The purpose of the document was to give comprehensive instructions to each family on how to use the system and what all the various features were. There was a shortened version of this document provided to parents in the Control group that contained information about only the features included in that version of the software.

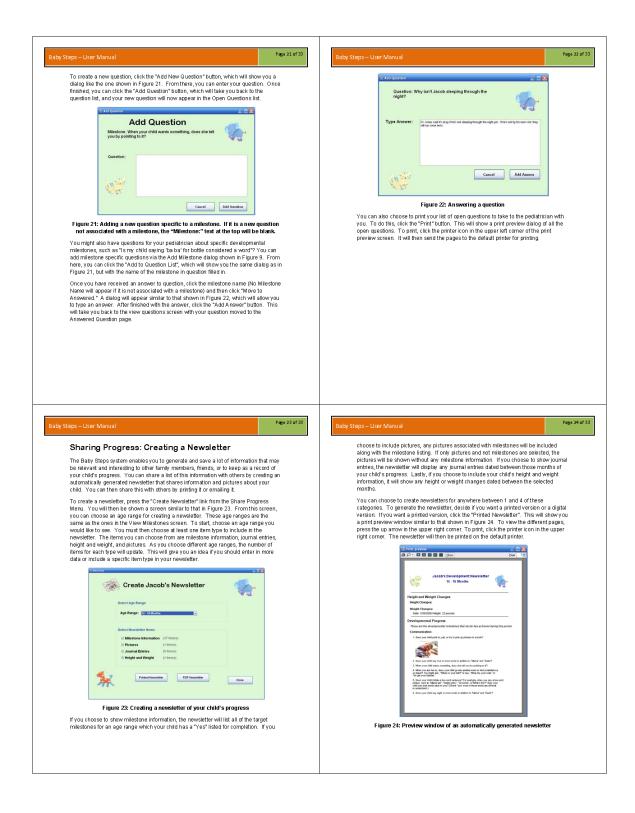
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| User Manual for Parents | Baby Steps – User Manual Page 4 of 33 |
| Getting Started – The Main Menu and Adding People The Baby Steps program is launched by double clicking the giraffe icon on your double clicking the giraffe icon on your strategies the Main Menu screen (See Figure 1). This Main Menu will be your first stop whenever you use the Baby Steps system. | Add and Edit PeopleDistrictSharing RecipientsImage: Start and Sta |
| Figure 1: Main Menu with no child added Figure 1: Main Menu with no child added When you first start the system, you will need to add your child to the system. To do that, click on the "People" button. This will take you to a screen where you can add your child or children and yourselves as caregivers (See Figure 2). | enter your child's first name, his or her gender, and his or her date of birth (See Figure 3). Once you add the information, you can click 'Add' and it will then appear in the list of children. |



