Designing Capture Applications to Support the Education of Children with Autism

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Abstract. We explore the social and technical design issues involved in tracking the effectiveness of educational and therapeutic interventions for children with autism (CWA). Automated capture can be applied in a variety of settings to provide a means of keeping valuable records of interventions. We present the findings from qualitative studies and the designs of capture prototypes. These experiences lead to conclusions about specific considerations for building technologies to assist in the treatment of CWA, as well as other fragile demographics. Our work also reflects back on the automated capture problem itself, informing us as computer scientists how that class of applications must be reconsidered when the analysis of data in the access phase continually influences the capture needs and when social and practical constraints conflict with data collection needs.

1 Introduction

Parents and teachers of children with autism (CWA) often use several therapeutic interventions, keeping vast records to assess improvement in behavior and learning. Automated capture technologies and the associated access interfaces for exploring past experiences are particularly promising for monitoring the effectiveness of these interventions for behavioral and learning disabilities in children. Behavioral and learning data can be captured, analyzed, and mined over time to provide valuable evidence to track the progress of any intervention. Prototypes developed for this problem must address both technical and social factors to be successful. These factors include providing for all elements of the care cycle, understanding the need for qualitative richness of collected data, minimizing the effort required to use capture technology, addressing privacy concerns, and considering financial constraints. Technically, designers must account for integration of manually and automatically captured data, appropriate distribution in the system architecture and tools for data analysis and visualization that allow for flexible adaptation of capture.

Four researchers conducted two ethnomethodological studies to uncover areas of need in the work practices of caregivers for CWA. The most often reported need

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involved the recording, storing, and analyzing of data about CWA. We developed three prototypes designed for activities involved in treating CWA and in keeping records about this treatment. Although initial feedback on these prototypes indicated they would be useful in meeting many caregiver needs, no individual prototype meets all of the constraints and characteristics uncovered in our qualitative studies. What we learned as ubiquitous computing researchers is a lesson about the design of automated capture applications. Specifically, in this domain and other related ones, there exists a reflective relationship between access and capture that requires more dynamic configuration of capture capabilities.

This work offers two major contributions. First, the problem domain of monitoring intervention therapies for CWA is important and shares features with other care giving scenarios. Automated capture and access is well suited to providing a solution to this problem. Second, the in-depth social, practical, and technical exploration of this problem sheds light on automated capture and access itself. We describe the two field studies in Section 2 and resulting prototypes in Section 3. The important considerations and recommendations discovered through this work are discussed in Section 4. We discuss related work in health care, education, and ubiquitous computing in Section 5 before concluding with a summary of contributions and future work in Section 6.

2 Methods for Studying Caregivers

Our initial task was to explore the space of data gathering and record keeping in caring for CWA. We defined *care* as all of the education and therapeutic interventions that CWA experience and *caregivers* as the individuals who administer and monitor these interventions. Our research included two separate field studies: the first of which focused on stakeholder interviews at a specialized school and research center for treating CWA, and the second expanded the scope of research to include other places and intervention techniques and included a series of interviews, field data using participant observation, and artifacts from care providers and families of CWA. Our goal in all of these qualitative studies was to determine who was involved in the care, what types of care were provided, how groups of caregivers communicated with one another, and what kind of records and assessment of progress were involved. We initially concluded that the use of capture and access applications could assist with care of CWA because of the reliance on tabulating commentary on live interactions and the difficulty of doing that accurately.

2.1 Interviews and Participant Observation

For two months, we observed the daily activities of a special school, the Walden School at the Emory Autism Center, providing services for CWA in an inclusive setting (a mixture of CWA and neurotypical children). This school is part of a research center on autism, with an emphasis on understanding the relationship between the particular intervention approach to autism and the progress of CWA. In addition to educational activities intended for all students at the school, teachers and research assistants record data on behavioral interventions designed for CWA. We interviewed representatives of various stakeholder groups associated with this school: teachers, researchers, and parents. Interviews were conducted at the school and lasted 30 to 45 minutes. The data consisted of handwritten notes of the observations and interviews.

To broaden our perspective on approaches to intervention therapies for CWA, we conducted a four-month study consisting of more interviews with families, teachers, and other caregivers for CWA. Although we interviewed one current and one former staff member from Walden, most of these new interview participants were not associated with the school. These individuals employed a variety of care techniques including occupational therapy, sensory integration, and discrete trial Applied Behavior Analysis (ABA) [1]. We used semi-structured interviews and participant observation [20] to identify current practices, needs, and privacy concerns of the stakeholder groups. The data consisted of audio and video recordings and observer notes. Participants included two individuals associated with a local school system, six professional therapists from three different consultancies, three parents of CWA, and two part-time therapists. Interviews lasted one to two hours and were conducted in a variety of locations based on the participants' preferences: our offices, the participant's home or office, or the home of a child for which the participant was caregiver. Researcher observation periods were 30 minutes to three hours at a time.

