Designing for Collaborative Reflection
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Keywords

Health information technology, coordination of care, electronic health records, special education, behavioral and mental health services, social informatics, organizational information systems, organization science, action research, anthropology, human-centered design, participatory design, user experience design, field studies, human-computer interaction, computer-supported cooperative work, ubiquitous computing, pervasive computing.

Abstract

A rise in chronic conditions has put a strain on our healthcare system. Treatment for chronic conditions spans time, agencies, and providers, making coordination a complex problem. Information systems such as electronic health records should be helping with the challenge of coordination, but research shows that often they do not. This thesis aims to alleviate this problem by examining the design of health information technology with an emphasis on social and organizational processes. The focus of this thesis is on the implications of continuous care over time: the shift from a single provider to team-based services, the emergence of patients and families as primary caregivers in the home, and the diffusion of data-driven decision making. I investigated these trends to understand the role of data in coordinating long-term care, and inform the design of information systems.

I studied behavioral and mental health services for children, which are coordinated across clinical, home, and special education settings. I found coordination that was unstructured, unpredictable, and adaptive. I developed a conceptual framework, collaborative reflection, to describe my observations and distinguish my findings from the processes of time-critical and protocol-based care. I also found ways in which coordination was not data-driven, due to a lack of support and tools. Collaborative reflection thus illustrates how long-term coordination works when it is data-driven, informing a discussion of what is needed for coordination to be data-driven.

Based on the process of collaborative reflection, and using participatory design, I developed Lilypad—a tablet-based information system for data-driven coordination. I conducted a five-month deployment study of Lilypad in the field, to examine its social impact. This study validated designing for collaborative reflection to improve the use of data in coordination.

The contributions of this thesis are: a description of unstructured and informal workflow that drives long-term coordination in health services; the theoretical construct of collaborative reflection to inform the design of systems that improve coordination; a field deployment validation, demonstrating how designing for collaborative reflection improves coordination and avoids common unintended consequences of health information technology.

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Chapter 1

Coordination of Chronic Care

> *"The system for healthcare delivery in the United States, in regard to physical and mental health, is neither logical nor a system. In reality, it is a nonsystem… a conglomerate of health practitioners, agencies, and institutions, all of which operate more or less independently. There often is little or no effective planning or coordination."*
>
> William C. Cockerham, *Sociology of Mental Disorder*

Coordination of health services is one of the defining challenges of today's healthcare system. The U.S. healthcare system has grown highly complex due to: a high pace of advances in science and technology; increasing expectations from patients who are more informed and better connected than ever; higher complexity of U.S. laws, regulations, and payment; and an increase in chronic illness. Half of Americans have at least one chronic condition, defined as a physical or mental illness that lasts more than 3 months. Long-term care of chronic conditions requires the coordination of multiple providers and agencies, resulting in 75% of direct medical expenses devoted to chronic conditions. There are so many providers that 17% of the U.S. workforce is employed in medical care. The complexity of coordination among so many providers is illustrated in Figure 1, a care map drawn and shared by a blogger to show how many health services she must navigate as a caregiver for her son, who has complex health care needs (Lind, 2012).

1.1. The changing face of health services

It is important for providers and agencies to coordinate care over time, but they do not have the support or the incentives to do so. Coordination is a relatively new need, because medicine began as an autonomous and paternalistic practice. David Lawrence, Chairman Emeritus of Kaiser Permanente, the largest non-profit health care system in the world, explains the root of the problem: "medicine began as a craft practiced by independent, autonomous professionals who relied on one another only when they had to… this model persists to this day" (2003, p. 11-12). Donald Schön (1983) explains that a reliance on one provider's knowledge and expertise no longer works for addressing problems within a large and complex healthcare system—a problem which affects other professions as well:

> *"Professional knowledge is mismatched to the changing character of the situations of practice—the complexity, uncertainty, instability, uniqueness, and value conflicts which are increasingly perceived as central to the world of*

professional practice. In such fields as medicine, management, and engineering, for example, leading professionals speak of a new awareness of a complexity which resists the skills and techniques of traditional expertise. As physicians have turned their attention from traditional images of medical practice to the predicament of the larger health care system, they have come to see the larger system as a 'tangled web' that traditional medical knowledge and skill cannot untangle." (p. 14)

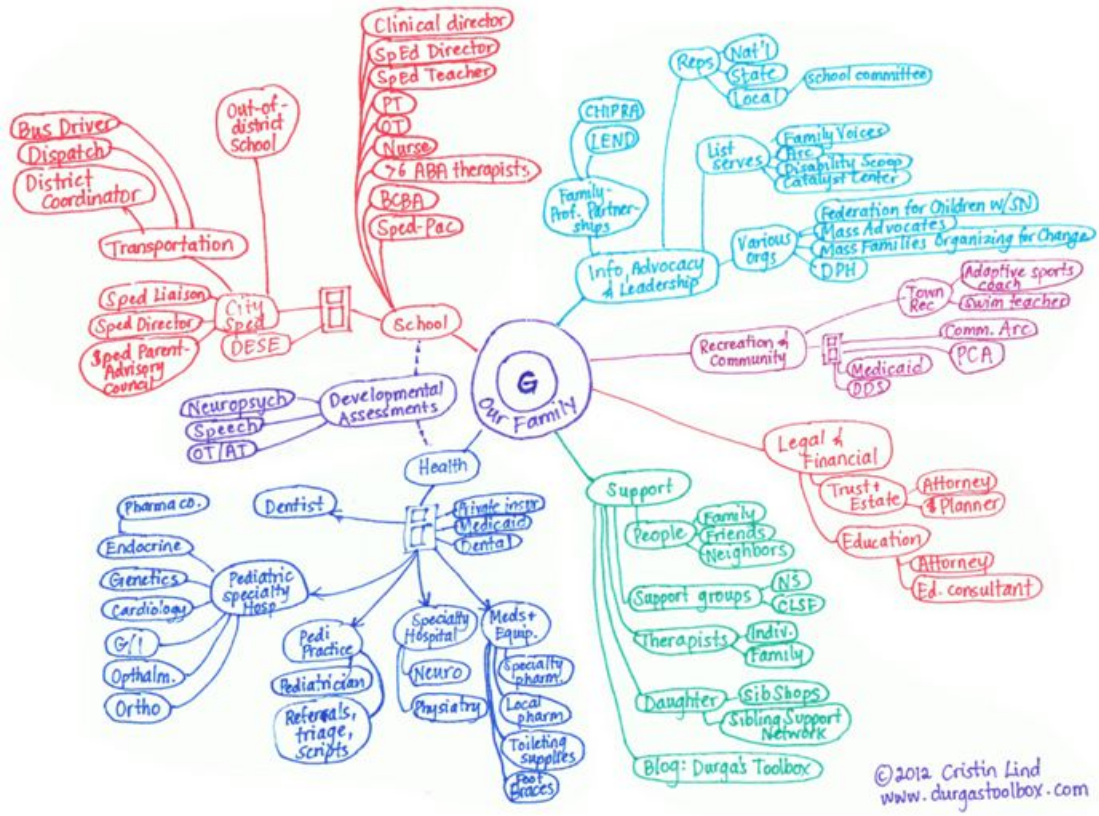

Figure 1. Cristin Lind's care map, illustrating the health services she navigates as caregiver of a child with complex special needs.

