

Why Do They Still Use Paper? Understanding Data Collection and Use in Autism Education

Gabriela Marcu, Kevin Tassini, Quintin Carlson, Jillian Goodwyn, Gabrielle Rivkin, Kevin J. Schaefer, Anind K. Dey, Sara Kiesler

Human-Computer Interaction Institute, Carnegie Mellon University

{gmarcu@cs, qcc@andrew, jgoodwyn@andrew,

grivkin@andrew, kjschaef@andrew, anind@cs, kiesler@cs}.cmu.edu, tassini@punchcut.com

ABSTRACT

Autism education programs for children collect and use large amounts of behavioral data on each student. Staff use paper almost exclusively to collect these data, despite significant problems they face in tracking student data *in situ*, filling out data sheets and graphs on a daily basis, and using the sheets in collaborative decision making. We conducted fieldwork to understand data collection and use in the domain of autism education to explain why current technology had not met staff needs. We found that data needs are complex and unstandardized, immediate demands of the job interfere with staff ability to collect *in situ* data, and existing technology for data collection is inadequate. We also identified opportunities for technology to improve sharing and use of data. We found that data sheets are idiosyncratic and not useful without human mediation; improved communication with parents could benefit children’s development; and staff are willing, and even eager, to incorporate technology. These factors explain the continued dependence on paper for data collection in this environment, and reveal opportunities for technology to support data collection and improve use of collected data.

Author Keywords

Fieldwork; Contextual inquiry; CSCW.

ACM Classification Keywords

J.4 Computer Applications: Social and Behavioral Sciences; K.3.1 Computers and Education: Computer Uses in Education.

General Terms

Human Factors; Design.

INTRODUCTION

Children with special needs such as autism enter special education programs when conventional schools are not able to support their learning and behavioral needs. Children with special needs require support to learn subjects such as math and reading at their own pace, and to learn language, social, and motor skills that may be underdeveloped. Children with special needs also may exhibit problem behaviors such as anxiety, disruptiveness, and aggression. These behaviors need to be understood so appropriate

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interventions can be applied to help the child overcome them. To individualize students’ education based on their unique needs, staff in special education programs collect learning and behavioral data that help them diagnose problems, evaluate the effectiveness of interventions, and monitor progress over time. Under U.S. special education laws, quantifiable evidence of progress is required for reports to parents, school districts, and state agencies.

Each child with autism has unique, complex, and changing needs, making each day in special education unpredictable. To set the scene for this paper, we developed the following scenarios from our fieldwork. They highlight the issues that impact data collection in the autism classroom, which we refer to throughout the paper.

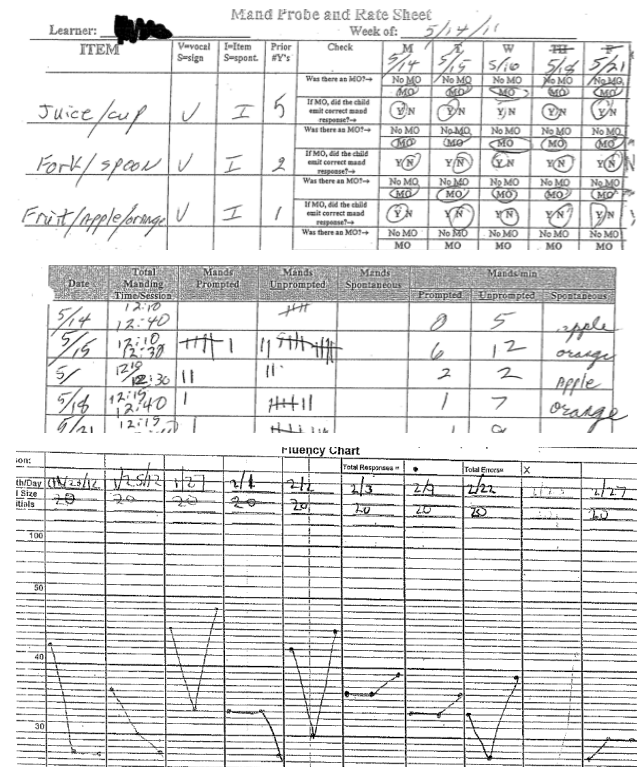


Figure 1. Three sample sheets used to collect behavioral data on paper. (Top) Two sheets filled out *in situ* while working on the language skill, manding—verbally requesting a desired object such as a cup of juice or an apple. (Bottom) A chart used to graph student fluency data—i.e., the ability to recall mastered skills—by hand each day.