Our research team also participated in discrete trial as therapists. Certified behavior therapists trained the researchers to conduct sessions that lasted two to three hours and were designed to help a child meet goals in such areas as language and motor development. We also recorded behavioral data at those sessions and attended weekly group meetings to assess progress and plan future sessions. The researchers conducted 27 therapy sessions with CWA and attended 40 meetings and three training sessions, conservatively totaling 144 hours of participant observation.

2.2 Artifact Collection

The caregivers we studied employed a variety of techniques to capture data about children, to analyze this information, and to communicate it amongst themselves. Caregivers collected some or all of three distinct types of data:

- Duration: How long was the child engaged in activity X, where activity X can be appropriate (sitting quietly at table) or inappropriate (screaming loudly)?
- Performance: How often is the child correctly responding to request/question Y, where Y might be "Give me the apple." or "Come sit down."
- Narrative: In this case, the caregiver might simply write a few notes or several pages describing the child's behavior.

Caregivers use forms to collect much of the duration and performance data and notebooks or other informal means to collect narrative data. We examined 33 different forms and 12 different types of data graphs used by caregivers and examined 3 notebooks used by care networks to share narrative data among members of the team. We reviewed standardized tests in the special education literature used by schools for diagnosis and monitoring of progress for special needs children [16, 17, 19].

3 Prototypes

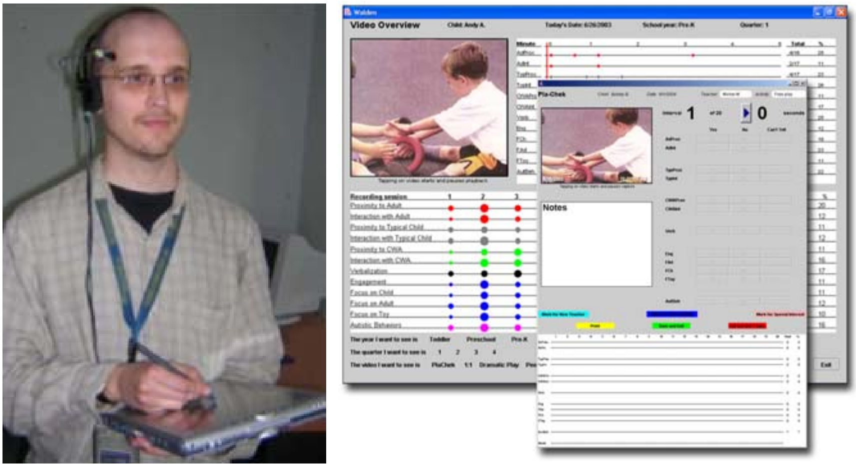
After completing the initial study at the specialized school for CWA, we developed a prototype system. Based on the subsequent studies in different locations of a variety of intervention therapies, we developed two other prototype capture and access applications. All prototypes were demonstrated to target user groups, and user comments contributed to the constraints and recommendations discussed in Section 4.

3.1 Walden Monitor: Wearable Prototype for Recording Observation Data

Walden Monitor (WM) is a combination wearable and Tablet PC based system that combines two existing paper-based data-collection instruments: the Child Behavior Observation System (CBOS) and the Pla-Chek (pronounced PLAY-check). CBOS and the Pla-Chek are used to record largely the same data in two different ways. The Pla-Chek is a paper spreadsheet used to record behavioral variables in the inclusive classrooms at the special school we studied. Each calendar quarter, research assistants enter the classroom for ten consecutive days and observe a particular CWA. The research assistant mentally counts a ten-second interval, then records positive or negative results for twelve variables such as proximity to an adult (within 3 feet) or an adult interacting with the target CWA. The research assistant repeats this process twenty times. These data are also gathered using CBOS, in which a research assistant enters the classroom with a handheld video camera and records the child for five minutes. Another researcher watches the video and codes the variables on a spreadsheet similar to Pla-Chek. The teacher tabulates the data and includes it in written reports. Parents may see the videos upon request, but they are not routinely shown.

WM was designed for use by an individual whose primary task is recording data. While we initially considered a distributed solution in which cameras mounted in the room collected video and the researcher carried a TabletPC to record observations, we quickly determined that a localized wearable solution was the most practical and effective approach. WM is based on a TabletPC with a head-mounted bullet camera (see Figure 1a). The research assistant observes the child for a ten-second interval and is then prompted by a beep in the earpiece for optimal user awareness and minimal classroom distraction to record behavioral variables by tapping buttons on the Tablet PC display. As with Pla-Chek, this process is repeated for twenty intervals. The data are synchronized to the appropriate intervals in the video, meaning all observations about a ten-second interval are linked to the beginning of that interval.

The video and handwritten annotations captured — with metadata describing when, what, and for which child information is captured — are stored in a relational database. Two levels of detail are available for access (see Figure 1b). A single session (the twenty recorded intervals) can be viewed, and a timeline interface is provided to replay each ten-second video observation next to the observations made for that interval. Observation columns can be selected to provide more random access through the video observations. Summary statistics for a session are automatically calculated, and a second view visualizes this summary data across many sessions.