Today there is a much higher need for coordination. Due to increased complexity of health needs, "85 percent of the problems a doctor sees in his office are not in the book" (Schön, 1983, p. 16), so providers have a higher need for one another's expertise in order to solve problems. Patients and family caregivers like Lind are also more involved in managing care. Lawrence even found himself in the position of a caregiver just like Lind, when his aging father's health deteriorated quickly in 1999:

"In those last weeks before his death, though, I was unprepared for how hard it was to get the information I needed to help him make decisions about his treatment and care arrangements. Being a local medical-school graduate and

an executive in a large medical organization didn't help. I was just a son, joining my brother and sister and father's wife to help our father navigate a medical-care system ill-suited to deliver what he required." (p. xiv)

That Lawrence's experience navigating decisions and providers was as difficult as Lind's, despite his expertise and well-connected position, is telling. The complexity of today's health care system makes it extremely difficult to navigate even for an expert. In part, Lind's account indicates that services are difficult to navigate due to remnants of a paternalistic and autonomous model of medicine. She wrote, for example, that showing providers the care map in Figure 1 seemed to remind them that they are not her son's only provider:

"I can't say for sure, but it felt as if they treated me with a bit more respect when they could see how many balls I was juggling. One doctor helped me prioritize upcoming appointments once she saw what we were dealing with. In one case, one said that they felt humbled to realize that all this time they considered themselves so central to my son's care, yet there were so many other people in his life who were doing just as much." (Lind, 2012)

In this thesis I address the need described by a growing body of literature as *continuity of care*: to provide a sense that services are connected over time and place by improving information exchange and communication among providers (Gulliford, Naithani, & Morgan, 2006; Jee & Cabana, 2006; Miller, Condin, McKellin, Shaw, Klassen, & Sheps, 2009). My focus is on coordination among providers and caregivers of children with special needs, illustrated by Lind in Figure 1. The challenges of caring for a child with special needs require coordination across various agencies. At the core of this coordination is information sharing across home and school. A child's daily life revolves around these settings, so care is coordinated primarily by caregivers in the home and providers within a specialized school setting.

1.2. Coordination in behavioral and mental health services

I studied collocated team members who provide behavioral and mental health services in special education programs. These programs integrate treatment typical of psychiatric clinics within the school day, enabling a child to live at home and attend school while receiving support to address behavioral, emotional, or social challenges on a daily basis. Children in these programs have diagnoses such as autism spectrum disorders, neurological impairments, and emotional disturbance. Symptoms and behaviors of these disorders vary and change over time, making it important to document behavior and progress (or lack of progress) from treatment interventions. Decision-making is complex due to the long-term nature of treatment and the invisibility of underlying conditions. Teams rely on manually

recorded behavioral data (e.g., social behaviors, aggressive behaviors, behaviors related to skills for independent living) for evidence of progress.

Similar to studies that have examined electronic medical records (Park, Pine, & Chen, 2013), I was interested in what the appropriation of paper-based tools could tell us about information and coordination needs not being met by HIT. The context of special education provided a perspective on formal and informal, objective and subjective aspects of coordination. Contrasting the more rigid and standardized use of HIT in hospitals, in this context HIT use and protocols are only partially standardized and require a significant amount of flexibility (Marcu, Tassini, Carlson, Goodwyn, Rivkin, Schaefer, Dey, & Kiesler, 2013). Behavioral data are formally and informally recorded to evaluate the effectiveness of behavioral interventions and psychiatric medications. Treatment teams coordinate in order to subjectively interpret, and act on, long-term behavioral data. Objective and automated measures cannot be used, though research in computational behavioral science aims to make this possible in the future.

I was surprised to find that coordination for a child with special needs is driven by behavioral data recorded almost exclusively on paper. Despite the emergence of electronic health records and a general trend toward paperless service delivery, what I observed in this context was a reliance on paper despite open frustration with its limitations. Existing health information technology (HIT) was mismatched to the coordination needs in this context, and efforts to transition away from paper had been unsuccessful. To address this problem, I answer the following research questions:

- What is the role of data in coordination?
- What is needed for coordination to be data-driven?
- How can an information system support data-driven coordination?

By posing these research questions within the context of behavioral and mental health services, this thesis addresses a gap in the literature. Most of the literature on health service collaboration has been drawn from studies of hospital environments – *e.g.,* Abraham & Reddy, 2008; Bardram & Bossen, 2005; Mentis, 2010; Paul & Reddy, 2010; Park, Pine, & Chen, 2013; Sarcevic, Marsis, & Burd, 2012. Health services in hospitals involve a large number of protocols and standardized workflows for data-driven decision-making. Examples of formalized structure are the coordination of schedules, staff, patients, space, and equipment (Abraham & Reddy, 2008), computerized physician order entry systems (Niazkhani, Pirnejad, Berg, & Aarts, 2009), and diagnosis and treatment aided by decision support

systems (Kane, Toussaint, & Luz, 2013; Kientz, Hayes, Abowd, & Grinter, 2006). System design has often focused on standardization, which is needed in hospital settings for time-critical care. Time- and safety-critical collaboration has been studied in-depth in trauma resuscitation (Sarcevic, Marsic, & Burd, 2012) and emergency rooms (Paul & Reddy, 2010). In these high-risk environments, information sharing is focused and fast, supporting mutual awareness and distributed cognition.

The literature is biased toward time-critical (or acute) care, which tends to be more structured, predictable, and standardized. This thesis complements the literature by investigating long-term (or chronic) care, which tends to be more unstructured, unpredictable, and adaptive (Figure 2).