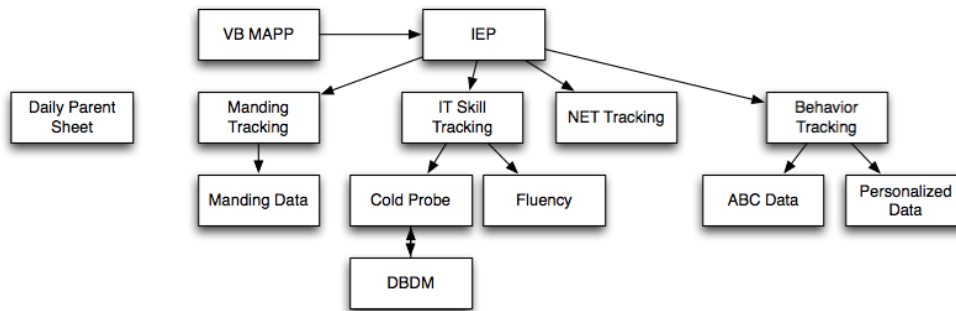


Figure 2. (Left) Our model of the data sheets used by a school, demonstrating the complexity caused by a large number of highly specialized sheets. (Right) A teacher's desk at the same school, with a lot of storage for data sheets – a bookcase full of binders on the left, and a filing cabinet on the right.

Behaviors. Amanda, 10 years old, has suddenly begun displaying negative reactions to balls. Her mother reports similar behavior at home. Her siblings can no longer play basketball in front of their house because Amanda will become very upset. Having removed all anxiety-provoking objects from Amanda's sight, the staff are now applying an intervention to gradually introduce balls back into her life. They begin with desensitizing her to seeing a ball in the room, and collect data on her behavior during encounters with a ball to help them track her progress.

Skill learning. A teacher, Clara, has prepared a lesson plan for her 13-16 year old students on different types of cows. Sitting at desks in a circle with her four students, she reads aloud a sentence at a time while showing them pictures of each cow. She asks each of her students in turn to repeat words from the lesson plan, as a way of practicing verbal communication and social skills such as taking turns to speak. One student, Drew, becomes unexpectedly upset and hits the table repeatedly. In response to the loud noise, Albert stands up and runs out of the room. While one teaching aide tries to calm Drew, another follows Albert. Clara calmly tries to continue her lesson in an effort to avoid further arousal of the other students. When the chaos subsides, the staff collect data on each student's behaviors.

Interruptions. Jeremy, who is 15, is a big fan of elevators and is easily distracted by them. His teacher, Tim, tries to keep him focused as they walk by an elevator, but Jeremy makes a beeline into the elevator. Tim stands in the doorway to prevent the elevator from leaving, but she cannot convince Jeremy to exit the elevator. They stay in the elevator for about 30 minutes until Jeremy is finally willing to come out. In the meantime, Tim asks the librarian next door to attend to his classroom to ensure there is adequate supervision for the other students. Tim later records data about this episode and its antecedents so that he can try to determine triggers for the behavior and work to decrease its frequency.

DATA COLLECTION PROCESS

Special education staff, including teachers, aides, and therapists, collect data on a regular basis. They collect data *in situ* in a variety of ways to monitor students' mastery of

skills. For example, staff record the number of consecutive days in which a task such as counting or spelling was successfully completed. The staff will also time students to measure how quickly they can recall mastered skills. To monitor behaviors, staff will also record the frequency of specific behaviors that may happen anytime throughout the school day. Sometimes capturing data in the moment is not possible, and the staff write down what happened at a later time, affecting the accuracy of data. Though the staff value the data, data collection often falls in priority due to their students' needs for individual attention.

Figure 1 shows examples of data sheets filled out *in situ*. The top sheet was completed while working with a student on the language skill, "manding," that is, verbally requesting a desired object such as a cup of juice or an apple. The bottom chart shows student's "fluency" data, which measures his ability to recall mastered skills.

The left panel of Figure 2 shows our model of one school's system of data sheets. The thirteen kinds of data reveal the complexity of data collected about each student every day. A significant number of data sheets are generated, requiring the staff to use large binders to store data for each student. A teacher's collection of binders takes up a large amount of storage space at her desk (Figure 2, Right). Staff may review collected data as often as once per day to check each student's progress and adjust daily goals accordingly.

Given the burden of collecting so much data, the importance of using it to aid student development, and the necessity of reporting it by law, it is surprising that staff use paper almost exclusively for collecting, and even graphing data. This reliance on paper is all the more surprising given the widespread use of assistive technology by the students themselves to support learning, skill building, and independence. As we discovered in this work, staff are accustomed to having assistive technology in the school and are eager to introduce new kinds of technology into their activities. Yet the schools almost exclusively use paper to collect, share, and use data. Given the complexities of collecting data in this domain, we explored why technology has been unable to meet the needs of these users.

WHY PAPER PERSISTS IN THE WORKPLACE

Researchers have explored the use of paper in everyday work practices within other domains where complexity made the transition to technology difficult. Mackay [14] studied the role of paper flight strips by air traffic controllers – whose work practices are similar to those in special education because they are complex, social, collaborative, and the wellbeing of others depends on them. Mackay’s work on interactive paper using augmented reality stemmed from observations similar to those we have made in special education:

Contrary to what many believe, users are not Luddites, clinging to paper as a way of resisting change. On the contrary: most are excited by the benefits offered by computers and some are even accomplished hackers. Their resistance is, in fact, extremely practical. New computer systems are either less efficient or simply cannot perform many required tasks. [15]

In this paper, we discuss the excitement in special education surrounding use of technology, and the practical reasons why, despite this enthusiasm, technology is not being leveraged for the collection and use of student data. While Mackay recommended augmented paper as a way of introducing technology in air traffic control, other domains have required different solutions. Shehory *et al.* [19] applied a web-based multi-agent infrastructure to replace notes and sketches made on paper during a standardized process for aircraft maintenance repair. However, unlike these two domains, special education does not have standardized or well-established work practices. Due to the individualized needs of each student and the unpredictable nature of the special education work environment, best practices are applied in customized ways and adjusted frequently. In our fieldwork we studied these complexities to understand how technology might be able to replace paper in this domain to support complex data collection.