(a) (b) (c)

Figure 1: (a) researcher using WM (b) access interface shows video and a timeline (c) capture interface shows video and provides space for recording data.

3.2 Abaris: Environmental Prototype for Recording Discrete Trial Data

Discrete trial ABA therapy consists of one or two therapists requesting a child to perform a predefined set of instructional programs multiple times and recording of data on the child's success in performing each task. For example, in one observed scenario, Katie[1] leads a team of several therapists hired by the parents of Sam, a CWA. Before starting the therapy, Katie, with Sam's teachers and family, evaluated him to find areas of deficiency and designed a tailored education program. The team of therapists takes turns working with Sam for 2-3 hours every day, often completing over a hundred trials in a session. At the end of a session, the therapist sums the data, calculates percentages of trials completed successfully, manually completes graphs that track progress, and writes narrative notes for Katie and the other therapists. This is a tedious and expensive manual process that is prone to error. When Katie conducts therapy, she also examines the discrete data and narrative notes left by therapists the previous week to monitor Sam's progress. Without video, she often discerns that she is missing information and cannot diagnose problems or plan lessons without spending time observing therapy sessions, and she cannot guarantee that the manually recorded data is accurate and complete.

The Abaris prototype[2] automates some of this process and equips teams of therapists in monitoring the progress of a therapy regime. Abaris was designed for a single user in a confined setting to capture and integrate therapist data with video of the

[1] All names of care givers and children have been changed to protect their anonymity.

[2] Abaris was a figure in Greek mythology who was the priest of Apollo and who possessed a golden arrow that, among other things, helped to cure diseases.

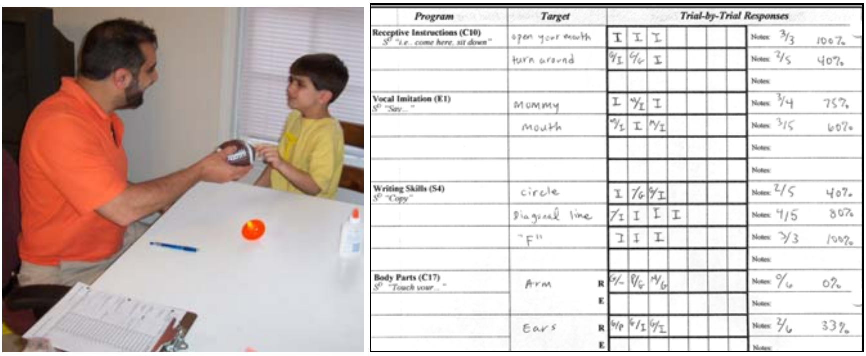


Figure 2: (a) A therapist interacts with a child and records data on a nearby clipboard. (b) Example of ABA paper form.

therapy session. Therapists use the tablet application to customize the child's daily therapy and record data. The therapist records performance data in a form interface on a Tablet PC (see Figure 3, right) while a separate system records audio and video, from a fixed environmental camera and microphone, synchronized to the form data. Because of the variability of routines between therapists, perfect synchronization between grades on the form and capture video is not yet possible, but some simple temporal heuristics associate a grade for a given trial to a segment of video. There are opportunities to use activity recognition during the therapy, but we did not pursue this challenge in initial prototypes. The access interface (see Figure 3, left) allows changes to grades, because therapist error is possible. Summary statistics are calculated automatically and available for graphing.

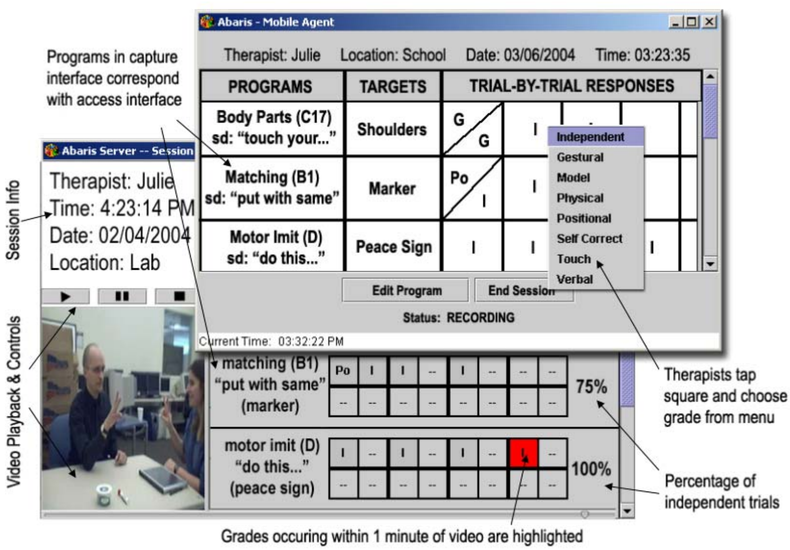


Figure 3: Users score performance data by choosing a value for each trial. They can replay the entire video of a session or go to salient points using discrete data.