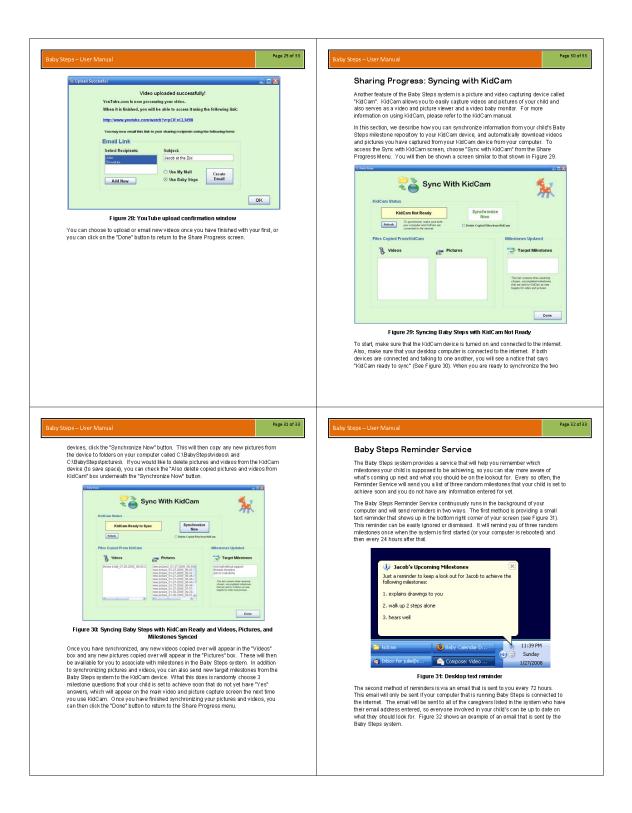


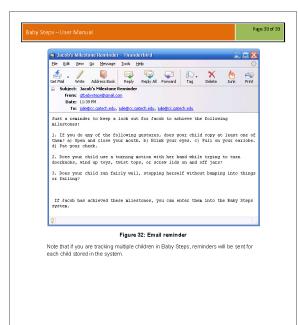






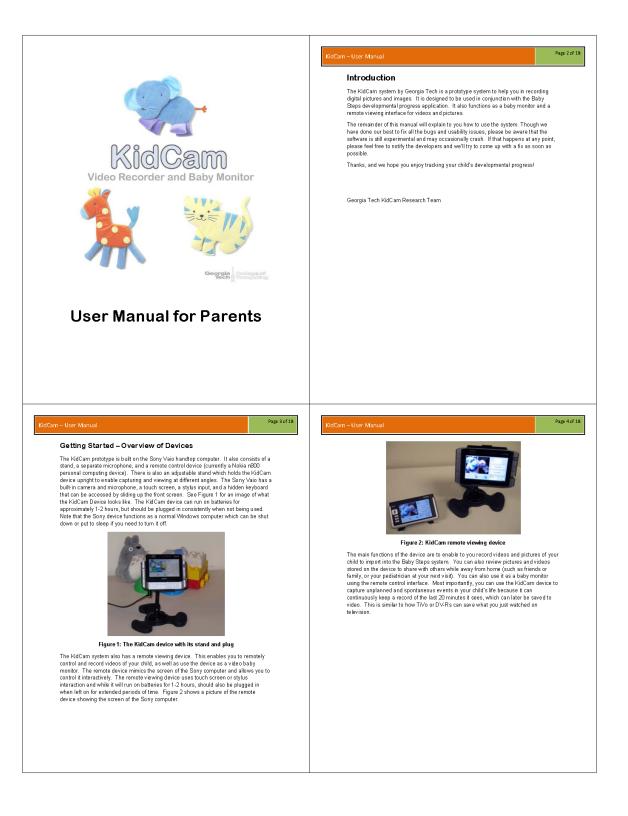






C.3 KidCam

In this appendix section is the User Manual for the KidCam recording device I provided to the Experimental group for the Baby Steps and KidCam study. This document provided information for parents on how to record and review pictures and videos, how to use the device as a baby monitor, and how to transfer videos and pictures back to the Baby Steps system. This document was only provided to the Experimental group. There was no equivalent for the Control group.



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The Main Menu

Most interaction will be done using the Sony KidCam device using an application built on the computer. To start the KidCam application, click the giraffeicon on your desktor. This will alunch the Main Meru screen or the KidCam applicatern. Additionally, the KidCam application will start up if the computer restarts. Figure 3 shows a view of the the KidCam Main Menu screen. From there, you have the option to record new videos, take pictures, review videos, or neview pictures.



Figure 3: KidCam Main Menu

To exit the application, click the Exit button. You will be asked to confirm exit, as the KidCarn application is designed to run continuously on the device. However, if you shut off the Sory device, you should exit and restart the application upon waking up. Fage 6 of 30

Recording and Saving Videos

To start the continuous recording of video, press the "Record Videos" button. This starts the video capture device. Note that it will take approximately 5 seconds for recording to start once the button is pressed. KdiCarn will then continuously save video for 20 minutes at time, then automatically deter videos older than 20 minutes. Thus, you can save videos of anything that happened on the kldCarn device in the last 20 minutes. While recording, you will see a screen similar to that shown in Figure 4. While video is recording, you will see a preview screen of what the camera sees in the upper left correr. This shale's you to positon the camera in such a way that it will record the field or view that you're interested observing. You can use the adjustable device stand to opsition the camera.