Use of data is also limited in special education due to the constraints of having data on paper and little time to review it. In other domains, customized tools have been developed to help specialists use data in more powerful ways. Bier, Ishak, and Chi [1] developed a software tool to help intelligence analysts make sense of the data they collect in an electronic document – including going through data more efficiently and drawing more connections in the data. This kind of sensemaking also happens in special education. Due to a still limited understanding of autism and other special needs, and the uncertainty and variety of interventions used, sense making is complex. The staff make decisions based on their expertise and an intimate knowledge of students. Therefore, we draw from Mackay’s recommendation that flight strips for air traffic controllers be augmented but not changed, to “leave the user interface and its subsequent evolution in the hands of the people most responsible, the air traffic controllers themselves.”

In special education, we view “the user interface and its subsequent evolution” as the data sheets and data collection

model currently used. In this work, we did not set out to fundamentally change the way data is collected. Staff in the special education domain need support to collect and use data, but we did not want to change their fundamental methods, as they alone are the experts on their data collection process. We explored how technology can support staff in collecting and using data so that their human expertise and collaboration can still drive the process and empower nuanced sense making.

This approach differs from other work on improving data collection in the autism domain in two ways: (1) we focus on staff playing an active role in collecting data, and (2) we seek to understand the complexity of complete data needs within a classroom. Other work has been aimed at reducing burden on users as much as possible, by seeking to automate data collection using capture and access, sensors, and other highly augmented collection methods. These types of systems collect large amounts of data automatically while a child is engaging in an activity [8, 21], or with minimal involvement from staff or caregivers [7, 9, 10, 16, 17]. Our work complements these systems by providing an understanding of the expert’s role in collecting data *in situ*. We considered the implicit processes at play when experts (teaching staff and therapists) collect and use data, and we tried to make these processes explicit to inform the design of technologies that support or automate data collection. We focused on understanding current data collection methods without changing them in order to learn about experts’ work practices. We also studied use of the data, including information sharing among staff and the ability to craft reports about multiple kinds of data for multiple stakeholders. Finally, we looked at data collection and use broadly in the classroom setting, rather than within the context of a particular therapy or activity, to address the multiplicity and complexity of the complete data needs.

Abaris, a system designed to support a specialized approach for *autism therapy*, was developed using a model closer to our own, that is, supporting collaborative collection and use of data for decision-making [12]. We build on this work by studying a variety of approaches and interventions at several schools, and understanding how a system like Abaris could operate in the complex and unpredictable setting of a school. AMA, a tablet application for annotation, monitoring, and analysis, was developed with goals similar to ours [18]. We contribute to the development of these kinds of applications by providing a real-world investigation of how they can be used in special education, and understanding why similar, widely available applications are not currently being used in schools.

In our fieldwork, we wanted to understand work practices in special education around the collection and use of behavioral data. We set out to find what role technology can play in supporting these work practices without changing them or interfering with them.

Why the staff use paper to collect data	1. Data needs are complex and not standardized
	2. Immediate demands of the job interfere with thorough <i>in situ</i> data collection
	3. Existing technology for data collection is inadequate
Why technology could improve sharing and use of collected data	4. Data sheets are idiosyncratic and not useful without human mediation
	5. Improved communication with parents could benefit children’s development
	6. Staff are willing, and even eager, to incorporate technology

Table 1. We identified six factors that affect data collection and use in autism education: three factors explain why paper is being used to collect data, and three factors reveal opportunities for technology to improve sharing and use of data.

METHODS

Six researchers conducted fieldwork over the course of six months. Our field sites were 7 special education programs in 4 states providing services to children with autism and other special needs. Six of the sites were schools (two with residential programs), and one was a therapy center providing after-school services. While the organizations differed somewhat, their services for children with autism were similar. Participants were recruited by word of mouth. All activities were approved by our university’s review board, and the sites’ review boards if required.

Our fieldwork included 58 person-hours of observation and 62 interviews with staff. We primarily interviewed teachers [n=14], because they play the largest role in data collection. In one school, we surveyed 130 of their 150 staff, with 49 of the staff also participating in two focus groups. In our fieldwork we interacted with teaching staff, therapeutic staff (e.g., speech, physical, occupational), and administrators. We observed staff and students in the school environment but did not interview any children.