3.3 CareLog: A Distributed Prototype for Recording Semi-structured Data

Diagnosing and treating behavior can be particularly difficult when those behaviors are not seen all the time or are very situation specific. In one reported instance, a school autism consultant, Mark, was trying to diagnose a particularly irregular behavior of a child named Sam. He attempted to escape from the group of classmates and teachers walking down the halls at seemingly irregular times. Sam typically exhibited this behavior once a month. Furthermore, Mark only visited the school once a week, and the likelihood that he would be there when Sam made his attempt was small. The teachers worked together with Mark and school administration to secure hallway security tapes of the incident and eventually found a pattern and were able to change the behavior. Without the serendipitous access to security tapes, however, Mark reported that he would not have solved the mystery.

Because of these difficulties and the impracticality of ubiquitous capture devices (*e.g.,* security cameras) in the life of a child, automatic collection of rich data is nearly impossible. Instead, caregivers are asked to record informal data about incidents in everyday life. These data are usually discrete but can include narratives. CareLog is a mobile system using a confederation of capture and access devices designed to collect this information.

Of all the applications discussed, CareLog has the greatest variety of users. Families and teachers not trained in special education in addition to specialists all keep these types of informal records. Therefore, CareLog requires a distributed architecture allowing the caregiver to use any available wirelessly enabled device (*e.g.,* classroom PC, PDA, home PC, etc.) to record observational data. We wanted to centralize the collected data in order to ease later access. Because the child is the one consistent player in all of these observations, we decided to tie storage to the child, through a pocket-sized device, approximately the size and weight of a deck of cards. This device, a Personal Server [23] (PS), holds a database with all of the child's information and acts as a wireless application server for the CareLog application. The child can leave the PS in a pocket or backpack. Assuming they are within a short distance of the PS, members of the caregiver network can record behavioral data about that child through any nearby device with wireless connection to the PS. When a caregiver makes notation of an incident, the date, time, caregiver, and note-taking device are logged automatically to the child's device. The caregivers can also enter discrete data by checking a box by each characteristic of the incident that applies (e.g. the child was *kicking* in the *kitchen* after a *loud noise*) and add a handwritten or typed note to the record. Users can access data through a standard web browser. The CareLog applet communicates with a SQL database running on the child's PS and loads a custom UI based on information stored in the database and properties of the accessing device.

Based on caregivers' expressed needs, a summary screen supports a detailed visualization of captured data on a large-screen interface, such as a desktop PC. Because these visualizations are quite large, initial attempts to scale them down to a pocket-sized version were met with apprehension from users. Caregivers also reported doing this type of analysis in situations where a larger display is readily available, such as an office. Quantitative records of each incident are available as temporal graphs for any range of dates chosen by the therapist. CareLog provides the facilities to plot any combination of behaviors concurrently on the same graph (see Figure 4) or the user can open multiple

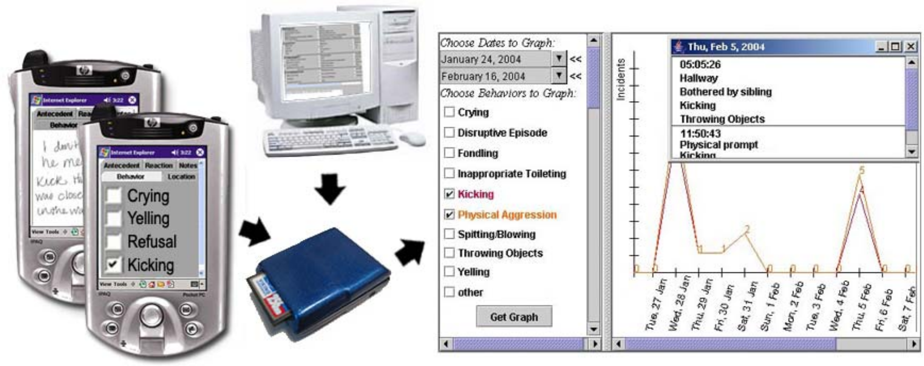


Figure 4: Input is sent to the child's PS, providing views of the data through any PC. Users select a range of dates to view and "drill down" by choosing a day.

CareLog windows to examine these graphs side by side. Users can "drill down" into the details of an individual day by clicking on that day, which displays a new *DayDetails* window with all of the characteristics and context captured about incidents during that day. By clicking on a record, the user can toggle the display of narrative data about that incident on and off. Users might want to examine multiple days concurrently to compare the records of those dates. To accomplish this, CareLog allows users to display multiple *DayDetails* at once. Thus, caregivers can quickly get a sense of how a child is doing or gather more data in an attempt to solve a particular problem or track a particular event.

4 Social, Practical, and Technical Considerations for Capture Applications for Supporting CWA

The formative studies and experience with the three prototypes highlighted a cyclic *care cycle* surrounding the caregiver workload. This cycle imposes particular human constraints on design: the need for rich data, the balance of effort involved, privacy and control considerations, and financial burdens. We further explored certain technical considerations of importance to these applications: the integration of manually and automatically captured data, the level of distribution of the system architecture, and data analysis and visualization techniques.