Figure 4: The Record Videos screen

The Sony device has cameras on both the front and back of the device. To record using the camera on the back of the device, the screen will need to be raised so the keyboard is showing. If recording from the front of the device, the keyboard can be hidden. To switch which camera view is recording, a small Sony window will appear that will allow you to choose the front or the back view. This window can be dismissed once the view is chosen.



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On the Record Video screen, you will see in the upper right corner a list of 3 milestone targets. These will appear once you have sprichtomoted the KidCard Mexice with the Baby Elsep system for the first time. See the Baby Steps price and for guidance on how to synchronize kidCarwith the Baby Steps application. The milestones shown will be 3 randomy chosen milestones that your child should be activering soon. You can use these as a guide for things you might want to record videos or pictures of. If you want to save a video of it, click on the desired milestone.

When you are ready to save a video, click the "Save Video" button. You will then be shown a screen similar to that shown in Figure 5. If you've selected a milestone from the list, the recording name shown in the Recording Name field will automatically be filled in for you. Otherwise, you can use the keyboard to type whatever name you want, or leave it its "more recording". Note that the current date, time, and video length will automatically be saved into the video file name.



Figure 5: The Save Video interface

Next, you should use the orange and gray scroll bar to adjust the start point and stop point of the video. If the video recorder has been running for more than 20 minutes, you will be able to save a video up to 20 minutes ago. You can also save a video up to 10 minutes in the future. Thus, the maximum size of a video is 30 minutes long. There is a black line marked 'now' which indicates the point where you pressed the 'Save Video' buton. To adjust the start and end points of the video to be save you can touch and drag the two ends of the gray square along the orange bar. As you adjust the ends, the n – User Ma

video preview screen will show what the video looks like at a particular moment. There is also a label called Video Length that will update to tell you how long of a video you are saving. When you have set the start and end points to where you want them, you can then click the "Save" button, which will save a copy of the video you specified and preum you to the Record Videos screen. You can also decide to not save anything and press the "Cancel" button to return to the Record Videos screen. After you save videos, they will be available for viewing in the Review Videos screen accessible from the Main Menu.

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Note that if you saved a video which records into the future, when you return to the Record Videos screen, a red dot will appear to let you know that the current content is being saved. See Figure 6 for an example of what this looks like. This red dot will disappear after the video has stopped saving.

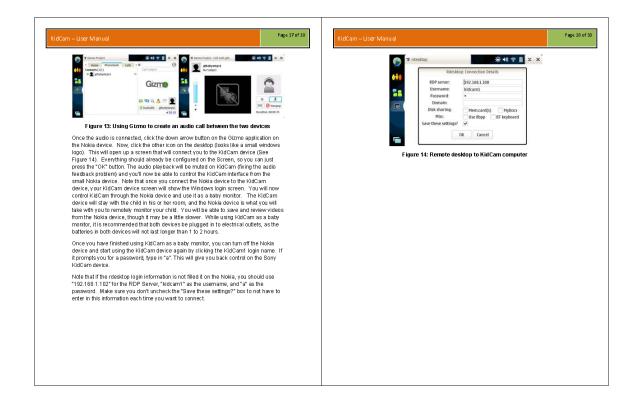


Figure & Record Video screen with red dot indicating that current video is being saved

Lastly, you will also note that there is a "Clear Buffer" button. This video can be used to delete everything sared in the last 20 minutes. You might use this if something happened that you definitely do not want recorded or don't want anyone else to record. This is main for privacy purposes, but also note that anything older than 20 minutes that is not explicitly saved will be deleted regardless.







APPENDIX D: ABARIS FOR HOMES STUDY MATERIALS

D.1 Interview Guides

Interview Guide for Regular Therapist

- 1. What were things you liked about Abaris?
- 2. What were things you didn't like about Abaris?
- 3. Can you suggest any more features you would like to see in Abaris?
- 4. Can you think of features of Abaris that are unnecessary?
- 5. How do you feel Abaris affected the way you conducted therapy sessions?
- 6. How do you feel Abaris affected the way team meetings were conducted?
- 7. How do you feel about watching videos of yourself doing therapy while by yourself?
- 8. How did you feel about watching videos in front of others at the meeting?
- 9. Did seeing videos of yourself change your impressions on how you were doing therapy?
- 10. How did you feel about others watching videos of your therapy sessions if you were not in attendance at the meetings?
- 11. Can you compare what it's like to use Abaris with some therapy sessions and not use it with others?
- 12. Predict what it will be like to go back to the paper based system for [child's name].
- 13. Can you see yourself using this with any of your other clients?
- 14. Can you make any guesses on whether the use of Abaris improved or hindered the therapy practice? (*i.e.*, microphone was distracting, more time spent with [child's name])
- 15. Is there anything else about the system that you want to say or ask about that we didn't already cover?