Children with autism are reactive to change in their environment, so the presence of even passive observers may be disruptive and distracting. We therefore used mixed methods to gain as accurate of a picture as possible of the natural daily activities of all our participants. We conducted contextual inquiries [2] with the staff to understand their workflow and tools. We used interviews and focus groups to gain an understanding of aspects we would not be able to capture only through naturalistic observation [6, 13]. During fieldwork we took detailed notes, and the research team met after fieldwork sessions to discuss and interpret the data. We used affinity analysis [2] to combine data from different sites, collected by different researchers.

We also conducted a competitive analysis to understand the data collection tools currently available. This knowledge enabled us to discuss tools during fieldwork, helping us discover why the tools were not their meeting needs. We focused on mobile apps for data collection because of the ease of integrating their use *in situ*, the abundance and popularity of these apps, and the high degree of interest we observed in iPads. We searched app stores, blogs, reviews, and forums, identifying apps using two criteria: 1) popular apps that were the most downloaded, discussed, and

reviewed, and 2) apps that are representative of the type of functionality available. We identified 5 apps: ABC Data Pro, Autism Tracker Pro, Behavior Journal, Behavior Tracker Pro, and Catalyst HD. All were available for download on the iTunes App Store. One was free, one had a monthly subscription fee of \$40, and the rest ranged from a one-time payment of \$10 to \$30. The comparative costs were not reflected in the quality or functionality of the apps. These five apps were analyzed based on established usability principles [3, 20], and user experience metrics adapted for ubiquitous health technologies [4].

RESULTS

Through our fieldwork, we identified six factors affecting data collection in special education (see Table 1). Three factors suggest why paper is still being used to collect data. Three other factors suggest opportunities for technology to improve sharing and use of data, in addition to supporting and streamlining data collection.

Why they use paper to collect data

During our formative research, we narrowed our focus from the use of technology in special education to the collection and use of data. We were surprised that technology was not being used in this area, and it became very clear that these processes are both critical and cumbersome. For those two reasons, data collection was one of our most frequently encountered topics. As our fieldwork continued we found two challenges staff face in collecting data: data needs are complex and not standardized, and the immediate demands of their job interfere with thorough *in situ* data collection. These challenges explain the persistence of paper due to the complexities of the domain and demands on the staff. Later, we discuss how existing technology is not meeting the needs of the staff as a result of these demands.

1. Data needs are complex and not standardized

Data needs in special education derive from the individualized nature of teaching. Skills that need to be developed in special education include life skills such as sitting correctly in a chair, learning goals such as reading and counting, social skills such as greeting a stranger, as well as curbing any aggressive or disruptive behavior. Each student’s learning goals will differ, and a student’s goals will change based on his development. As such, data help staff track these changes and make decisions about interventions and approaches to use with each student.

One teacher described a particular data sheet as the “backbone” of her work with students. Staff depend on data sheets for making everyday decisions to help their students succeed. Each student progresses differently, and sometimes working on a particular skill may take months of painstaking work before staff see progress. Data is sometimes the only way to judge a student’s progress.

Perhaps due to the high need for individualization and flexibility, there is little standardization of methods for data collection in special education. For example, the model shown in Figure 2 (Left) is only representative of one school we studied. The other programs used different systems and entirely different sheets for collecting the data. Each program determines its own system for collecting data, and each staff member may adapt the system to her own work practices. These systems are so complex that they take a significant amount of time to learn:

“The time to learn a data recording system can take anywhere from a week or two to over a month depending on the employee’s position and type of data that they record.” –Staff member in a focus group

Data collection enables the staff to monitor a student’s development, and adjust interventions regularly depending on how a student is progressing. If an intervention is improving a student’s learning or behavior, staff must have evidence of that progress to show that the approach works well for that student. If an intervention is not resulting in improvement, the staff need to recognize this in order to change course and evaluate other interventions.

Due to the range and transience of student goals, teachers develop lesson plans with activities more complex than typical subjects such as math or reading. Lesson plans integrate many skills in order to address the individual needs of students. In order to help students generalize what they learn to different situations, teachers randomize the skills they work on and the order in which students will work on them. According to Tracy this dynamic and unpredictable approach to teaching “gets [students] ready for the real world, it helps them be flexible”. However, it also makes data collection a complex process. Collection methods need to be dynamic and flexible enough to keep up with constant changes. This was a main reason paper seemed to be the only reliable method of collecting data. We saw staff adapt data sheets to their own personal work practices so they could be as efficient and accurate as possible. Even small adaptations such as adding an extra column seemed to help make a data sheet more usable.

During our contextual inquiries, we noticed staff would make these minor adaptations to data sheets for themselves. Interestingly, when we probed about the possibility of the sheets being designed to suit their needs better or help them work more efficiently, the staff were unable to suggest many improvements, stating that they weren’t sure because out of necessity they had figured out how to make that sheet

work for them. As Alicia put it, “maybe I only like [the sheet] because it’s what I’m used to... it works.”