Although these domain specific constraints and the tensions inherent between them can be identified up front, only end users can appropriately assess how they should be satisfied at any one time. End users must be allowed to evolve the system themselves through iterations on the services available in the environment and the application interface. Evolutionary capture and access applications can better address the social and technical issues identified by capturing minimal data initially in convenient locations and allowing users to hypothesize about the data and test these hypotheses by iterating on the system. For each consideration, we examine how an iterative approach in which caregivers use information accessed from the application to influence what and how they will capture in the future can affect these issues.

4.1 Social and Practical Considerations

For the successful deployment and adoption of working ubiquitous computing systems, designers must consider domain specific human concerns. These issues may be social in nature, focusing on how users work and interact with one another and computing systems. They may also be practical in nature, focusing on the possibility that users can afford new systems and are willing and able to use them effectively.

4.1.1 The Care Cycle

Interventions for CWA emphasize a cycle of care that revolves around recording data about the patient and providing care based on that data. This cycle existed in some form across all of the interventions we studied. The basic steps that therapists perform are:

- Diagnosis based on observation and/or interview data collection.
- Goal setting with various parts of the caregiver network. These goals can sometimes amount to a "contract" with the family or with other caregivers.
- Intervention based on learning and behavior modification particular to the child.
- Evaluation of goals being met or not based on data collection from observation and/or interviews. All of the interventions include some notion of accomplishing pre-determined goals whether by "mastering" a skill or by reducing inappropriate behavior. Although criteria for mastery differ slightly (e.g. 80% vs. 100% success accomplishing a task), they are similar across therapies.
- Based on this evaluation, the cycle begins again with a new diagnosis.

This cycle of care is extremely important to the way therapy is conducted in all of the interventions we studied. The caregivers we interviewed who regularly interacted directly with the child reported commonly setting and assessing goals. Caregivers who interacted with the child less frequently also reported this cyclical behavior. However, they expressed some frustration with occasionally being unable to assess progress towards these goals. In these cases, the hurdle to success was primarily in the data recording capabilities of those individuals directly interacting with the child. The desire to improve data collection techniques motivated all of our prototypes.

WM was designed to support one portion of the care cycle, gathering observational information of certain behaviors. It does not allow users to change the kind of observations they are making based on data gathered previously, but the access interface does allow users to view aggregate data over time and then analyze details. Abaris provides summary views of individual therapy sessions, but users pointed out missed opportunities for seeing trends across a single program over time and across therapists. These additional views of the captured data would better support the iteration on future programs to track. CareLog was designed with the strongest influence from the iterative nature of the care cycle, allowing users to capture data and analyze it at multiple levels through graphs and specific details. Information from this analysis can then be used to configure the capture interface for later use.

4.1.2 Need for Rich Data

Most of the caregivers studied who were responsible for gathering data during teaching sessions expressed some preference for rich, narrative commentary. Those individuals responsible for analyzing that data also recognized this preference but reported being "bogged down in narrative data" and having difficulty in parsing the information contained therein. To avoid this phenomenon, these analysts have developed forms for recording this data. The forms also build in a "prompt" to the caregiver recording the data about what information needs to be gathered. Use of these forms often resulted in caregivers recording data more often, but without the corresponding narrative, the information could be incomplete.

All caregivers we observed were involved in recording data about a child, analyzing that data, or both. Furthermore, all caregivers we interviewed expressed concern about the tension between the need for richer data, including video, and the effort of retrieving and analyzing that data. By using the natural actions of the caregiver to provide effective indexes into rich data, like video or audio, automated capture and access applications can help the users navigate this potentially enormous sea of data.

WM supports capture of rich data through video captured from a head mounted camera and narrative notations captured through the Tablet interface. Abaris automatically captures video associated with a particular therapy session through an environmental service focused on the location of therapy. CareLog limits the richness of the data that can be captured, allowing only for discrete data and occasional short notes. There may be an opportunity in the future to link audio, video or other sensor data to the discrete data, but this may come at a cost to other considerations.

By examining minimal captured data users can estimate when, where, and how they need to gather richer data. They can then add sensors and multimedia capture services to gather the most appropriate data at the most appropriate time. The capture of rich data is a user desire naturally in conflict with many of the other constraints mentioned. An iterative approach allows users to balance dynamically these constraints more effectively as detailed in the following paragraphs.

4.1.3 Reducing the Effort Required to Use the System

When considering healthcare and education, particularly the care networks for CWA, the need to lessen the caregiver's burden becomes magnified. Often in these cases, the user benefiting from the data collection is not the individual directly interacting with the child. Instead, the individual analyzing data and developing therapies benefits from its collection. End users must see an appropriate balance between their required efforts to use the technology and the benefits they will accrue. This is very reminiscent of lessons from the design of groupware systems [13].

Furthermore, it is particularly important that the task of keeping records fades into the background and does not distract from the primary task of educating the child.

Much of the resistance to using technology or to manual recording was due to this secondary task taking away from caring for typical children and for CWA. Capture and access applications will be successful only if relevant information is recorded without undue distraction to caregivers, primarily providing support to CWA [21].

