Pervasive Computing and Autism: Assisting Caregivers of Children with Special Needs

Pervasive computing technologies can support children with autism and their caregivers. Work continues on systems that aid record collection and analysis, decision making, communication, and assessment of children's internal states.

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Caring for children and older individuals with autism is often a complex, lifelong challenge. Families and care networks for children with autism often face numerous choices regarding types of therapies, doctors, and drug and diet regimens. Each child's unique nature makes predicting which treatments will work difficult, and timeliness is often critical. For these reasons, parents might choose to try several treatments simultaneously, making it even harder to determine which treatments work and which don't. Further complications result when caregivers don't see the effects of treatment immediately, perhaps because the changes are minor or imperceptible.

Often, many caregivers help determine if a child is receiving the best treatments possible. The sheer amount of data they must collect can often cause difficulty in making the best choices for that child. Also, individuals with autism often can't communicate their internal states, so caregivers must rely on externally perceivable characteristics to determine the person's needs.

Technology can make caring for children with autism more efficient or hide some of its complexities. Data capture and analysis is an important part of making decisions about whether a treatment is working. Pervasive technology can help increase the amount of data collected, make it easier to collect, and help caregivers quickly scan through data to make better decisions. Technology can also help the caregivers on a child's team communicate more effectively and efficiently.

What is autism?

Pervasive development disorder, also known as autism spectrum disorder (ASD), is a cognitive impairment characterized by deficiencies in communication, social interaction, and creative or imaginative play.[1] This spectrum includes autistic disorder (autism), Asperger's syndrome, pervasive development disorder not otherwise specified, and Rett's disorder. Individuals on this spectrum often exhibit stereotypical, self-stimulatory behaviors such as rocking, hand flapping, or vocalizations. Autism is the most common on the spectrum, affecting an estimated 1.5 million Americans today and growing at the astonishing rate of 10 to 17 percent annually. Autism is typically diagnosed between the ages of two and six, although variations of ASD can sometimes be diagnosed earlier or later. The disorder has recently been a popular topic of discussion in the mainstream media, prob-

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Additional Computing Technologies Supporting Individuals with Autism

Other researchers have explored technology 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.[1] The Discrete Trial Trainer (www.dttrainer.com) is commercial software that attempts to replace the therapist by administering similar therapy and education through the computer. Simone Says and DTT can ease some of the burden on caregivers by letting a computer administer therapy.

Other technologies have focused on how to teach individuals with autism social skills and aid their communication. Andrea Tartaro has explored storytelling with virtual peers to teach social skills to children with autism in a risk-free setting,[2] while researchers at MIT have looked at how to emphasize people's images to help individuals with autism understand subtle emotional cues.[3] Recent work by Anne Marie Piper and her colleagues explored using a multiplayer tabletop game called Sides to encourage children with autism to learn social interactions and turn-taking.[4] These types of socially based applications, used in conjunction with other treatments, can provide a richer education in social skills and leave the caregivers with more time for other, more pressing issues.

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ably because it's being diagnosed at a much higher rate than ever before. Current estimates from the Autism Society of America are that 1 in 166 children will be diagnosed with some form of autism at some point in their life.

Although autism typically presents itself in individuals in some known ways, it manifests differently in each person and sometimes differently in the same person over time. This extreme variation among children has led practitioners and family members alike to make the anecdotal comment, "If you've seen one child with autism, you've seen one child with autism."

Evidence from the behavioral, educational, and social sciences indicates that early diagnosis and intervention could be key to achieving greater independence, an ultimate goal of these care activities.[2] As with other language acquisition disorders such as deafness, children who don't achieve functional language by school age can be severely limited in their future abilities to interact with others.[3] Thus, caregivers are often in a race against time to find treatments that will work for their children. Treatments include pharmacological interventions, special diets, holistic approaches such as occupational therapy and sensory integration, behavioral therapies such as applied behavior analysis or functional behavior analysis, and symptom-specific treatments such as speech or language therapy (see the sidebar "Additional Computing Technologies Supporting Individuals with Autism"). Moreover, caregivers often try different interventions simultaneously.

Three technologies to support caregivers

Our work at Georgia Tech for the past three years has focused on supporting individuals with autism and their caregivers with computing technology. We've explored several dimensions of the care cycle and network; here we present three of those projects.