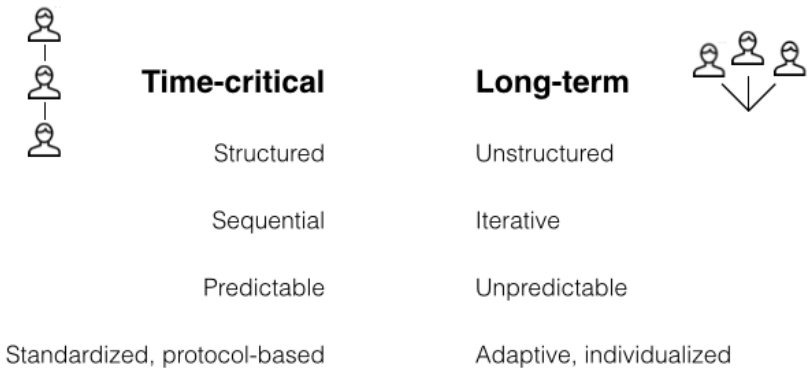

Figure 2. My review of the literature revealed a bias toward time-critical care, which this thesis complements by investigating long-term care.

Real-world practices are of course more complex and messy than these two classifications alone would imply. Even the most structured and protocol-driven settings will have unexpected events, and even the most unpredictable environments will include some standardization. In this thesis I use the simplistic classifications of time-critical and long-term care to distinguish and expose the aspects of coordination that have not been adequately explored in the literature. I use these classifications to examine the role of temporality in coordination, and its implication on the design of systems to support coordination.

1.3. Why long-term coordination is different

Many aspects of health services are not time-critical. Examples include exam rooms (Piper & Hollan, 2008; Weibel, Emmenegger, Lyons, Dixit, Hill, & Hollan, 2013), outpatient psychiatric treatment (Marcu, Bardram, & Gabrielli, 2011), home-based therapy (Kientz *et al.*, 2006), and school-based health services (Marcu *et al.*, 2013; Piper, D'Angelo, & Hollan, 2013). These contexts require a unique kind of coordination that involves ongoing, and often informal, information sharing and decision-making.

The persistence of paper that I observed is not unique to the context of behavioral and mental health services. A broader literature suggests that paper-based tools persist because they are flexible enough to support informal and mobile coordination (Park, Pine, & Chen, 2013; Sarcevic, Weibel, Hollan, & Burd, 2012; Weibel *et al*., 2013). Bardram and Bossen (2005) have characterized coordination within a hospital as "mobility work", explaining that recent trends toward HIT have introduced new challenges because the point of access to information is typically a stationary PC. To support the nature of mobility work, they recommend "systems architectures for more ad hoc, peer-to-peer based interaction" (2005, p. 157). In this thesis I address the design of such systems by studying natural workflows and proposing an organic system design that matches social practices. Like Berg (2003), I believe "'flexible standardization' is not a contradiction in terms" (p. 78). This thesis shows how HIT can include tools for informal mobile coordination that allows for *ad hoc* work and contingencies:

> *"For two reasons mobility work is constantly needed: firstly, even with routine mobility work and [protocol] there still is a need to establish ad hoc configurations of people, places, resources and knowledge since the routines and [protocols] do not cover all needs for the exchange of for example information and resources. Secondly, contingencies often arise that require unforeseen configurations"* (Bardram & Bossen, 2005, p. 151)

As a result of significant focus on time-critical care, many existing tools are not designed for mobility work. Tools for coordination are often designed to support on-the-spot decision-making driven by protocols. Stationary displays have been a popular solution for supporting collaborative work among health service teams. For example, shared displays have supported protocol-based decision-making (Kientz *et al.,* 2006), distributed cognition (Sarcevic, Marsic, & Burd, 2012), temporal and spatial awareness (Bardram, Hansen, & Soegaard, 2006), creation of a communication record (Kane, Toussaint, & Luz, 2013), and conversations between patients and clinicians (Piper & Hollan, 2008).

Mentis predicts that new technologies in healthcare "will inevitably overlook aspects of coordination that are less formal (and thus difficult to represent as part of a persistent and far-reaching digital record), but are just as important as the more objective elements of patient care" (2010, p.5). Even in time-critical decision-making people rely on workarounds, informal documentation, and spontaneous communication (Harrison, Koppel, & Bar-Lev, 2007; Marcu *et al.*, 2013). In these cases, HIT has been supplemented by paper-based documentation and face-to-face communication (Bardram & Bossen, 2005; Park, Pine, & Chen, 2013; Sarcevic, Weibel, Hollan, & Burd, 2012; Weibel *et al*., 2013).

1.4. Bringing anthropology to HCI

The literature therefore identifies a need to focus more on social practices and subjective aspects of work. Berg (2003) summarizes the state of HIT this way:

> *"Currently … health information management deals first and foremost with the challenge of integrating health information systems in health care work in such a way that the quality of that work is improved. This sounds obvious, but … it is not. Health information management is about the complex task of handling technical innovation simultaneously with organizational transformation." (p. 2)*

The design and integration of HIT, then, is a wicked problem – a complex, ill defined, and interconnected social problem that is difficult to solve (Buchanan, 1992). The purpose of this thesis is not to solve this problem, but to learn about it, especially through design and evaluation of a system in context. The goals of this work are to influence and inform future directions of HIT, a task described by Kolko (2012):

> *"Because of the role of design in developing infrastructure, designers can play a central role in mitigating the negative consequences of wicked problems and positioning the broad trajectory of culture in new and more desirable directions. This mitigation is not an easy, quick, or solitary exercise. While traditional circles of entrepreneurship focus on speed and agility, designing for impact is about staying the course through methodical, rigorous iteration. Due to the system qualities of these large problems … this demands interdisciplinary collaboration, and most importantly, perseverance."* (p. 11)

To this end, I have used anthropology-inspired design methods in this work. In my methodology I drew from approaches used in a variety of disciplines, including action research (HCI: Hayes, 2014), action design research (information science: Sein, Henfridsson, Purao, Rossi, & Lindgren, 2011), community-based participatory design (public health: Israel, Eng, Schulz, & Parker, 2012), and applied social research (human services: Monette, Sullivan, & DeJong, 2010). These approaches have rich traditions in other disciplines, but are relatively new to the design of HIT, where they can address wicked problems by combining technical problem solving (what Schön calls professional, craft-based problem solving) with social problem solving (the alternative to what Forsythe (1992) calls 'deleting the social' and muting the voice of users). I used these methods iteratively and followed emerging themes, because "bringing new technology into being is a complex process in which goals are discovered, determined, and modified along the way" (Schön, 1983). Each activity informed the others: I conducted fieldwork to

drive design work, I applied action research and participatory design in the development of a prototype, and I evaluated the prototype through a field study.

I began formative fieldwork at seven organizations providing behavioral and mental health services, to understand the role of coordination. I then focused on two of these organizations to investigate what is needed for coordination to be data-driven, and begin design work on a prototype, Lilypad. Lilypad is designed to support data-driven coordination, and was validated in a field deployment at one of the organizations. Themes that emerged from my formative fieldwork across seven organizations aligned with those that I found in broader literature. Therefore, the formative work focused on services primarily related to autism and special education, but this thesis makes contributions to a broader range of health services. Similarly, the design work delved deeper into two of the organizations and the deployment was in one organization, but frequent comparisons to my own and others' data enabled me to make broader contributions to health service coordination.