WM reduces user effort by collapsing the video recording activity with the data tabulation, but some users expressed apprehension about wearing a head mounted display, and carrying a Tablet PC that is much heavier and more difficult to use than a clipboard with paper forms. Abaris minimizes user effort by automating several of the activities involved in care that were previously manual, such as tabulating and graphing discrete data. We were pleasantly surprised to see that the Tablet PC interface was not much different to use in this less mobile setting than the original paper forms. CareLog was designed to require minimal effort to record an incident, but all data captured requires some user action. Users can employ handheld devices, a similar form factor to notepads in use by some caregivers, or larger tablet or laptop devices. We also considered other wearable form factors for data collection, aimed at reducing the time between observation and recording. We have yet to determine whether this model of using a variety of devices reduces the hurdles to capture in real life.

By avoiding premature fully automated continual capture and employing an iterative approach, users view many fewer irrelevant data points directly answering the concern of being "bogged down in narrative data." After initial information is accessed and analyzed, users can choose to capture richer data when they believe that it is relevant. This reduces the amount of effort required and can also make users more willing to expend effort, because they have visibility into how the information they are gathering is relevant and useful.

4.1.4 Privacy and Control of Data

The automatic or even semi-automatic capture of very rich and sensitive data, such as video, continues to raise concern about privacy in the ubiquitous computing literature, legislation and the popular press [4, 9, 14]. In the home, where many therapies occur, this concern is arguably somewhat less pressing. At school, however, parents of other children as well as teachers must consent to the capture of any data that might identify themselves, their children or their teachers. The collected information is both personally identifiable and could be considered sensitive. Teachers and school administrators reported that the benefits of continuous capture would not outweigh the invasion of privacy at their schools, which casts doubt on whether a proportionality test (such as those described in [4]) for balancing services against privacy would succeed. Schools also raised concerns about liability, noting that they would not want persistent video data that could be used in a lawsuit between parents and the school or parents and each other. Therapists who worked with teachers voiced concerns about the "closed door policy" common to classrooms, wherein teachers locally negotiate the activity in their classrooms daily and will prevent any interference with or visibility into that process. Parents of typical children might perceive no benefit of this kind of capture, because their children do not need the records for their education and care, so they are less likely to consent to recording.

Incidental to the privacy discussion is one over control of data and responsibility. The individuals providing the care were sometimes not the ones designing it; those who were recording the data were often not the same as those who would analyze it. In designing systems to support these disparate groups of caregivers, we must consider who determines what needs to be captured. Individuals we observed tended to resist those activities in which they had little input or control. As context changes over time and greater benefits of use can be realized, they may then be willing to adapt the application in ways suggested by their supervisors and analysts.

One reaction to this problem of privacy and control in schools would be to track progress only in the home or to use special self-contained classrooms away from neurotypical children for the education of CWA. However, current thinking in the educational and therapeutic communities endorses the approach to including CWA and other special needs children in "regular education" classroom settings. These trends are also encoded in legislation in most industrialized countries, such as the Individuals with Disabilities Education Act (IDEA) in the United States, guaranteeing children with disabilities a "free appropriate public education" in the least restrictive environment [5], often "regular education" classroom settings. Furthermore, the No Child Left Behind Act, which requires that schools track progress of all students and report on that progress regularly [8], provides incentive to school systems to record data about the progress of CWA that cannot be gleaned from standardized tests used to track the progress of typical children.

The WM system only captures what is in the view of the researcher recording data, which can be focused on a particular child. It also operates in a research environment where specific human subject consent is gathered for all children. Because it is wearable, the user can remove the camera or pause recording. Abaris was initially designed for a home environment, and its deployment in schools would likely be confined to special purpose locations tailored to prevent inappropriate recording. It also allows users to change the potential tasks to be performed and for which data will be recorded, thereby controlling what is captured. CareLog allows end users to configure the discrete data that can be collected giving them control over the capture interface. CareLog does not allow for the capture of discrete data about unrelated individuals, but its potential to capture rich data about unrelated individuals incidental to the discrete data is a risk. All of a particular child's data is stored on that child's personal device, simultaneously reducing privacy concerns by keeping the data owned by its subject and increasing security concerns with a single point of failure for data loss.

Using an approach in which end users iterate on the capture services, users of the system are added only as necessary and data is captured only when appropriate to the tasks being addressed, whether changing a behavior or teaching a new skill. Many fewer people can possibly be identified with an iterative approach because rich video data is being captured in fewer locations at fewer times. This reduction in the possibility of identification inherently reduces privacy concerns as well as the need for consent from individuals who might not be relevant to the problem. Interviews suggested that caregivers would be more willing to sacrifice their own privacy and to participate in the recording of the data for the good of the child's care if they reasonably believe that what is being captured is relevant to the care.

We are aware that complying with responsible data protection principles in such a special application also requires addressing the related issues of retention time, system administration and security, and informed consent. For the sake of space, however, we do not address these issues in this paper.