Interview Guide for Team Member not at Meetings

- 1. What were things you liked about Abaris?
- 2. What were things you didn't like about Abaris?
- 3. Can you suggest any more features you would like to see in Abaris?
- 4. Can you think of features of Abaris that are unnecessary?
- 5. How do you feel Abaris affected the way you conducted therapy sessions?
- 6. How did you feel about others watching videos of your therapy sessions if you were not in attendance at the meetings?
- 7. Predict what it will be like to go back to the paper based system for [child's name].

- 8. Can you make any guesses on whether the use of Abaris improved or hindered the therapy practice? (*i.e.*, microphone was distracting, more time spent with [child's name])
- 9. Is there anything else about the system that you want to say or ask about that we didn't already cover?

Interview Guide for Behavioral Consultant

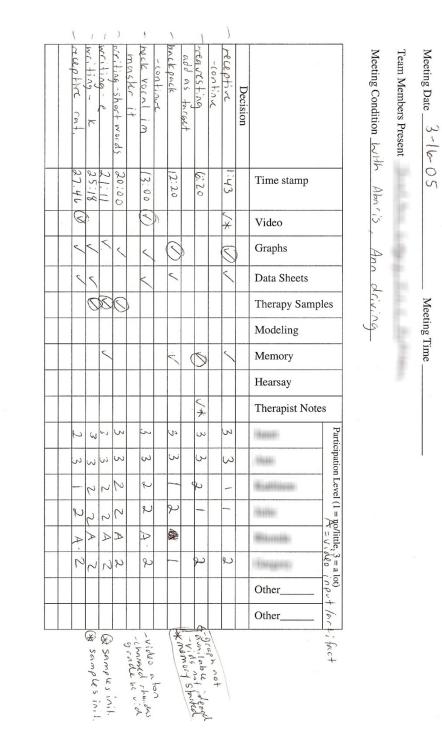
- 1. What were things you liked about Abaris?
- 2. What were things you didn't like about Abaris?
- 3. Can you suggest any more features you would like to see in Abaris?
- 4. Can you think of features of Abaris that are unnecessary?
- 5. How did Abaris affect your preparation for team meetings?
- 6. How do you feel Abaris affected the way team meetings were conducted?
- 7. How did you use the videos during meetings?
- 8. How did you feel about watching videos of others in front of them at the meeting?
- 9. Do you feel that using Abaris affected your control/dominance in meetings?
- 10. How did having everyone being able to see the data affect how meetings progressed?
- 11. Predict what it will be like to go back to the paper based system for [child's name].
- 12. How did our enthusiasm affect the use of the system? Would it have been different if we weren't a member of the team?
- 13. Can you see yourself using this with any of your other clients?
- 14. Would you like to use this with any of your other clients?
- 15. Can you make any guesses on whether the use of Abaris improved or hindered the therapy practice?
- 16. Can you see yourself using Abaris to train new therapists?
- 17. Is there anything else about the system that you want to say or ask about that we didn't already cover?

Interview Guide for Lead Therapist

- 1. What were things you liked about Abaris?
- 2. What were things you didn't like about Abaris?
- 3. Can you suggest any more features you would like to see in Abaris?
- 4. Can you think of features of Abaris that are unnecessary?
- 5. How do you feel Abaris affected the way you conducted therapy sessions?
- 6. How much did you use the Abaris session viewer outside of the meetings?
- 7. How much did you use Abaris while at your house?
- 8. How did you use the videos of therapy sessions outside of meetings?
- 9. How did Abaris affect your preparation for team meetings?
- 10. How do you feel Abaris affected the way team meetings were conducted?
- 11. How did you use the videos during meetings?