1.5. Contributions

This thesis contributes to human-computer interaction, health informatics, social informatics, and user experience design. I describe naturalistic coordination in behavioral and mental health services, and use this context to explain the role of data in long-term coordination (Chapter 2). I provide a theoretical construct, collaborative reflection, to show how long-term coordination works when it is data-driven and distinguish this from when it is not data-driven (Chapter 3). Comparing my findings to other health service settings and themes in the literature, I then use the characteristics of an organic system to isolate and describe what is needed for coordination to be data-driven (Chapter 4). Finally, the Lilypad prototype (Chapter 5) and results of a field deployment (Chapter 6) illustrate and validate this approach.

The contributions of this thesis are: a description of unstructured and informal workflow that drives long-term coordination in health services; the theoretical construct of collaborative reflection to inform the design of systems that improve coordination; a field deployment validation, demonstrating how designing for collaborative reflection improves coordination and avoids common unintended consequences of HIT.

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Chapter 2

What is the role of data in coordination?

This chapter illustrates the role of data in coordination through a study of behavioral and mental health services provided in a school setting. I studied treatment teams who recorded and managed large amounts of behavioral data on children with special needs to develop individualized, data-driven interventions. These teams managed data on frequency and duration of behaviors relating to social interactions and emotion management. The subjective and individual nature of this type of data required a trained behavioral specialist to interpret and record events manually. HIT were difficult to implement in this setting due to the challenges of managing behavioral data, which requires a human to observe an event in the real world, interpret the event to record it in a useful way, and then use their understanding of the child to understand what the data reveals about a child's progress over time.

2.1. Organizational context

My work focused on the clinical services that were integrated with educational services to address behavioral, emotional, and mental health needs. Clinical services were provided by treatment teams comprised of psychiatrists, mental health therapists, behavioral specialists, personal aides, and clinical supervisors. Children had diagnoses such as attention deficit hyperactivity disorder, autism spectrum disorders, trauma, oppositional defiant disorder, and anxiety disorder. The organizations I studied provided structure and treatment in the form of behavioral intervention, frequent positive reinforcement, cognitive behavioral therapy, and psychiatric medications.

Coordination was an ongoing and iterative process in the special education environment. Children had unique needs and developed at their own pace. Therefore, staff relied heavily on data to understand how children were developing and adjust interventions as needed. A large number of stakeholders coordinated on a daily basis around the data, as part of an iterative process of determining, applying, and evaluating interventions. Their coordination was embedded in everyday practices, because staff spent the majority of their time working directly with the children, leaving little time for formal coordination.

Data were manually recorded throughout a school day, and they were not recorded uniformly. People, locations, activities, and types of data sheets changed many times throughout one day. Different people collected data in different situations. These sources of variance increase the complexity of using data for coordination. First, the various stakeholders who collected and used the data were dependent on one another because they each only knew part of the story – *i.e.*, they were present for different events, and

they had different perspectives and expertise with regard to the data. Second, the dynamic environment required coordination to happen in many contexts, from formal case review meetings, to chaotic moments in the classroom, to informal run-ins with other staff in the school hallway.

To give children the resources and support they needed, staff combined perspectives and expertise regularly in order to coordinate services. On a typical day, a teacher, teaching aide, speech therapist, occupational therapist, psychiatrist, and supervisor could all be discussing one child's data. For example, a clinical specialist such as a speech therapist or psychiatrist was depended upon for expertise, however an education paraprofessional such as a teaching aide worked with a child on a daily basis and had the most intimate understanding of that child's progress. Both types of stakeholders contributed their personal knowledge to managing a child's case. They also combined their interpretations of data, since they often collected data separately. However, they most often discussed the data when running into one another in the hallway – they only sat down and discussed a case in detail once every few months at a formal review meeting.

2.2. A paradoxical persistence of paper

I was surprised that staff used paper almost exclusively to record data, manually noting children's behaviors throughout the day. Multiple data sheets were used to capture behavioral data that was quantitative (frequency, duration) or qualitative (antecedent, detailed account of a behavioral episode)—see Figure 1. These data were meant to support coordination by informing treatment decisions and enabling monitoring of the treatment's impact on behaviors. However, staff faced significant problems with manually recording data *in situ*, as well as sharing and using the data for coordination.

By investigating the role of data in coordination, my fieldwork illuminated why existing HIT had not met staff needs, causing them to persist with the use of paper. I 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. I also identified opportunities for technology to improve sharing and use of data. I 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 coordination in this context, and reveal opportunities for technology to support data collection and improve use of data for coordination.

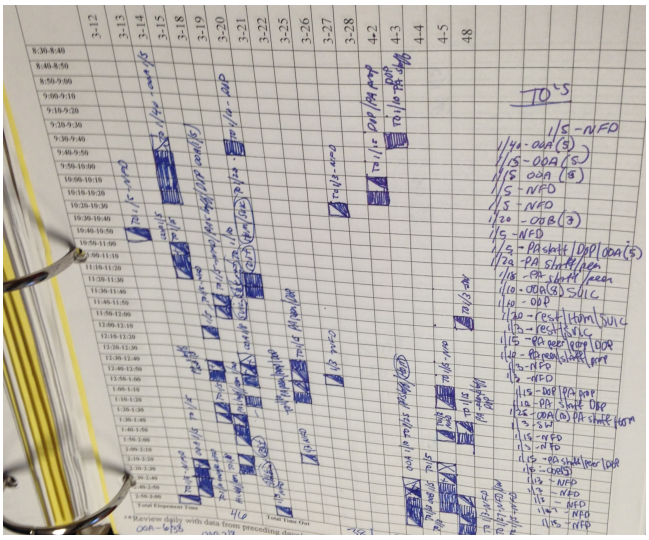

Figure 1. A data sheet used to record quantitative and qualitative data on a child, then stored in a binder.

Figure 2 (left) illustrates one school's record system of thirteen different data sheets, showing the complexity of data collected about each child every day. A significant number of data sheets were generated, requiring the staff to use large binders to store data for each child. A teacher's collection of binders took up a large amount of storage space at her desk (Figure 2, Right). Staff reviewed data as often as once per day to check each child's progress and adjust daily goals accordingly.