4.1.5 Financial Constraints

Traditional capture and access systems typically have not been built with financial considerations as a primary design constraint. However, the numbers of CWA worldwide are growing at incredible rates. For every two children registered through Individuals with Disabilities Education Act (IDEA) with autism in 1992-93, there were almost eleven by 1999-2000 [22]. Changes in the way CWA are diagnosed and awareness of autism may contribute to some of this increase, but do not account for the entire change. Caring for CWA is a costly endeavor, one that is shouldered by families and school systems that are often already greatly impoverished. Thus, caregivers repeatedly noted that the adoption of any system into their care routine would have to demonstrate significant benefit for the cost incurred.

When designing systems to be truly ubiquitous, researchers must consider not just the cost of a single research installation but also the cost of instrumentation in every environment. Although most classrooms have a PC, many families have a PC in the home, and some of the caregivers interviewed carry a PDA, a wireless network is rarely available in these environments, and the cost is too high to expect caregivers to invest in them. In schools, CWA often change classes throughout the day, both with the other students and to attend special care. They also tend to spend a lot of time in facilities belonging to a disparate group of caregivers, friends, and family members. Capturing rich data in all of these environments can be an enormous undertaking.

All of the prototype solutions we have developed would show significant cost savings over time, because they eliminate much of the paid human work to collect and graph data manually. System acceptance was affected not only by cost over time but initial cost to families and school systems already very low on expendable funds. By these metrics, WM is not a particularly cost effective solution, requiring a dedicated caregiver to record data and each classroom to invest in a Tablet PC and head mounted camera display or to purchase and share some group of them at the school. The cost of the initial implementation of Abaris in a single environment is quickly recovered by the savings of not paying individuals to tabulate data manually. In a single environment, ad hoc networking can be used, and only a few devices need to be added, the most expensive of which is a Tablet PC. This distributed solution, however, would require an expensive implementation in every environment in which therapy takes place and a network between them, making cost an issue as the location numbers rise. CareLog addresses the financial considerations of users by requiring only the purchase of one additional device, the child's device, leveraging the already existing desktop machines and PDAs in the classroom. These systems would need to be augmented with wireless connectivity, but this represents a small incremental cost.

As opposed to instrumenting every person and every location for automatic capture all the time, an iterative approach allows users to capture data only when really needed. As relevant locations change, new equipment can be added or old equipment can be moved. For families and school systems already burdened with heavy costs of education and care, the ability to add or reuse equipment after initial deployment may make adoption possible when high upfront costs might make use of new applications impossible.

4.2 Technical Considerations

Domain-specific human considerations influence and are influenced by technical factors, like available services and architecture of capture and access applications.

4.2.1 Integration of Manually and Automatically Captured Data

One value of an automated capture and access system comes from the integration and synchronization of different streams of captured activity. Because human users sometimes need rich data and systems must remain easy to use, capture applications must relate the streams of data to each other as closely as possible. As designers, we needed to make decisions about how to relate observational data, provided by a human, to the situation being observed. In some cases this is made easy by the routine behavior of the observation. For example, the WM prototype took advantage of the strict protocol for observing and recording data. In other situations, the protocol for recording observations is not as rigid, and the timing between incident and record-keeping can vary between caregivers and from situation to situation. There is an opportunity to use activity recognition to link observational data to recorded incidents, a promising alternative for semi-structured activities like ABA, and we will investigate this for Abaris. For less structured activities that are the subject of CareLog, the challenge of integration remains.

Caregivers accessing and analyzing information about a child would ideally like as much rich data as possible. However, end user decisions made at the point of capture based on the social factors described previously will inevitably determine whether or not this data is available. For example, in deciding how much privacy to preserve, users determine which data streams are captured. A difficulty that arises when allowing users to dynamically evolve the capture application is that different streams of information might or might not be available for a particular event. Allowing end users to iterate on the capture requires support for end-users to iterate on the integration algorithms, using the heuristics known to them near the point of capture. One analyst reported "Families know when they can record data…They'll know they are going to take a few minutes dealing with what happened to write down what happened…And this can take longer sometimes, like during dinner."

4.2.2 Level of Distribution of System Architecture

A capture and access system can vary in the level of distribution of its constituent parts, and these differences may have impact or be impacted by the human concerns discussed. For example, we previously discussed the importance of where data resides for providing user control and answering privacy concerns. In any capture and access application, storage is a key component that can be overlooked. There are many architectural options for its placement as seen through the different prototypes. For CareLog, distribution is important, because we want to maximize the opportunities for different individuals in the same and different settings to be able to record observations. A standalone solution might be easier to implement, but it would require effort to move that system with the child throughout the course of the day. Our decision to separate video capture from observation data in the Abaris prototype makes video capture easier to implement but requires a replicated system for every environment, a costly decision for a school system. WM began as a distributed system but was quickly changed to a standalone wearable solution due to both cost considerations and a desire to give greater control of data capture to the researcher doing the observation.