- 12. How do you feel about watching videos of yourself doing therapy while by yourself?
- 13. How did you feel about watching videos in front of others at the meeting?
- 14. Did seeing videos of yourself change your impressions on how you were doing therapy?
- 15. Predict what it will be like to go back to the paper based system for [child's name].
- 16. How did our enthusiasm affect the use of the system? Would it have been different if we weren't a member of the team?
- 17. Can you see yourself using this with any of your other clients?
- 18. Would you like to use this with any of your other clients?
- 19. Can you make any guesses on whether the use of Abaris improved or hindered the therapy practice?
- 20. Can you see yourself using Abaris to train new therapists?
- 21. Before using Abaris, you would observe therapists doing their therapy and provide feedback. How did using Abaris change this practice?
- 22. When we first started using the system, you expressed that you were worried about whether you would be losing control over [child's name]'s therapy. Did this end up being a problem in the end?
- 23. Is there anything else about the system that you want to say or ask about that we didn't already cover?

D.2 Sample Video Coding Sheet



* used before meeting

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APPENDIX E: ABARIS FOR SCHOOLS STUDY MATERIALS

E.1 Post-Study Interview Guide

Interview Guide for Teachers – Abaris for Schools

- 1. What did you like about using Abaris? What was difficult about using Abaris?
- 2. When you used Abaris, did it require any changes in your typical teaching routine?
- 3. How often did you review graphs of your students' data outside of regular meetings with Shane?
- 4. How did having the graphs shown on the screen where you printed the data forms influence the frequency of looking at them?
- 5. How often did you look at graphs of discrete trial data using the "Review Data" interface?
- 6. How often did you look at graphs of free choice data using the "Review Data" interface?
- 7. How did the availability of the graphs change the frequency in making decisions about a student's skill program?
- 8. How did the availability of the graphs change your confidence level in the decisions being made about the student's skill program?
- 9. Did you ever discuss a student's data with another person? How frequently did this occur? Did it occur in formal or informal settings?
- 10. How did the availability of graphs affect the collaboration with other teachers?
- 11. How did you feel about the possibility of having continuous video taken in the classroom?
- 12. What changes or additions to Abaris would you recommend?
- 13. Do you have any comments in addition to what you've told us so far?

APPENDIX F: BABY STEPS AND KIDCAM STUDY MATERIALS

F.1 Screener Survey

Primary Contact Information

| Name | | |
|--|-------------------|------------------------------|
| Address | | |
| City | _State | _ Zip |
| Phone | Email | |
| Best Time of Day to Phone | | |
| Preferred Method of Contact | | |
| Date of Next Well Baby Appointr | nent | |
| Which month visit (e.g., 9 monthead of the second s | hs, 12 months, 15 | months) is this appointment? |
| | | |

Who is your primary pediatrician at Johns Creek? _____

Family Information

1. List all family members in your household, along with their gender and ages:

| Name | Gender | Date of Birth |
|------|--------|---------------|
| 1 | | |
| 2 | | |
| 3 | | |
| 4 | | |
| 5 | | |
| 6 | | |

2. Do you have anyone outside the family who cares for your child? (*e.g.*, nanny, daycare, family member, baby sitter) If so, please describe:

3. Does your child have any known medical conditions, developmental delays, or is at risk for these conditions? If so, please describe: _____

Demographic Information

| 1. What is you | ır marital st | atus? (circle o | one) | | |
|-----------------|---------------|-----------------|-------------------|----------------|-----------------------|
| Married I | _iving Toget | her Single | e | Divorced | Separated |
| Y | Widowed | Civil Union | Other | | |
| 2. What is you | ır total year | ly household | income | ? (circle one) |) |
| \$0-\$25,000 | \$25,001-\$ | 50,000 \$50 |),001-\$ 1 | 100,000 | |
| \$100,00 | 01-\$150,000 | \$150,001 | or over | - | |
| 3. What is the | first paren | t's highest ed | lucation | level compl | eted? (circle one) |
| High School | Assoc | iate's Degree | <u>,</u> | Special Trai | ning |
| Bachelor's De | gree | Master's De | gree | | |
| Ph.D. | Othei | | | | |
| 4. First parent | t's occupati | on | | | |
| 5. Number of | hours first p | oarent works | outside | the home pe | er week |
| 6. What is the | second par | ent's highest | educat | ion level con | npleted? (circle one) |
| High School | Assoc | iate's Degree | <u>)</u> | Special Trai | ning |
| Bachelor's De | gree | Master's De | gree | | |
| Ph.D. | Other | - | | | |