This response spoke to the incredible adaptability of special education staff, in making a system work for them so that they can focus on helping their students. Their job pushes them to be creative in most aspects, yet because they are so reliant on current data collection methods they are forced to adapt to them rather than think past them to what might be more effective. For technology designers, this means these particular users may not provide much in the way of design ideas. Moreover, this finding speaks to a certain amount of rigidity when it comes to changing an established data collection process. Not only is the process deeply integrated into classroom activities, but staff have also worked so hard to make the process work for them that they can’t seem to be able to consider another possible process. Changing the process may therefore lead to staff resistance or stress.

At the same time, each teacher’s adaptation of the sheets led to increased inconsistency in how data was collected:

“It’s not consistent. Sometimes I won’t know what data is being collected. I won’t know how to read someone else’s data sheet.” –Staff member in a focus group

Problems with inconsistency, which were common, suggest that a change in process would improve the impact of data collected. Administrators from one school spoke frequently about the importance of inter-rater reliability amongst all of the staff collecting data on their students. Staff at this school regularly performed inter-rater reliability checks.

Another problem with data inconsistency is when students are transferred between classrooms or schools:

“When you transfer a student you’re looking at the data sheet and you’re trying to figure out how they worked with it. Instead of just having a system that goes with them and stays consistent year to year.” –Staff member in a focus group

A lack of standardization, coupled with individual staff members’ necessitated adaptations of sheets, often leads to problems using data that was previously collected on a student. This challenge seemed to leave staff with unusable data, forced to guess about a student’s past history and start data collection from scratch. Sometimes, students arrived at a new school with no data at all.

2. Immediate demands of their job interfere with thorough in situ data collection

Adding to the difficulty of collecting data, the staff need to make sure the data is accurate by collecting it *in situ*. Whether tracking each time a student exhibits a type of behavior, or monitoring the acquisition of a skill through repeated trials, staff need to work closely with a student and observe his behavior carefully. A piece of paper is always nearby—at arm’s length whenever possible—for recording data during most activities. However, the staff’s work with the children and collection of data naturally interfere with one another, creating conflicting demands on their attention. Data should be collected *in situ* to ensure

accuracy, but by writing down that data, they take some of their attention away from students.

Staff reported that they sometimes don't have a chance to capture data because they are in a situation in which they absolutely cannot afford the distraction. This kind of situation may happen if a student is having a difficult day and unable to stay on task, or if it is a particularly chaotic day in the classroom overall. Many staff reported that they sometimes have to record data on sheets at the end of the day instead, though admitting "I have trouble remembering the exact details of all behaviors from one day" (Tracy, teacher). The demands of their immediate responsibilities to their students can get in the way of data collection, and despite the fact that they recognize the value of data, in the moment they will choose their students over data.

A day in special education is rarely typical, making it difficult to rely on predictable methods of collecting data. Special education is rarely predictable and often chaotic. Student behaviors are quite unpredictable, and a day can be turned upside down by one student having a difficult day. When staff have to respond and attend to one student who is having a difficult day, the rest of the staff must help to cover for one another. Moreover, one student's anxiety and behaviors can affect another's, quickly spreading tension or chaos to an entire room. Staff respond to these events using best practices they've been trained in, but their response will be highly based on their own expertise and their nuanced understanding of each individual student. Each child with autism is unique, and special education is work that is inherently and complexly human and social – as such, it is an environment that is difficult to automate.

However, a significant opportunity for technology to support staff in collecting data is to free up their attention so they can focus on their students. One staff member participating in a focus group, describing how cumbersome it is to collect data on paper and transfer that data several times, lamented that "it's taking time from the kids." One of the complaints we heard most frequently from staff was the amount of energy spent on paperwork. They found the cumbersome process frustrating because the most important aspect of their role is their direct work with children, and as a result they often have to take any unfinished paperwork home at the end of the workday.

One staff member wanted to involve students in data collection, to help him engage with the children rather than taking his attention away from them. He used a wall display with pipe cleaners to count behavior points where they were visible to students, rather than on a piece of paper only he could see. Students had greater awareness of when they were receiving or losing points (which can be effective reinforcement), and by engaging them in the collection, this method helped to bring his attention back to the students. However, it also increased the burden as it took him additional time to transfer the data to paper afterwards. If technology supports data collection and can also engage

students (similar to [5, 11]), it can reduce burden on staff and also enhance motivation to collect data by leveraging the staff's desire to engage with their students.

Though we expected other factors—such as cost, politics, or resistance to new technology—to contribute to the difficulty of adopting technology in schools, we discovered that time was the single most limiting factor. Staff in special education are regularly overburdened, and face-to-face time with their students always comes first. As a result, little time remains for their other responsibilities such as data collection or staff collaboration, and there is almost no time for researching or learning new technologies. From our focus groups and survey at one school, we found that professional development was a problem that administrators were aware of and staff expressed frustration with:

"New tech training has kind of been trial by fire. I wish there was more a chance to learn new systems before being thrown in there." –Staff member in a focus group

The staff struggle to learn and incorporate technologies with the little time and training they have available. Changing their data collection processes from paper to technology would require significant effort, and adequate professional development would be critical.