In general, the need for rich data, particularly if that need changes often, necessitates the availability of modular capture services. A distributed architecture allows users to add new capture services physically into the environment. Common to software engineering practice, a separation between components (*i.e.,* a separated architecture) enables capture devices to be added easily. Different devices provide different levels of computational power as well as different user affordances. It might be easier for a user to take a note on a PDA, but it would be impractical to use a PDA to capture video. The applications should support dynamic changes to the physical environment by robustly accessing services as available and supporting manual record keeping even if a user has chosen to remove all automatic capture.

4.2.3 Data Analysis and Visualization

Caregivers use the captured data to inform decisions about structuring future therapies as well as to provide evidence to concerned parties about the effectiveness of interventions. They often look for trends in the data as a part of the analysis but also require the ability to examine data points at a more in-depth level. Access interfaces must support both high-level visualizations and querying as well as detailed "drill down" views of the data, while maintaining the link between related streams of information. The WM system provides two levels of visualization, one for a single session of twenty 10-second interval observations and one for viewing aggregate data across these sessions. Abaris provides a query interface to assemble views based on therapist or program. However, it does not provide the ability to view multiple therapist behavior side-by-side, a feature users indicated as important. It also exports data out of the system for generating graphs of performance over time. This feature supports an overview but misses opportunities to link those views to other recorded data. CareLog better integrates the visualization of data over time.

Continued discussions with users reveal that there is also a need to support "what if" exploration of this data. When caregivers first access the data, they begin to formulate hypotheses about it. They must configure their own graphs and charts dynamically depending on these initial assumptions and use custom built visualizations to more easily uncover potential trends. This analysis helps them to determine when and where they need to focus data collection in the future. This narrowing of contexts for data collection helps them to balance many of the social issues discussed previously. With an iterative approach, they can feed back the analysis into the design of capture services, essentially allowing them to test the hypotheses they have just made, while respecting the concerns of the other stakeholders.

4.3 Balancing Considerations

The human constraints imposed by the care cycle of caring for CWA influence and are influenced by the technical considerations inherent to ubiquitous computing and capture and access applications. Applications must balance needs such as ease of use with an architectural separation of concerns. Although designers can identify these needs and the tensions between them, only end users can appropriately assess how they should be satisfied at any time. We recommend an approach in which end users can iterate on the available services and evolve their own applications to dynamically balance these issues and satisfy the constraints specific to that situations. For each factor, we examined how such an iterative approach affects these issues and concluded that the appropriate solution is to allow end users to evolve their applications.

5 Related Work

Both research and commercial software have targeted the tracking of health and education data. The CareView system "utilizes a set of visualization techniques to increase the visibility of temporal trends in clinical narratives" from home healthcare nurses [15]. The Intelligent Dosing System (IDS) uses a custom decision support protocol for doctors managing and treating patients with diabetes [12]. The software provides tools for analysis of an individual's progress with a set of medications over time. The LifeLines project provides a visualization environment for personal medical histories in which the initial screen and visualization act as menus for direct access into the data [18]. Although similar in some ways to application areas we have explored, CareView, IDS, and LifeLines differ from our proposed solution in that caregivers were not able to configure the systems to capture different data based on previously captured information.

Specifically geared towards the treatment of CWA, commercial products like Discrete Trial Trainer [2], CompuThera [11], Labeling_Tutor [6], and Earobics [3] focus on teaching skills such as labeling familiar objects and developing auditory processing skills. They provide interactive activities and games and often adapt to the child based on their responses. Another commercial product, mTrials [7] supports electronic capture of discrete trial data. These products do not, however, provide the level of information access and analysis that capture and access applications can provide.

Capture and access applications offer the type of data collection, mining and analysis capabilities needed by CWA caregivers. Traditional capture applications in classrooms, meeting spaces, and other fixed locations have been designed to provide users with the capabilities to record, view, and analyze important information about human experiences [21]. In an educational environment, the Smart Kindergarten provides parents and teachers with the abilities to investigate young students' learning processes [10]. Although we are similarly motivated to track educational progress, the Smart

Kindergarten project concentrates on the collection, management, and fusion of sensor information. Traditional capture and access applications, such as those discussed in [20], lack the configurability, mobility, and real time interaction required by caregivers. Our approach, on the other hand, concentrates on the iterative inclusion of capture services, both multimedia and sensor, to an inherently human controlled application, compensating for the unfulfilled need to balance user concerns in any context.

6 Conclusions and Future Work

While investigating how technology might address problems in the specific domain of caring for CWA, we have found that automated capture can be successfully applied in a variety of settings to assist with the education and giving of care to CWA, while also providing a means of keeping records of those activities. We built three distinct prototype systems to address the constraints most important for particular tasks. However, predetermined capture and access applications are not malleable enough to support the cyclical activities involved in caring for CWA, and we hypothesize in education and medicine more generally. We have concluded that end users must instead be able to iterate on the capture and access applications, services, and data integration processes available to them through distributed modular systems. When end users can modify their applications in these ways, they are better able to balance their own considerations and satisfy constraints appropriate to the context of their environment. We are currently in the process of developing capture and access applications that can be evolved by the end user and will deploy and evaluate these applications in the future.

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