7. Second parent's occupation _____

8. Number of hours second parent works outside the home per week _____

Household Computer Information

1. How many computers do you have in your home?

2. What type of computer(s) do you have? (*e.g.*, Windows or Mac, Desktop or Laptop, *etc.*)

3. What do you use your computer for? _____

4. What type of internet connection do you have at home? (circle one)

No internet Dial-up DSL (*e.g.*, AT&T, Bellsouth)

Cable Modem (e.g., Comcast) Other _____

5. Do you have wireless internet? (circle one) Yes NoNot Sure

6. Check off each of the following you own:

| Digital Camera | (List make and model) |
|----------------|------------------------|
| Camcorder | (List make and model) |
| Web Camera | (List make and model) |
| Baby Monitor | (Audio only? Video?) |

| Other recording device | (|) |
|------------------------|---|---|
| Other recording device | (|) |

Household Computer Information Continued

- 7. How proficient is the first parent with computers? (check one)
- _____ No experience (never used a computer or very little exposure)
- _____ Beginner (can do basics such as writing documents)
- _____ Intermediate (uses internet, email, plays games, digital pictures)
- _____ Expert (can program or fix problems with computers)
- 8. How proficient is the second parent with computers? (check one)
- _____ No experience (never used a computer or very little exposure)
- _____ Beginner (can do basics such as writing documents)
- _____ Intermediate (uses internet, email, plays games, digital pictures)
- _____ Expert (can program or fix problems with computers)

F.2 Interview Guides

Pre-Study Interview Guide – Parents

- 1. Tell me a bit about your child. How old is he/she? What kinds of things can he/she currently do?
- 2. Were there any complications with the birth or any concerns about his/her health? Has he/she ever been sick?
- 3. How often does your child see a pediatrician? For checkups? For other reasons? What are other reasons your child sees the pediatrician?
- 4. How would you assess your relationship with your pediatrician? Do you understand the things he/she tells you? Do you wish he/she spent more time with your child? Are you satisfied with the level of care your child receives?
- 5. Do you feel that your child is developing normally? How do you make this assessment? How confident are you in your knowledge of your child's development?
- 6. What records do you currently keep on your child? How do you go about recording them? How often do you review them? What would you change about this process?
- 7. Do you have any concerns about your child's development? What hopes or fears do you have about how your child will develop?
- 8. How often do you use a computer in your family? What kinds of things do you use it for? Do you use it for anything related to your child? If so, what?
- 9. Does anyone outside the household every watch your child? If so, who? How often?

Mid-Study Interview Guide – Parents

- 1. How are things going with using the software? What kinds of things have you done with it so far?
- 2. What problems have you had with using the software?
- 3. What do you like about using it? What do you dislike about it?
- 4. What features do you think would be good to add to the system?
- 5. What changes would you make about the system's design?
- 6. Who used the software to enter milestones? How often did you use it? Did anyone outside your household (*e.g.*, a baby sitter) ever use it?
- 7. Did you contact your pediatrician's office for anything in the past month?
- 8. Walk me through the software and point out anything else that you might want to share about the system.

Post-Study Interview Guide – Parents

- 1. What milestones did your child achieve in the last 3 months?
- 2. How do you know which milestones your child received? Did you record them somewhere?