3. Existing technology for data collection is inadequate

We encountered hardware such as iPads and Smart Boards in schools, but the staff had difficulty incorporating them into their activities due to a lack of adequate software applications that would make these devices useful for them. Grants made iPads and Smart Boards attainable for three schools we studied. One school had provided an iPad for each staff member. Another school purchased three iPads to trial, and our survey at this school revealed that iPads were in high demand among the staff—they were one of the most common topics of responses to both closed-ended and open-ended questions. Administrators at this school were in discussions to purchase additional iPads, but wanted to understand first how they would be used and what software was available, rather than purchasing them as a hardware device without a specific purpose.

The hesitation of these administrators points to a key reason that paper is still being used for data collection—existing technology is inadequate. There is no existing system that is widely known and recommended for data collection, which is unusual in a domain where many creative parents and staff discover and share effective solutions. For example, Proloquo2Go is a popular communication app for children who have limited speech, and Talking Tom Cat is a popular game that appeals to children with autism. When apps are as effective as these two examples, they become popular through word of mouth, parent support groups, online forums and educational blogs. So, it is unusual that there is no well-known app for supporting data collection and use—and an indication that existing apps are inadequate.

Another school we studied had set out to find an app to use on the iPads they already own. They were even able to

devote some time to this endeavor, having several staff members test existing apps on their iPads. However, their disappointment with the functionality and usability of these apps led them to abandon their search and continue to use paper. Our competitive analysis of existing apps revealed what aspects made them fall short of meeting their needs. Our findings echo the complaints reported by the school.

Not practical for collecting data on multiple students. We first discovered that many of the apps were designed for collecting data on a single student. Few supported separating data by student, which is critical for the school environment. In addition, data could only be collected using a single device and was stored locally on the device. This kind of use is not practical given the number of staff interacting with a student in a school day, and the unpredictability that causes the staff to have to cover for each other often. More importantly, data cannot be stored locally on devices due to personal health and educational data privacy laws (HIPAA and FERPA, respectively). These laws ensure student data is protected, and make it impossible to use many existing apps in schools.

Tradeoff between burdensome customization and limited functionality. Given the complexity of collecting different types of data on each student depending on individualized goals, apps failed to manage an important tradeoff between burdensome customization and limited functionality. Those that provided simple and easy to use collection methods were too limited in their functionality, and lacked customization for a variety of students. However, those apps that provided customization added significant burden to the user, and tended to also suffer from usability issues. Some apps included so many options for data collection that the amount of time it takes to complete a report would not be practical in a special education environment. We also saw apps attempting to enable a variety of data collection methods by using such unconventional interactions as a triple tap and two-finger tap. These interactions are unintuitive and not feasible to use in an unpredictable environment that is demanding on the staff's attention.

Lack of support for data use and analysis. Most apps were focused only on the collection of data, and did not support users in sharing or analyzing the data effectively. Some provided low-fidelity line graphs or a means of sending raw data by email from the application. Based on our fieldwork findings that we discuss in the next section, these features would not provide much value to staff, who need sophisticated analyses of school-wide data, and quick ways of sharing digestible snippets of key data.

Attempts to be engaging impeded usability. Most of the apps embraced their context of use and used school-related design elements such as pencils, crayons, notebooks, and primary colors. However, these design elements, coupled with interactions that broke with convention, tended to be distracting or confusing and ultimately impeded usability. One app had an interface mimicking a multi-section

notebook, but inconsistently implemented this metaphor. For example, clicking on a section tab opened a pop-up window rather than mimicking a page turn to that section.

Schools reported the same shortcomings that we found in existing systems, and pointed to those shortcomings as reasons for sticking with paper and pencil.

Why technology could improve sharing and use of collected data

The staff is limited in how they can share and use data that has been collected on paper. Data on paper is difficult to reproduce or share with others. The demands on staff also leave little time to review the data and use it to inform their decisions. With the support of technology, we discovered opportunities for sharing and use of data: improving collaboration among staff, and communication with parents. In addition, the eagerness of staff to incorporate technology into their work shows the feasibility of adoption if systems can meet their data collection needs and offer improvements in collaboration and communication.

4. Data sheets are idiosyncratic and not useful without human mediation

One of the most important uses of data is to help staff monitor student development and make decisions about the most appropriate interventions and approaches to use with each individual student. Collaboration among different types of staff (teachers, teaching aides, speech therapists, occupational therapists, *etc.*) is involved in deciding on interventions for each student. Though some best practices exist for interventions, each child with autism is unique and staff must be creative in applying interventions to each individual student's case. Teaching staff spend their time with the same set of students—those in their classroom—while other types of staff have larger caseloads assigned to them. For example, a speech therapist we interviewed covered two classrooms. Other therapists have even larger caseloads, working with a larger portion of the school.

The teaching staff know their own students best, while therapeutic staff are experts on developing particular skills. Together they determine interventions and goals for each individual student. When teachers struggle with a student's grasp of a particular skill, they seek advice from one of the therapists on how to best help the student. Similarly, therapists spend one-on-one time with students a few times a week, evaluating their skills and working with them in focused therapy sessions. Therapists then report back to teaching staff, so that the same work with the student can continue in the classroom. Jamie, a speech therapist, explained that this type of collaboration is critical "because therapy doesn't work if you're only doing it two times a week". The interventions used by the therapists should match those used by the teaching staff.