Abaris: Supporting collaborative decision making

Discrete Trial Training (DTT) therapy is a current best-practice intervention for children with autism in which therapist teams teach basic skills intensively and one-on-one. Therapists assign a grade for the level of independence at which the child was able to complete the skill. After each therapy session, the therapists calculate the percentage correct for each skill and then plot the data points on hand-drawn graphs. Every one or two weeks, all the therapists meet to discuss the child's progress and how they might change their therapy practice to make the child more successful. During these meetings, common discussion points are the skills the child can accomplish and clarifications on the grading of particular skills. To be effective, DTT involves rigorous data collection and analysis. Unfortunately, it's also subject to inconsistencies and inaccuracies because all therapists have different skills and different interpretations of therapy's progress.

We developed the Abaris system to support teams of DTT therapists.[4] Abaris supports this practice through phoneme-spotting voice recognition, which pro-

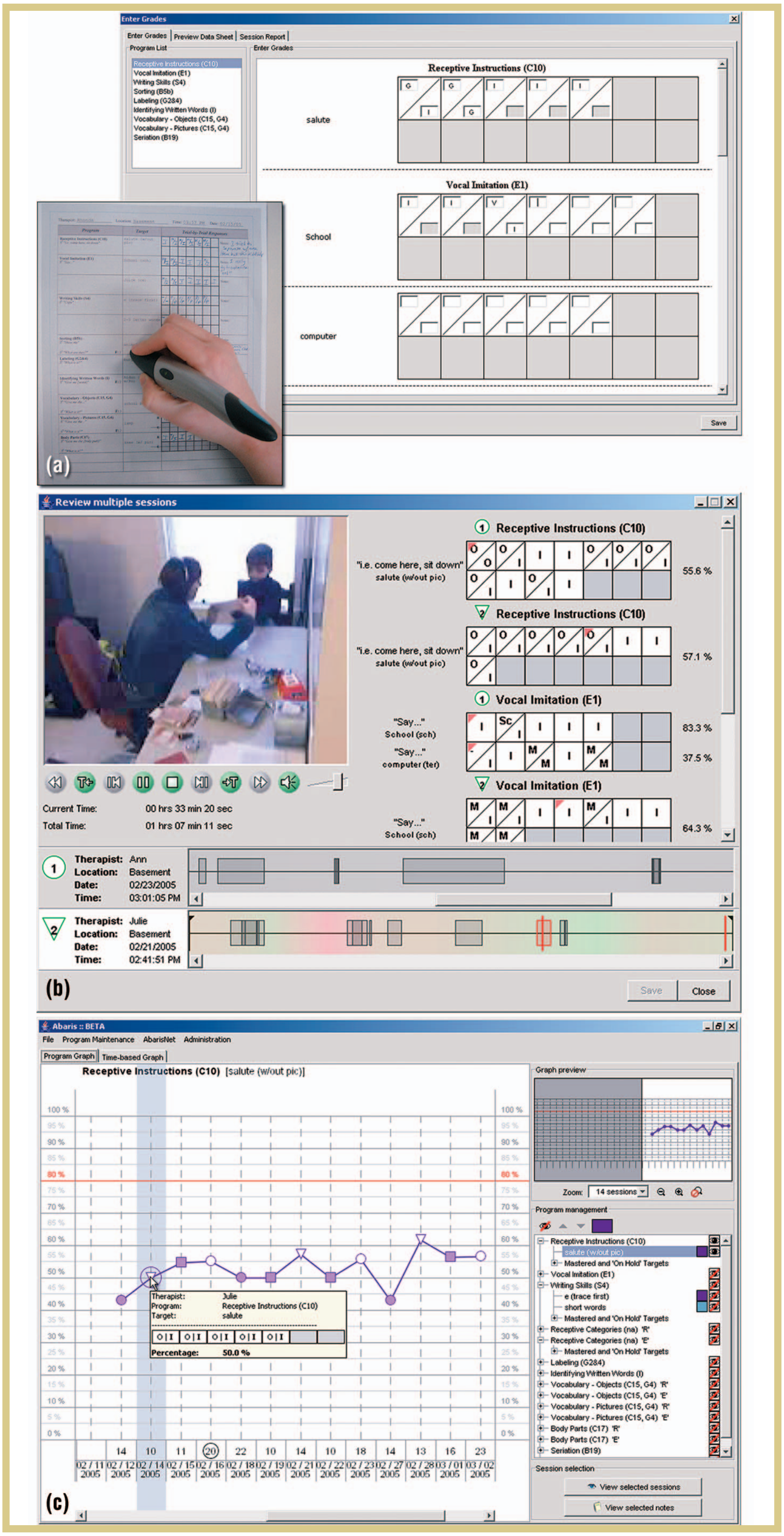


Figure 1. Screen shots from Abaris data capture and analysis technology: (a) capture interface, (b) video preview screen, and (c) data analysis graphs of a child's progress.

vides indices into videos of therapy sessions (see figure 1a). Therapists use an Anoto digital pen to capture data and provide additional indices to the videos. Therapists can access the videos during their team meetings via an interface (see figure 1b). Because of the easy indexing, a therapist can use video evidence to review progress, find inaccuracies in grading, and show problem areas to other caregivers. Abaris also lets therapists automatically generate graphs and associate them with the data sheets they used during therapy (see figure 1c).