- 3. How often did you record your child's milestones over the last 3 months? Did using the computer to do it change anything?
- 4. What did you like about using the computer to record milestones?
- 5. What did you dislike about using the computer to record milestones?
- 6. Can you think of other features that the computer program should have?
- 7. How often did you record videos of your child's progress? What did you use to record them?
- 8. Do you feel more aware of your child's milestones after using the computer to record them? Do you feel more confident in your knowledge of your child's progress? If so, did you have any concerns about this? Any feelings of accomplishment or anxiety?
- 9. How often did you communicate with your pediatrician? Did you ever use the computer to communicate information with him or her? Did anything you did on the computer prompt you to contact him or her? Did you ever refer to anything you noticed on the computer during your well baby visit?
- 10. What was your general process in preparing for your well child visit with your doctor? Did this change after using the software?
- 11. Do you think you would continue using the program now that the study is complete? If not, what are the reasons why? Is there anything that could be improved to make you want to use it more?

Pre-Study Interview Guide – Doctors

- 1. Can you describe your job for me? What kinds of things do you do on a day-today basis?
- 2. How often do you see a given child?
- 3. How often do Well Baby visits last in general? What is the general process for them?
- 4. How long is a parent typically in your office?
- 5. What are some common questions parents of children less than 2 tend to ask?
- 6. What records do you keep on individual children? Do you ever ask parents to record information for you? If so, what do you ask them to record?
- 7. How do parents contact the office if they have questions? Do you ever speak to them over the phone?
- 8. How many clients do you serve? How much do you remember about each patient you see?
- 9. How do you handle diagnosis of developmental delays?
- 10. What is the biggest problem you face in detecting delays or disorders?

Post-Study Focus Group Guide – Doctors

- 1. What suggestions do you have for technology that might be able to aid in tracking the developmental progress of children?
- 2. Did you notice anything out of the ordinary for the patients you saw who used the system to record their milestones?

- 3. What types of questions did the parents in the study ask during their visit?
- 4. Did you have any developmental concerns on any child who was involved in the study? How did those concerns come about?
- 5. Did you find that parents had more knowledge of developmental milestones? If so, did this have any impact on the parent/pediatrician relationship?
- 6. How do you think that parents being more knowledgeable about their child's developmental progress might impact the dynamic between parents and pediatricians during the Well Child Visits?
- 7. Can you comment on how parental reporting of and knowledge about a child's developmental progress might impact confidence in making decisions about developmental delays?
- 8. What suggestions do you have for improvement for our software?
- 9. What are the next directions you think this work can go? Do you have any suggestions for how we might make this more widely available?
- 10. Is there anything else about the study that you would like to say?

F.3 Parent-Completed Pediatrician Survey

| # | Question | Strongly Agree | Agree | Unsure | Disagree | Strongly Disagree | Does Not Apply |
|-----|--|-------------------|-------|--------|----------|----------------------|-------------------|
| 1. | The doctor went straight to the nature of the visit without first greeting me or the baby. | 1 | 2 | 3 | 4 | 5 | |
| 2. | The doctor greeted the baby and me pleasantly. | 5 | 4 | 3 | 2 | 1 | |
| 3. | The doctor tried to build a rapport with the baby before examining her. | 5 | 4 | 3 | 2 | 1 | |
| 4. | The doctor seemed to pay attention as I described what was happening with my baby. | 5 | 4 | 3 | 2 | 1 | |
| 5. | The doctor made me feel like I could talk about any problem related to my baby. | 5 | 4 | 3 | 2 | 1 | |
| 6. | The doctor asked questions about my baby's development that didn't seem relevant (he didn't give me a sense of what his questions were in relation to). | 1 | 2 | 3 | 4 | 5 | |
| 7. | The doctor handled the baby roughly during the examination. | 1 | 2 | 3 | 4 | 5 | |
| 8. | The doctor explained the reason why I should be on the lookout for particular milestones | 5 | 4 | 3 | 2 | 1 | |
| 9. | I felt the doctor concluded that the baby was fine without enough information. | 1 | 2 | 3 | 4 | 5 | |
| 10. | The doctor seemed to rush. | 1 | 2 | 3 | 4 | 5 | |