Despite the importance of staff collaboration, our participants frequently discussed the issue of time:

"I wish we had time. I feel like staff here are really innovative. People work in teams and do cool things. This

year I lost all my time... we need time to mess with things and see what works.” – Staff member in a focus group

Staff collaboration was described as running into each other in the hallway, talking in passing while doing something else such as cleaning up, or stopping by someone’s office to try and catch them. One staff member estimated that 60-70% of collaboration is done in passing. Staff use email and phone to reach out to one another, but rarely have the time to sit down for a scheduled meeting. Scheduled face to face time may be every few weeks, but during busy times of the school year these meetings are cancelled. Jared, a member of the teaching staff said this situation is “pathetic”.

Due in part to the limited time the staff have for collaborating, they share little data among one another. First of all, the lack of standardization makes it difficult to interpret data collected by someone else. Second, a lack of face-to-face collaboration makes it difficult to share and discuss data. Jamie, a speech therapist, shares with teachers the data that she collects during one-on-one therapy sessions, but she knows many of them do not look at the data. She feels that she can make a bigger impact by walking into a teacher’s classroom and briefly explaining some advice she has for working with a student based on her data. She can only hope that teachers put her advice to use and that it influences their teaching. Overall, she feels there is only so much she can do because she knows that the teaching staff have a lot of demands on their time and so are not likely to be able to look at data that she provides. This concerns her given the importance she noted of continuing therapy outside of one-on-one sessions, and inserting it through the school day. There is an opportunity for technology to help someone like Jamie communicate her data to other staff in a palatable way. Given the impromptu nature of collaboration, data analysis and visualization could help staff prepare and discuss data more efficiently.

One of the schools we studied had a particularly strong interest in data, originating from an administrator who wanted to improve collaboration. She had recently joined the school and enforced a system for more structured and frequent data collection based on a standardized point system. At first, staff did not like the extra work involved in the incorporation of this system. However, the school’s new system grew on staff as they came to understand the value of data and the administrator’s vision for it:

“Data basically needs to be available to the rest of the team, parents, therapy providers, changes in staff, supervisors. It needs to be analyzed on many different dimensions: within classrooms, across the school, across gender.” –Stephanie, Administrator

While data is now more available, Stephanie recognized that technological tools to empower both collection and analysis were missing. As long as data is still on paper, they are significantly limited in what they can do. This school had attempted to find and adopt an iPad application for data collection, and in their search evaluated the same apps that we did for our competitive analysis. Echoing the issues we

found with the apps, Stephanie said none of them met their needs so they were forced to stick with paper.

There is significant opportunity for technology to provide visualizations and other tools for easily sharing important snippets of data and supporting collaboration and decision-making around the data. In addition, schools want to be able to make school-wide comparisons, for example across days of the week, gender, staff members, or interventions. Tools for analyzing large data sets would be influential for schools, which are working to find what works for their students and provide evidence for their success, within a domain that has limited standardization and best practices.

5. Improved communication with parents could benefit children’s development

U.S. laws require special education programs to report to state agencies regularly on student progress, and online systems are becoming more common and widely utilized for standardized reporting. Several times a year, school staff must put additional effort into summarizing and reporting data to meet this requirement, as well as to communicate student progress with parents and other staff members. Despite little standardization in data collection, reporting mechanisms are standardized across states, forcing the staff to use tools that they do not find easy to use. Transferring data into these reporting tools adds to their workload and frustration. Technology to aid the transfer of this data would significantly reduce staff burden.

In addition to state-mandated reporting requirements, the staff sees additional value in improved communication with parents. Despite staff’s hard work within the school environment, they recognize that a child’s development is highly dependent on their home life. When parents are knowledgeable and involved with their child’s learning and behavioral goals, children make the most significant progress in their development. Therefore, staff are often looking for ways to engage parents by keeping them informed about what happens with their child at school, and what they can do to continue working on goals at home.

Our focus group participants spoke at length about their efforts to improve communication with parents. For example, because they cannot assume that all families have access to the Internet at home, they had developed a newsletter to send home relatively easily as a mass mailing to all parents. However, they discovered that parents did not want to know generic information about goings on at the school, but rather specific details about their child. Preparing individualized reports would take a significant amount of time, so a parent committee developed a sheet for staff to fill out, in an attempt to make it easier for them. However, this sheet is very unpopular, with both parents and staff, in part because it is sent home each day. Staff feel overburdened and even report having to cut time with their students short in order to have the time to fill out the sheets. On the other side, most parents seem too busy to read such

reports on a daily basis, which staff are aware of because they find the sheets still in their students' backpacks.