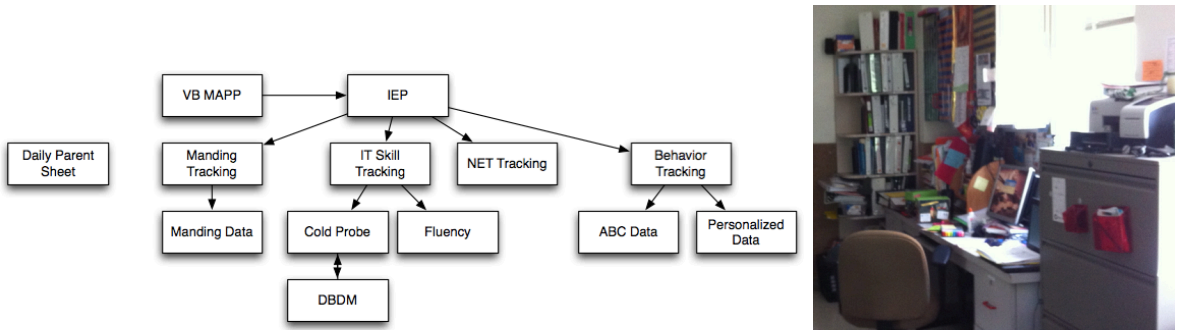

Figure 2. (Left) The large number of data sheets used by a school. (Right) A teacher's desk at the same school, with a lot of storage for data sheets – a bookcase full of binders on the left, and a filing cabinet on the right.

Given the burden of collecting so much data, the importance of using it to aid child development, and the necessity of reporting it by law, it was surprising that staff used paper almost exclusively for collecting, and even graphing data. This reliance on paper was all the more surprising given the widespread use of assistive technology to support learning, skill building, and independence. As I discovered in my fieldwork, staff were accustomed to having assistive technology in the organization and

were eager to introduce new kinds of technology into their activities. Yet the organizations almost exclusively used paper to collect, share, and use data for coordination.

2.3. 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 (2000) 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 and Fayard's (1998) 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.*

In this chapter, I 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 data. While Mackay recommended augmented paper as a way of introducing technology in air traffic control, other domains have required different solutions. Shehory, Sycara, Sukthankar, and Mukherjee (1999) 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 child 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 (2006) 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 children. Therefore, we draw from Mackay's (2000) 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, "the user interface and its subsequent evolution" take the form of a prescribed model of recording and managing data (the implications of administrators prescribing this model, without significant input from those using it, are discussed in Chapter 4). In this work, I did not set out to fundamentally change the way data is recorded. Staff in the special education domain need support to record and use data, but I did not want to change their fundamental methods, as they alone are the experts on the management and use of their data. I explored how technology can support staff in recording and interpreting data, with the goal of their human expertise and collaboration driving the process and empowering nuanced decision-making regarding interventions. Ultimately, however, any HIT inevitably changes workflow in some way – Chapter 5 touches upon this issue.

My approach in this work differs from other work on improving data collection in the autism domain in two ways: (1) I focus on staff playing an active role in collecting data, and (2) I 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 (Hayes, Hirano, Marcu, Monibi, Nguyen, & Yeganyan, 2010; Westeyn, Abowd, Starner, Johnson, Presti, & Weaver, 2012), or with minimal involvement from staff or caregivers (Hayes & Abowd, 2006; Hayes, Gardere, Abowd, & Truong, 2008; Nazneen, Boujarwah, Rozga, Abowd, Arriaga, Oberleitner, & Pharkute, 2012; Plotz, Hammerla, Rozga, Reavis, Call, & Abowd, 2012). My work complements these systems by providing an understanding of the expert's role in collecting data in situ. I 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. I focused on understanding current data collection methods without changing them in order to learn about experts' work practices. I 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, I 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 close to my own, that is, supporting collaborative collection and use of data for decision-making (Kientz, Hayes, Westeyn, Starner, & Abowd, 2007). I 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 (Sano, Hernandez, Deprey, Eckhardt, Picard, & Goodwyn, 2012). I 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 this study I set out to understand the role of data in coordination, to ultimately inform the role of HIT in supporting these practices with data.

2.4. Methods

I conducted fieldwork with a team of six researchers over the course of six months. 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 my university's review board, and the sites' review boards if required.

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, I surveyed 130 of their 150 staff, with 49 of the staff also participating in two focus groups. During fieldwork we interacted with teaching staff, therapeutic staff (e.g., speech, physical, occupational), and administrators. We observed staff and children 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 informants' natural daily activities. We conducted contextual inquiries (Beyer & Holtzblatt, 1998) 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 (Esterberg, 2002; Lofland, Snow, Anderson, & Lofland, 2006). During fieldwork we took detailed notes, and the research team met after fieldwork sessions to discuss and interpret the data. We used affinity analysis (Beyer & Holtzblatt, 1998) 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 (Brooks, 1994; Tognazzini, 2012), and user experience metrics adapted for ubiquitous health technologies (Connelly, Caine, Siek, Kientz, Kutz, Hanania, Khan, & Choe, 2012).

2.5. Findings

I identified six factors affecting the use of data for coordination in special education (see Table 1). Three of the factors suggest why paper is still being used to drive coordination. Three other factors suggest opportunities for technology to increase sharing and use of data, in order to improve coordination.

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 *in situ* 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. Six findings about the use of data to support coordination in special education.

2.5.1. Why they use paper to collect data

During our formative research, we followed emerging themes to narrow our focus from the use of HIT in special education to the use of data for coordination. 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 for coordination: 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, I discuss how existing technology is not meeting the needs of the staff as a result of these demands.

2.5.1.1. 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 child's learning goals will differ, and a child'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 child.

One teacher described a particular data sheet as the "backbone" of her work with children. Staff depended on data sheets for making everyday decisions to help the children succeed. Each child 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 child'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 child's development, and adjust interventions regularly depending on how a child is progressing. If an intervention is improving a child's learning or behavior, staff must have evidence of that progress to show that the approach works well for that child. 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 treatment 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 children. In order to help children generalize what they learn to different situations, staff randomize the skills they work on and the order in which children will work on them. According to Tracy this dynamic and unpredictable approach to behavioral intervention "gets [children] 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 the children. 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 the children. Staff at this school regularly performed inter-rater reliability checks.

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

> *"When you transfer a child 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 child. This challenge seemed to leave staff with unusable data, forced to guess about a child's past history and start data collection from scratch. Sometimes, children arrived at a new school with no data at all.

2.5.1.2. 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 child exhibits a type of behavior, or monitoring the acquisition of a skill through repeated trials, staff need to work closely with a child 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 the children.