We deployed Abaris for four months with one particular home-based DTT team and found that the system enabled therapists to use objective evidence more frequently in the decision-making process.[5] Therapists used videos, graphs, and data sheets more frequently than they did without Abaris. Prior to Abaris, they would rely on their own recollections of what happened during therapy and only consult written data sheets if necessary. We also determined that using Abaris during team meetings increased collaboration among the therapists.

CareLog: Capturing and analyzing behavioral data

Children with autism and other developmental delays exhibit behaviors that are often inappropriate and might be disruptive or dangerous to themselves or others. To address these behaviors, teachers, specialists, and parents often try to understand their cause. One best practice for determining cause is known as *functional behavior assessment*. When done in the natural environment, FBA includes direct observation. Caregivers, seeing a behavioral incident, note the incident's context and what happened directly before (antecedent) and after it (consequence). Once the number of incidents recorded by the

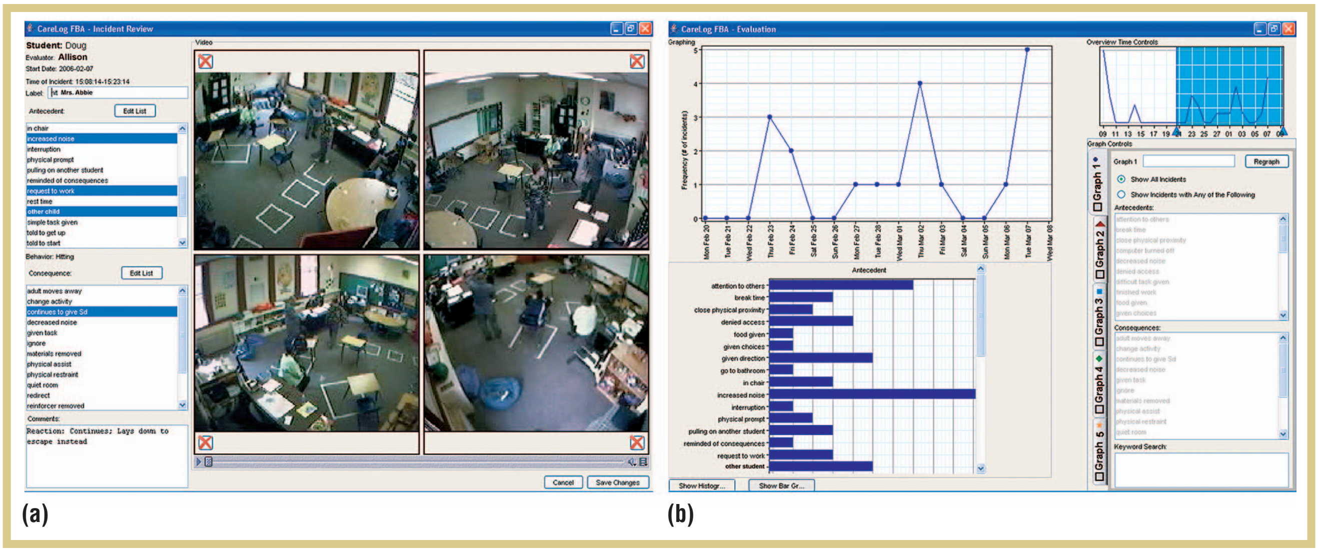


Figure 2. Screen shots from the CareLog functional behavior assessment system: (a) video viewing and annotation screen with four camera angles and (b) automatically generated graphs showing when and how often a particular behavior occurs.