| # | Question | Strongly Agree | Agree | Unsure | Disagree | Strongly Disagree | Does Not Apply |
|-----|--|-------------------|-------|--------|----------|----------------------|-------------------|
| 11. | The doctor behaved in a professional and respectful manner toward me and the baby. | 5 | 4 | 3 | 2 | 1 | |
| 12. | The doctor seemed to brush off my questions about the baby. | 1 | 2 | 3 | 4 | 5 | |
| 13. | The doctor seemed to brush off my concerns. | 1 | 2 | 3 | 4 | 5 | |
| 14. | The doctor used words I didn't understand. | 1 | 2 | 3 | 4 | 5 | |
| 15. | The doctor did not give me all of the information I thought I should have been given. | 1 | 2 | 3 | 4 | 5 | |
| 16. | I would recommend this doctor to a friend. | 5 | 4 | 3 | 2 | 1 | |
| 17. | In total, I spent more time with the nurse than the doctor. | 1 | 2 | 3 | 4 | 5 | |
| 18. | Because of the Wellness Visit, I have a good sense of the milestones I should be looking out for in the next few months. | 5 | 4 | 3 | 2 | 1 | |
| 19. | The doctor gave me a good sense of how my baby is developing cognitively. | 5 | 4 | 3 | 2 | 1 | |
| 20. | The doctor gave me a good sense of how my baby is developing physically. | 5 | 4 | 3 | 2 | 1 | |
| 21. | The doctor gave me a good sense of how my baby is developing socially and emotionally. | 5 | 4 | 3 | 2 | 1 | |

| # | Question | Strongly Agree | Agree | Unsure | Disagree | Strongly Disagree | Does Not Apply |
|-----|---|-------------------|-------|--------|----------|----------------------|-------------------|
| 1. | The parent was knowledgeable about his/her baby's progress. | 5 | 4 | 3 | 2 | 1 | |
| 2. | The parent asked many good questions about his/her baby's progress. | 5 | 4 | 3 | 2 | 1 | |
| 3. | I feel confident in my assessment of the baby's progress. | 5 | 4 | 3 | 2 | 1 | |
| 4. | The parent seemed very unsure of my assessment. | 1 | 2 | 3 | 4 | 5 | |
| 5. | I believe the baby is on track developmentally. | 5 | 4 | 3 | 2 | 1 | |
| 6. | The parent could be more proactive about telling me about their child's progress. | 1 | 2 | 3 | 4 | 5 | |
| 7. | The parent keeps good records on their child's development. | 5 | 4 | 3 | 2 | 1 | |
| 8. | The parent knows a lot about how children should develop. | 5 | 4 | 3 | 2 | 1 | |
| 9. | I wish the parent kept better records for me to make my assessment. | 1 | 2 | 3 | 4 | 5 | |
| 10. | The parent was unnecessarily concerned about her child's developmental progress. | 1 | 2 | 3 | 4 | 5 | |

F.4 Pediatrician Completed Parent Survey

| # | Question | Strongly Agree | Agree | Unsure | Disagree | Strongly Disagree | Does Not Apply |
|-----|--|-------------------|-------|--------|----------|----------------------|-------------------|
| 11. | The parent and I have developed a good rapport. | 5 | 4 | 3 | 2 | 1 | |
| 12. | I believe the parent will do what I recommend. | 5 | 4 | 3 | 2 | 1 | |
| 13. | The child is developing well cognitively. | 5 | 4 | 3 | 2 | 1 | |
| 14. | The child is developing well physically. | 5 | 4 | 3 | 2 | 1 | |
| 15. | The child is developing well socially and emotionally. | 5 | 4 | 3 | 2 | 1 | |
| 16. | I believe this child is at risk for a developmental delay. | 1 | 2 | 3 | 4 | 5 | |
| 17. | The parent and I made good use of the time spent together. | 5 | 4 | 3 | 2 | 1 | |
| 18. | The parent and I communicated well. | 5 | 4 | 3 | 2 | 1 | |

F.5 Well Child Visit Observation Sheet

| Observation Sheet - Well Child Visit #1 (Pre-Study) |
|---|
| Well Child Visit Attendees: |
| Time Keeping: |
| Parent and Child Entered Room: |
| Doctor Entered Room: |
| Doctor Left Room: |
| Pre-Doctor Procedures: |
| Post-Doctor Procedures: |
| Procedures Where Parent and Doctor are Together: |
| Questions Asked: |

General Notes:

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