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 child 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 the children 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 attending to a child over recording 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. Behaviors are quite unpredictable, and a day can be turned upside down by one child having a difficult day. When staff have to respond and attend to one child who is having a difficult day, the rest of the staff must help to cover for one another. Moreover, one child'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 child. 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 the children. 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 children 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 the children, rather than on a piece of paper only he could see. Children 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 children. 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 children (similar to Cramer, Hirano, Tentori, Yeganyan, & Hayes, 2011 and Hirano, Yeganyan, Marcu, Nguyen, Boyd, & Hayes, 2010), it can reduce burden on staff and also enhance motivation to collect data by leveraging the staff's desire to engage with the children.

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 the children 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.

2.5.1.3.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 children. We first discovered that many of the apps were designed for collecting data on a single child. Few supported separating data by child, 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 child 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 child 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 children. 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.

2.5.2. How HIT can 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.

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

One of the most important uses of data is to help staff monitor child development and make decisions about the most appropriate interventions and approaches to use with each individual child. Collaboration among different types of staff (teachers, teaching aides, speech therapists, occupational therapists, etc.) is involved in deciding on interventions for each child. Though some best practices exist for interventions, each child with autism is unique and staff must be creative in applying interventions to each individual child's case. Teaching staff spend their time with the same set of children—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 the children best, while therapeutic staff are experts on developing particular skills. Together they determine interventions and goals for each individual child. When teachers struggle with a child's grasp of a particular skill, they seek advice from one of the therapists on how to best help a child. Similarly, therapists spend one-on-one time with a child 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 child 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 informants 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 child 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, but the school's new

system grew on staff as they came to understand the value of data and the administrator's vision for it. While data is now more available, however, 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 each child and provide evidence for their success, within a domain that has limited standardization and best practices.

2.5.2.2. Improved communication with parents could improve interventions

Coordination within special education reaches beyond the individuals within the organization. There are many communication needs externally as well. U.S. laws require special education programs to report to state agencies regularly on a child's 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 a child's 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 children 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 children's 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 child 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 children 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 a child's 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 child gets to school, some parents let staff know by phone call or email. This kind of information helps staff not only predict children's 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, thus improving coordination.

2.5.2.3. 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 coordination 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. Informants 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.

2.6. Conclusions

This study provides evidence explaining why paper is used almost exclusively for collecting and using data to coordinate treatment in special education. I identified six factors affecting coordination in special 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 for coordination.

Three factors helped to explain the paradoxical use of paper despite its limitations. First, the individualized nature of special education requires collection of a significant amount of data for the purposes of tracking development. These data needs are complex due to the unique needs of each child, and methods for collecting the data are not standardized. Second, individual child 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 s 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 children, they do not support sharing or analysis of data, and many also suffer from usability flaws.

This study also identified opportunities for HIT to improve the use of data for coordination. 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 coordination and decision-making around the data, and also require limited prep time for the overburdened staff. Second, because a child's 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 HIT could improve the sharing of data that has been collected, better communication between staff and parents could benefit a child's development through better coordination of interventions. Third, staff's eagerness to incorporate technology into their work practices suggests that it would be feasible to pursue these opportunities for supporting coordination.

In special education, it is critical for multiple kinds of data to be collected *in situ* in order to inform and support coordination among staff. However, the number of interruptions and activities, and other people to be consulted, interfere with data collection. Informants in this study 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 for coordination. 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, HIT could empower their use of data for coordination.

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Chapter 3

Collaborative reflection: how coordination works when it is data-driven

The study presented in Chapter 2 showed that coordination in special education relies heavily on the use of manually recorded data, but the persistence of paper limits the effectiveness of data for coordination. Chapter 2 also began to propose ways that HIT can improve the use of data for coordination. In this chapter, I present continued fieldwork that more closely examined when coordination was data-driven and when it was not. In this phase of fieldwork, I developed a theoretical construct, collaborative reflection, which describes what is needed for coordination to be data-driven. The process of collaborative reflection that I observed in my fieldwork is (1) unstructured, (2) mobile, (3) reciprocally interdependent, and (4) long-term. Within this iterative process, I describe a short-term loop and long-term loop of reflection that connect the use of data to coordination practices over time. I further engaged informants in a participatory design process to understand how HIT could be designed to fit this process, and developed in seven design recommendations. This chapter presents the role of HIT as supporting the process of collaborative reflection in order to make coordination more data-driven. Findings from this study suggest that HIT could improve reliability of data recorded by multiple providers, improve availability and access for all team members to reflect on data, and help teams more frequently corroborate interpretations of data.

3.1. Data-driven coordination in behavioral and mental health services

In Chapter 2, I used the example of special education to illustrate how services are meant to be data-driven but managing and using data is not trivial. The unfulfilled promise of HIT includes a failure to support the informal documentation and communication that enable effective use of data (Oborn, Barrett, & Davidson, 2011; Park, Pine, & Chen, 2013; Pine & Mazmanian, 2014). For example, Pine and Mazmanian found that a hospital's existing standards applied as-is to the design of HIT caused "negative organizational outcomes, effectively undermining coordination and necessitating inaccurate accounts of work" (2014, p. 1). In this study I used qualitative fieldwork and participatory design to investigate how HIT could be designed to alleviate these problems.

I continued my fieldwork in the context of behavioral and mental health services because it provided a rich context for exploring informal and unpredictable coordination practices. Contrasting the standardization of HIT in organizations such as hospitals, in this context protocols are only partially standardized because services require a significant amount of flexibility (Marcu, Tassini, Carlson,

Goodwyn, Rivkin, Schaefer, Dey, & Kiesler, 2013). Behaviors are recorded to evaluate the effectiveness of behavioral interventions and psychiatric medications. However, behavioral data are difficult to both record and interpret. This type of data requires subjective manual entry by behavioral specialists. Objective and automated measures cannot be used, though research in computational behavioral science aims to make this possible in the future.

In addition to the subjectivity of the data, the highly social nature of providing data-driven health services complicates the design of HIT:

> *The development and implementation of such technologies are processes of ongoing negotiations, involving many different stakeholders that fight for their positions, and their views on how things should be organized. Second, because the 'final' IT application is the outcome of these processes, it itself 'reflects' this coming-into-being.* (Berg, 2003, p. 38)

I used an anthropological approach to this work in order to negotiate the meaning and role of a new system together with informants, and involve them in the process of the system coming into being. In order for a system to be accepted and make a positive impact in this context, it needs to fit into the existing workflow.