caregiver reaches a point of data saturation (usually 20 to 30 incidents over a few weeks), a behavioral specialist analyzes the data to determine the behavior's function—for example, the child might be screaming to gain the teacher's attention. In classrooms and homes, observing these behaviors rigorously enough to have confidence in an assessment can be difficult. Incidents might occur at unexpected times and places, and caregivers might not be able to write down what happened before or after while simultaneously managing the behavior itself.

CareLog is a prototype system designed to help caregivers document and analyze specific, unplanned incidents of interest as part of an FBA. CareLog uses audio and video buffering[6] to allow selective archiving of these media after events occur. Caregivers use a wireless button to trigger archiving. They then use a standard desktop computer to watch the videos and tag them with metadata (see figure 2a). Finally, CareLog provides graphs and other analytic tools for functional assessment (see figure 2b).

We deployed CareLog in four classrooms at a special-education school in the Atlanta area as part of a semicontrolled study of its effectiveness.[7] Each teacher conducted an FBA for two children, one using the traditional pen-and-paper method and one using our technology-augmented process. The ordering of the two methods was counterbalanced and groups randomly assigned. Overall, we observed increases in both the accuracy and the efficiency of the process. Furthermore, the teachers reported enjoying the process more while feeling less burdened and more confident in the results of their assessments using CareLog. One teacher will continue using CareLog with multiple students during the entire 2006–2007 school year.

Wearable sensors: Giving nonverbal children a voice

A major difficulty in caring for some children with autism is their inability to communicate when something is upsetting them or making them uncomfortable. Pervasive computing might be able to help caregivers sense when a child is upset. A defining characteristic of children with autism is self-stimulatory behavior, or *stimming*, which can include rocking, hand waving, clenching of the fists, or nonword vocalizations. Some researchers believe that the amount of stimming might indicate a child's affective state.[8] Monitoring stimming behavior might give caregivers a better idea of treatments' effects, when to try calming or soothing the child, or when the child might be most receptive to learning.

We've researched technological means for detecting self-stimulatory behaviors using wireless body-worn sensors. We developed a proof-of-concept system capable of collecting data from a child with autism and providing automatic indices into that data to aid researchers' analysis of autism.[9] Our pilot study involved several technical challenges regarding the selection and placement of sensors and recognition of collected data. Using wireless Bluetooth accelerometers (see figure 3), we specifically targeted self-stimulatory behaviors of repetitive movements because these are often the most socially disruptive.

Accelerometer positioning was a major consideration for this work. For example, if a child were exhibiting repetitive hand flapping, an accelerometer positioned at the wrist would be more appropriate than on the ankle. Our goal was to minimize the number of sensors needed to collect data for as many stimming events as possible. In the pilot study, an adult mimicked several trials of seven typical self-stimulatory behaviors interspersed with random daily activities. We affixed three accelerometers to the sub-

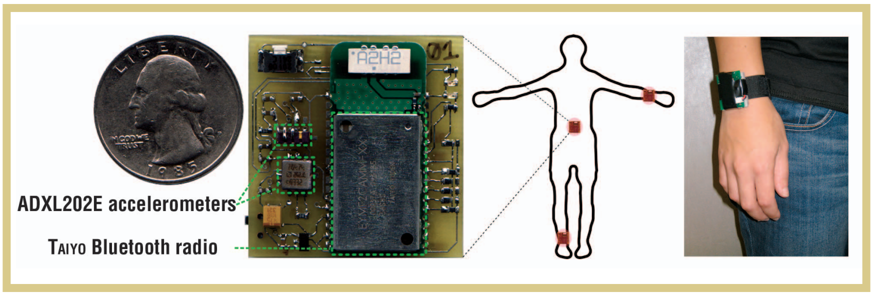


Figure 3. Relative size and placement of a wireless accelerometer and sensor on an adult.

ject's thigh, waist, and wrist using Velcro straps and used the Georgia Tech Gesture Toolkit for recognition experiments. Results showed that automatic indexing into data is possible (see figure 4). However, although we could accurately detect that a stimming event had occurred, we couldn't always label the type of behavior correctly. We plan to test a child-safe version of the sensor system on three children with autism.