Staff argued for communication that is more detailed and frequent, but not a large burden on them. Parents have a legal right to see their child's data, and it can help them make decisions outside of school:

"Parents can see any data sheet they want. Some ask to see all data, and a lot ask for behavior data to show to a psychiatrist—helps with deciding on what meds parents will or will not give their kids. [Sharing data is] needed to make home life better." –Tracy, teacher

In addition to providing data that will help parents at home, staff want data to be shared back and forth to help them do their job. For example, sometimes a behavior is achieved at school, but has not been generalized outside of that context. As a result, a student will not display the behavior at home, and parents may not even believe staff when they report this behavior. This situation is frustrating for staff, who have worked hard with students to achieve the behavior, and want to share data with disbelieving parents as proof.

Staff also wish they received more data from parents, because it helps them predict and respond to student needs:

"Predictors are really important. [We] need to know outside factors, such as changes in meds." –Dylan, behavior specialist

In addition to big changes such as medications, small pieces of information can be helpful to staff. For example, if something anxiety-provoking happens in the morning before a student gets to school, some parents let staff know by phone call or email. This kind of information helps staff not only predict student behaviors, but also interpret and respond to them appropriately. Unfortunately, parents rarely provide staff with this kind of information. Providing a different mechanism for sharing data could increase the amount of information shared by parents, by making it more convenient or creating more motivators.

6. Staff are willing, and even eager, to incorporate technology

Staff are open to and eager to try new technologies if they have reason to believe it would support their work practices and they see evidence of a technology's success. For example, the recent rise in use of the Apple iPad has made a significant impact on the special education community. The device is very affordable compared to traditional assistive devices that cost thousands of dollars each. Moreover, with a plethora of apps available, it can replace multiple devices created for a specific purpose. Staff and parents alike are excited by stories about various apps that have made an impact on children with autism. However, they find the number of apps available to be overwhelming, especially since the right app needs to be matched to each individual child according to his needs. Many feel that it would take too much time to look through all of the apps to find the right one for each child:

"I think there's a lot more out there available, but it just takes time and energy to find it." –Zoe, Teacher

Despite this drawback, there is still significant excitement about incorporating iPads into many aspects of special education. In our focus groups and many of our interviews, iPads came up as solutions to a variety of problems, especially data collection. Participants thought iPads would give them the mobility to collect data around the classroom and the power to store and analyze large amounts of data – however they were not sure how exactly this would work. Still, some staff were quick to point out that iPads are not a panacea, especially considering the time it would take to find the right app for many different individualized goals.

Technology was brought up frequently when we discussed data collection in our fieldwork. Staff pointed out many benefits of incorporating technology, including saving paper, saving time, and providing easier access to data:

"We have parent-teacher communication forms that have to be filled out every day. It's a ton of paper that's being wasted. Can we do this electronically? Teachers can sit down each day and say this is what has been covered. If you're looking for information on what's being done each and every day there should be somewhere you can go." –Staff member in a focus group

The eagerness of staff to use technology for data collection, and their astute suggestions as to how it would improve their process, made it all the more surprising that all of the schools we studied were still using paper. Even the schools that had been recently equipped with iPads or Smart Boards, and had them readily available, had not incorporated them into their activities. Time was the single most limiting factor in this environment, and revealed significant barriers to adoption of technology.

CONCLUSION

In our fieldwork, we found evidence explaining why paper is used almost exclusively for collecting and using data in autism education. We identified six factors affecting data collection in autism education: three explained why paper was used and technology had not been incorporated into data collection, and another three revealed opportunities for technology to support sharing and use of collected data.

Three factors helped to answer our primary research question: why are they using paper? First, the individualized nature of autism education requires collection of a significant amount of data for the purposes of tracking student development. These data needs are complex due to the unique needs of each student, and methods for collecting the data are not standardized. Second, individual student needs and the unpredictable nature of the special education environment create significant demands on staff, and interfere with the collection of data *in situ*. Third, existing technology for data collection is inadequate. Our participants confirmed what we found in a competitive analysis of apps currently available for download: they are not practical for use in the classroom, they do not provide appropriate customization for individual students, they do not support sharing or analysis of data, and many also suffer from usability flaws.

In addition to understanding what role technology could play in the collection of data, we identified opportunities for technology to improve the use of collected data. First, the data sheets used are idiosyncratic and are not useful without human mediation. However, the demands on staff in special education leave little time for discussions about data. Tools enabling the quick capture and sharing of important snippets of data would support discussion, enable more collaboration and decision-making around the data, and also require limited prep time for the overburdened staff. Second, because student development is dependent on the consistency of interventions applied in school *and* in the home, it is important for staff and parents to communicate. Both sides struggle to keep each other informed, so if technology could improve the sharing of data that has been collected, better communication between staff and parents could benefit student development. Third, staff's eagerness to incorporate technology into their work practices suggests that it would be feasible to pursue these opportunities for supporting collaboration and communication.

In special education, it is critical for multiple kinds of data to be collected *in situ*. However, the number of interruptions and activities, and other people to be consulted, interfere with data collection. Staff in our fieldwork perceived that paper is much easier for jotting down notes, editing them later, and collaborating with others on these notes than any technology they have tried. Paradoxically, we found that the persistence of paper reduces the amount of sharing and use of data. The large collection of data sheets is difficult to use. By replacing paper with technological tools that better fit the needs of *in situ* data collection and data storage, we hope to empower their use of data.

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