I followed up the formative fieldwork described in Chapter 2, which investigated coordination in seven special education programs, with a more focused study in two of the schools. Treatment teams in these schools were comprised of behavioral specialists, educators, personal aides, psychiatrists, mental health therapists, speech therapists, occupational therapists, supervisors, and administrators. The programs integrated treatment typical of psychiatric clinics within the school day, enabling a child to live at home and attend school while receiving support to address behavioral, emotional, or social challenges on a daily basis. Children in these programs had diagnoses such as autism spectrum disorders, neurological impairments, and emotional disturbance. Symptoms and behaviors of these disorders vary and change over time, making it important to document behavior and progress (or lack of progress) from treatment interventions. Decision-making is complex due to the long-term nature of treatment and the invisibility of underlying conditions. Teams relied on manually recorded behavioral data (e.g., social behaviors, aggressive behaviors, behaviors related to skills for independent living) for to make data-driven decisions about behavioral intervention.

3.2. Methods

In this phase of fieldwork, a research team of 15 interaction designers, developers, and HCI practitioners conducted 71 person-hours of observation and 67 interviews with staff. Our approach to collecting and analyzing field data was based on constructivist grounded theory (Charmaz, 2006). In particular, we focused on gathering rich data using theoretical sampling across team members and contexts, constant comparison with data previously collected, as well as opinions of domain experts at our field sites, and inductive thematic analysis. We visited sites at least once a week, sometimes several times a week. During fieldwork, members of the research team took detailed notes and photographs of the artifacts and environments. We used affinity analysis (Kolko, 2011) to identify themes inductively. We used an iterative process to discuss themes while continuing to gather field data. The research team met several times a week to analyze and compare fieldwork data. Using a collaborative approach grounded in data from field sites, models of knowledge sharing and implications of work practices were iteratively developed based on inductive themes.

In the spirit of action research (Hayes, 2011), we collaborated with our field sites to define the problem (recording and use of data for coordination) and decide on an iPad solution. We conducted contextual inquiries with school staff to understand their coordination practices and use of artifacts, and studied work practices using aspects of contextual design (Beyer & Holtzblatt, 1998). We used naturalistic observation (Lofland, Snow, Anderson, & Lofland, 2006) in combination with interviews and focus groups to understand coordination practices in detail. Applying the participatory design framework outlined in (Marcu, Bardram, & Gabrielli, 2011), which is tailored to mental health systems, we involved providers in designing a system that could meet their needs. We used interviews and focus groups with a variety of users, and iteratively showed design mockups to users for feedback over the course of one year.

3.3. Findings

The documentation and communication practices I observed, which I call "collaborative reflection", had four characteristics: they were (1) unstructured, (2) mobile, (3) reciprocally interdependent, and (4) long-term.

Prior use of the term collaborative reflection by Prilla, Degeling, & Herrmann (2012) describes people's reflections on their experiences and memories to aid learning. In this paper, we use the term differently, to mean pooling and reflecting on patient data to aid decision-making. In the sense that it emphasizes

collaborative information sharing and decision making, our use of the term is similar to what has been called collaborative sensemaking (e.g., Paul & Reddy, 2010). However, the sensemaking concept has often been used to describe information seeking, time-critical decision-making, and the input of individuals who are not reciprocally interdependent—aspects that were not part of the collaboration we observed. Prior work on collaborative sensemaking within the domain of children with special needs has focused largely on information sharing practices (e.g., Piper, D'Angelo, & Hollan, 2013), especially to increase the accuracy of data collection (e.g., Kientz, Hayes, Abowd, & Grinter, 2006). In contrast, we are concerned with supporting communication and collaboration for interpreting and using the subjective data that are collected in this domain.

The teams we studied reflected on data to monitor students' long-term behavioral change and treatment. As change occurred, the teams retrospectively re-interpreted data. They were reciprocally interdependent in decision-making, meaning that each depended on others to do their work, and decisions were often jointly made. Thus my use of the term reflection rather than sensemaking. The concept of reflection which I use draws from personal informatics, where the same process has been studied within an individual (Li, Dey, & Forlizzi, 2010).

3.3.1. Unstructured

Treatment teams used face-to-face communication and paper records in unstructured ways for virtually all of their collaborative work. We observed many informal interactions during which critical information and expertise were being transferred informally among team members. Therapists used the few minutes they were physically in the classroom to check in with a child's classroom staff, consisting of a teacher and several teaching aides. For example, an occupational therapist took a child from his classroom twice a week for a one-on-one therapy session. The therapist picked up the student from his classroom, walked him to her office for the session, and then escorted him back to his classroom afterwards.

In one instance of the brief interaction when an occupational therapist brought a student back to his classroom, there was a discussion about generalizing the skills learned in therapy. The therapist had used the day's session to work on the task of the child putting on his jacket independently. She asked the classroom staff what they typically do with his jacket at the end of every school day; do they hand it to him or put it on for him? She suggested they hand it to him, since he had shown enough progress that he should be able to put his jacket on by himself. Practicing everyday when he left school would help

him to continue making progress. This informal communication based on the therapist's observations was one example of how unstructured practices were more effective for treatment team collaboration than structured records and practices.

The flexibility and adaptability of paper records accorded staff the ability to more easily coordinate their unstructured work. Staff considered paper-based notes, charts, and to-do lists flexible and easy to use. For example, jotting something on a post-it note reminded a team member to share some information with someone else on the team. Paper data sheets and reports, although they typically comprised a form or template for tracking children's behavior and problems over time, also offered the opportunity for unstructured communication. Our observations of the appropriations of paper and frequency of *ad hoc* interactions helps to explain the ways in which information technology failed to meet the team's needs, as similarly reported by Marcu *et al.* (2013), Park *et al.* (2013), and Weibel, Emmenegger, Lyons, Dixit, Hill, & Hollan (2013). In our study, we saw that the process of reflecting involves unstructured and informal work that cannot be formalized.

3.3.2. Mobile

Team members exchanged information and knowledge in multiple places: meeting rooms for formal meetings, and informal interactions in hallways, classrooms, and the cafeteria. They used multiple resources, not just word of mouth, but also paper data collected in different ways by different people. Spontaneous informal meetings among team members happened everywhere. Team members might be in a formal meeting reviewing a child's case, they might be engaging with a child together, or they might run into one another in the hallway and have something to discuss about a child.

In their study of collaboration in hospitals, Bardram and Bossen (2005) identified four aspects of what they call mobility work: resources, persons, places, and knowledge. These observations resonate with ours. We found that paper records were critical resources that were shared and discussed within teams; the persons involved in reflecting on the data were a variety of specialists that make up a treatment team; the places where interaction takes place ranged from conference rooms (formal) to hallways (informal) to classrooms (at times chaotic); and finally, that reciprocal interdependence drove exchange of knowledge.

Resources

Behavioral data were recorded on a regular basis to evaluate and support a child's unique needs with customized interventions. Behaviors were recorded in two ways: positive behaviors that interventions

aimed to increase (e.g., following directions, appropriate social interactions) or negative behaviors that interventions aimed to decrease (e.g., verbal or physical aggression, anxiety-induced avoidance of social situations).