Design considerations

We found four issues that needed to be addressed as we designed Abaris, CareLog, and the wearable sensors.

Understand the domain

In the year before developing any technology and throughout our design cycles, we spent time conducting in-depth contextual inquiries of the autism domain.[10] These explorations included interviews with parents, caregivers, therapists, and teachers who interact with these children on a daily basis. We were also trained to become therapists and participated in therapy sessions and team meetings with therapists. We spent extensive time observing classrooms, home settings, therapy sessions of varied types, support groups, and other domain-specific activities. Our design team also included individuals with firsthand and expert knowledge of our user population, including parents of children with autism, autism researchers, and behavioral specialists. Having firsthand knowledge of children with autism helped us attune to how well our target users would adopt these technologies.

Make changes invisible

Getting groups of users to change their practices to adopt any new software is always difficult, but trying to change rituals with children with autism can be nearly disastrous. Many children rely on strict regimens and have difficulty adjusting to deviations. Pervasive computing can seamlessly blend into the environment and thus has a distinct advantage over other technological solutions in this domain. In the case of Abaris, we believe we succeeded in data capture because we continued to use the paper form factor, so the child was unlikely to notice a change.

When we did make changes, such as having the therapist use a headset microphone for voice recognition, they distracted the children—they often wanted to touch it. For CareLog, we placed cameras in the corners of the classrooms near the ceiling to reduce distraction. Despite these efforts, in one classroom, some higher-functioning students noticed the cameras. Also, in all classrooms, students clearly recognized changes when we were present for data collection (in addition to the installed cameras). This evidence shows that even minor changes to existing practices could interfere with the interventions.

The easier, the better

Teams of caregivers and educators are often diverse, coming from different backgrounds and having different levels of computing expertise. Additionally, they're rarely collocated and don't see each other regularly, if at all. In our studies, children often saw a behavior therapist, an occupational therapist, and a speech therapist all on the same day, where none of the experts could access the others' records despite the fact that doing so would be beneficial. Secondary caregivers such as therapists and behavioral specialists might have limited interaction with a child, see multiple children, and look at significant amounts of data every week. Even in schools, speech therapists were outside contractors, and the behavioral therapists moved between rooms and schools throughout the day. Low-tech solutions have included passing paper records with the child or parent; however, these records can be a burden and often don't capture the data that caregivers need.

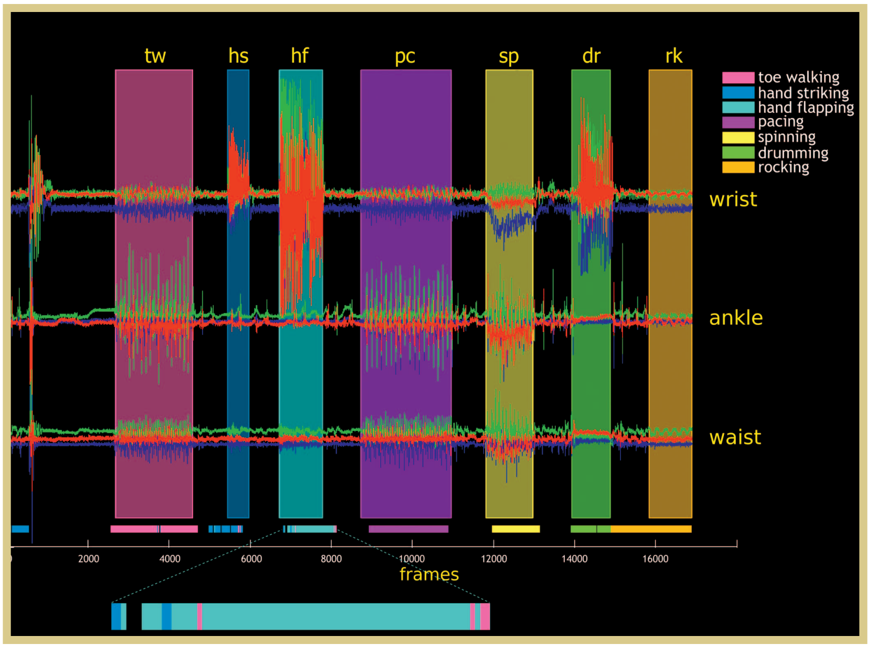
Technologies that can automatically collect and share data can help support these types of interactions. Keeping technology simple and straightforward can also help track all the data from all the caregivers involved.

Customizability is critical

Children with autism each have a unique set of behaviors, needs, and treatments. What works for one child might not work at all for another child with similar abilities. As a result, therapies and treatments must often be highly tailored to a specific child's needs. Any technology developed to support therapies or care must be able to reflect this uniqueness through customization. In the case of Abaris, the skills tested changed almost daily, so we had to design our system to support these changes.

With CareLog and behavior management, each behavior and its context can be incredibly different, even for the same child. For the wearable sensors, we had to consider many different types of stimming behaviors; in the end, we built a system that would be useful only in a small percentage of cases. In all these cases, the basic underlying process is relatively standardized, but the technology must support variable instantiation of that process for various children and conditions.

Figure 4. Three xyz-axis data streams (wrist, ankle, and waist) with corresponding hand labels (the vertical columns) and automatic-recognition results (the short horizontal bars directly under each column). The bottommost horizontal bar shows a zoomed-in view of one of the automatic-recognition results. Zooming in shows the classification of stimming events and minor boundary errors.



Design challenges

The studies we conducted also revealed three challenges that needed to be addressed.

Difficulties in relying on input from children

Autism inherently creates communication difficulties, and even those individuals who can communicate might know little about the processes caregivers use. So, relying on their input when designing technology is often difficult. Most children in our studies were unable to consent to the research process, let alone provide us with insights into what would work and what wouldn't. Instead, we generally relied on parents and caregivers to provide methods for working with these children. Although most caregivers have the child's best interests at heart, even experienced caregivers sometimes find it hard to know a child's needs.

In the case of wearable sensors, we had to design ones that would both provide good data and be comfortable to wear. This is a difficult problem because most activity recognition relies on a cooperative subject who can perform an activity on demand. Collecting training data for children with autism would be hard because they're unlikely to perform the desired activities on demand. Furthermore, these children are often sensitive to wearing restrictive clothing or new devices. Therefore, in developing our sensor system, we involved only neurotypical adults to help refine it before involving children.

Hardware for on-body sensing

Several trade-offs exist in the development of on-body sensing systems, including sensor type, power consumed, and form factor. The types and location of sensors influence the quality of data we can record. Also, sensors that require more power (such as cameras) will require large batteries, making the sensor heavy and heat-dissipating. Although we can use smaller, lighter batteries, they'll require more frequent charging, thus increasing system downtime and possibly burdening caregivers. Regarding the form factor, the sensor should be easy to charge, have maximum protection from daily wear, be unobtrusive, and remain in position during use. Keeping the sensor in the proper position is difficult for unwilling subjects. For example, a child might remove or damage bracelets and remove sensors in clothing or shoes.

With this vulnerable population, balancing these trade-offs is often difficult. Ideally, a sensor would require little maintenance and go unnoticed by the child wearing it. We might also be able to look for ways to use environmental sensors in addition to or instead of wearable ones.

Ethical and privacy considerations

Because children with autism often can't express their needs, it's crucial to ensure we meet their best interests. At the same time, caregivers, teachers, and other professionals have direct concerns regarding data collection that might affect their jobs or have legal repercussions, especially if videos are taken out of context. For example, restraining a child might provide comfort, but to uninformed outside viewers, this might look like abuse. With all the data-recording needs, some technologies might violate the child's or caregivers' privacy if not carefully considered.

In addition to these challenges, coordination between individuals includes issues regarding privacy, security, and legislative control. For example, in the US, patients are protected under the Health Insurance Portability and Accountability Act, and students are protected under the Family Educational Rights and Privacy Act. These regulations ensure that medical and educational data, respectively, are kept private and protected from malevolence, and software designed to share and discuss this data must ensure that data isn't misused. The design of applications that can follow these laws will also help address any concerns raised by the individuals receiving the care or caregivers close to that individual. Our CareLog system used selective archiving of camera recordings in the environment to balance the desire to catch relevant behavioral episodes retroactively against the privacy and information overload concerns of continuous recording throughout the school day.

What lies ahead?

Our work in pervasive technology for supporting the care of children with autism has given us and our collaborators the confidence and motivation to continue working in this domain, because many challenging problems remain to be solved. Our group has begun several new projects with other collaborators.

Early detection of autism

Early detection of autism and other developmental delays can be integral to providing appropriate individualized care for children with these delays. However, manually tracking children's many milestones is a huge challenge. We're working with the US Centers for Disease Control to design a computing system that will enable easier tracking and documentation of a child's developmental milestones. The system will proactively encourage caregivers to look for developmental progress and alert them when further investigation by a specialist might be advisable. The design and development of this system will examine how to use sensors and smart toys to detect automatically when children achieve milestones. To motivate parents to use the system, it will automatically create keepsakes for their child, such as scrapbooks or DVDs. We'll also determine how parents share information with other caregivers or medical professionals and find out how much information is needed to help medical professionals make better diagnoses.

Early detection of autism and other developmental delays can be integral to providing appropriate individualized care for children with these delays.

Collaboration in schools

The Abaris effort explored how a home therapy team working with an individual child can collaborate and use more reliable evidence in decision making. Our explorations with CareLog showed the need to aid data collection in schools because teachers must often engage in activities that might make them unable to capture data. In a project in collaboration with the University of Washington, we're exploring extending the technologies of Abaris and applying it to school settings. In particular, we're looking at how automatic data analysis and graphing can encourage teachers to visit Abaris more regularly. Additional computing problems in this domain will explore how multiple caregivers can collect data simultaneously for multiple children and how to combine related data from different therapy treatments for overall analysis.

Support for autism-related research

Many researchers specializing in autism in the education, neurology, or medical fields are interested in studying the effects of new drugs or treatments on children with autism. Many of these studies might benefit from having technology assist in data collection and analysis. For example, we're looking at how to use technology to observe the sleep behaviors of children with autism over time to see if a certain drug might help. Other work is looking at how wearable sensors can determine which factors might stress or calm children with autism.

Sound analysis for vocal stimming behavior

The difficulty of putting wearable sensors on children with autism has encouraged us to explore other ways to use sensing technologies to detect stimming behaviors. One way we're exploring this problem is by using wearable or environmental microphones to detect vocal stimming behaviors. This project will explore how sound-recognition technologies can characterize stimming and recognize it in real environments to get an overall impression of how frequently stimming occurs in children.

Adapting FBA technologies for home-based care

Although parents rarely conduct FBA and other formalized behavioral interventions at home, they often adapt school processes to support their needs. For example, at home, a goal might be to engage a child at the dinner table and keep him from getting up and running around or behaving in other inappropriate ways. Furthermore, parents also often need to share examples of both these and positive appropriate behaviors with other caregivers outside the home. Thus, we're developing a simplified version of the CareLog interface that takes advantage of selective archiving in the home. This prototype system, known as BICapture (behavioral-imaging capture), lets caregivers capture and share short snippets of audio and video through a streamlined interface similar to CareLog but without the more complex graphing and visualizations required for FBA.

The lessons we learned from these projects might benefit other researchers in the autism domain as well as developers of technologies to support long-term healthcare. Many of the design issues we've encountered extend beyond the autism domain and into the management of care for other chronic conditions. Caring for individuals with autism has many similarities to caring for the elderly or individuals with chronic conditions, such as diabetes or cancer. Additionally, many caregiver coordination issues share a common theme with that of computer-supported cooperative care.[11] We believe the promise of pervasive computing can help begin to address these common challenges.

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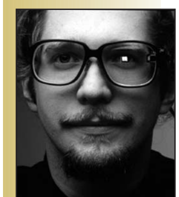

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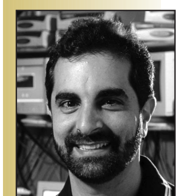

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