Teams implemented a token economy—a type of psychotherapy typically used for behavioral intervention, which reinforces desired behavior through the tracking of tokens (or points) that can be exchanged for rewards. The token economy was the main part of their data collection, and together with some free form note taking, formed the records used to regularly assess and make decisions about the individualized support provided to each child.

The teams struggled to find appropriate computer-based tools to support recording and use of data (Marcu *et al*., 2013). Much of their process was paper-based and cumbersome. Records were paper data sheets and paper scatter plots. Data were frequently transferred among various forms and reports. Summaries were overly abstracted, and human errors were difficult to avoid. Data were ultimately stored in binders, where they were not easily reviewed or shared.

Persons

Both programs had psychiatrists, mental health therapists, behavioral specialists, educators, personal aides, speech therapists, and occupational therapists. Each child was assigned a treatment team consisting of a subset of these specialists, based on the unique behavioral and mental health needs of that child.

Due to the difficulty of reviewing and sharing data, teams most often made decisions based on anecdotes, intuition, and highly abstracted data. While teams were able to achieve positive outcomes using these methods because they primarily needed to rely on human intuition and expertise, they recognized that significant untapped potential lay in the data, which was not used enough in determining trends and evaluating interventions.

Places

Team members were collocated within the school building. Their work practices were both synchronous and asynchronous. Teaching staff stayed mostly within the bounds of their classroom. Other staff, such as therapists and supervisors, worked across classrooms and moved throughout the school during the workday. Therapists moved between classrooms on a schedule, while supervisors were on call and moved between classrooms based on where they were needed.

Treatment team meetings, the only time team members were all in the same place at the same time, were held monthly. The long-term process of recording and using student data was therefore embedded in everyday practices that took place across different locations within the school building. Staff spent the majority of their time working directly with the children, leaving little time for formal collaboration. They most often discussed data when running into one another in the hallway; they discussed a child's case in detail once a month at the formal treatment team meeting.

Knowledge

An administrator described to us how she would like to use information technology to share knowledge:

> *"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."*

Her description reveals two aspects of how her program manages data and knowledge First, the entire treatment team (and ideally even stakeholders outside the team such as parents) is involved in analyzing the data to make sense of what it says about a child's progress with treatment. Second, the program is limited in how much it is able to analyze paper-based data for trends.

Team members contributed different types of knowledge, because they had different experiences with a child, and different perspectives and expertise based on their backgrounds. For example, a behavioral specialist depended on a therapist for direction in applying an intervention, and a therapist depended on a behavioral specialist for day-to-day information about how a child is responding to an intervention and progressing. We therefore found team members to be reciprocally interdependent.

Figure 3. Team members were distributed along a spectrum of knowledge, creating reciprocal interdependence.

3.3.3. Reciprocally interdependent

Reciprocal interdependence exists in a relationship in which both parties rely on one another for information to be able to complete their work (Thompson, 1967/2013). Reciprocal interdependence requires more than information sharing, it involves frequent communication and knowledge sharing. The team members we studied were reciprocally interdependent for several reasons: data were collected by multiple staff members and later aggregated; staff had unique experiences and data about one child; and staff were drawing knowledge from different areas of expertise.

Team members were reciprocally interdependent because they each only knew part of the narrative making up a child's story and trajectory. Team members worked with the same child in different contexts, so they each developed unique knowledge based on different behaviors they were witness to in different situations. Treatment teams integrated all of these perspectives through collaborative reflection, to understand a child's progress and make treatment decisions over time.

Team members were distributed along a spectrum of specialized knowledge, illustrated in Figure 1. Those who spent most time with the children had detailed knowledge about their day-to-day life, behaviors, progress, personality, and needs. These individuals, represented by the bottom of the lower triangle in Figure 1, were parents and paraprofessionals (e.g., teaching aides, personal care assistants). Some had formal training or expertise, and all applied practical knowledge from working hands-on with a focused caseload or loved one. Domain experts, represented by the top triangle in Figure 1, were clinical supervisors and psychiatrists. They managed a larger caseload, so they had a high-level understanding of each child without day-to-day details. These professionals used their expertise and knowledge of best practices to provide diagnosis, prescriptions, treatment plans, and other high-level direction.

Some team members, such as therapists, fell somewhere in the center of the spectrum. For example, speech therapists had expertise in speech-language pathology and applied it to their work with the same child once or twice a week. Although they had some regular contact with the child, outside of these one-on-one therapy sessions, speech therapists depended on other staff members for information about the child's regular progress.

3.3.4. Long-term

The safety-critical aspect of behavioral and mental health services is long-term rather than immediate. Teams tracked children's behaviors over time, and we heard references to concepts such as "predictors"

of behaviors over time. One of the schools tracked treatment periods of 20 days, comparing the current treatment period with the previous treatment period to evaluate the effects of interventions. Treatment team meetings were for reflecting on a child's progress and making decisions about interventions for the next treatment period.

Our observations brought to light information practices that held long-term weight in two ways. First, a multitude of daily decisions could impact long-term outcomes for a child. Second, the focus on change over time required records of children's behavior over time that could be compared, not just for change but also for "predictors." With good, easily accessible information, providers would be able to review large amounts of information and corroborate interpretations and decisions with others. Unfortunately, the mass of paper data in pages of charts and notes were not as useful as they might be for this purpose, as the data could not be manipulated or viewed in different ways to answer questions about a child's progress and treatment.

Our findings demonstrate a need for information technology that can support an understanding of information over time; help users identify and explain trends over time; and even help to predict behaviors or outcomes into the future.

3.4. Collaborative Reflection

The coordination practices we observed were not adequately supported by information technology. Treatment teams had evaluated existing technologies, especially iPad apps. They told us that none were an improvement over their paper methods. The limitations of apps they had tried, documented in more detail in (Marcu *et al.*, 2013), included poor usability, lack of scalability for their number of students, and lack of flexibility for recording and sharing data in their distributed environment. Improving their paper methods remained an unsolved problem. The challenges our field sites faced with incorporating information technology to help them record and share their data were similar to those experienced in other settings (Mentis, 2010; Niazkhani, Pirnejad, Berg, & Aarts, 2009; Park, *et al.*, 2013) suggesting that the collaborative processes we focused on are relevant for a variety of domains and systems.

I have named the process we observed collaborative reflection because team members were reciprocally interdependent on one another's knowledge and had to collaborate in interpreting data to make long-term treatment decisions. Further, making these ongoing decisions required retrospective reflection on the data as they changed over time. Figure 2 illustrates the collaborative reflection process, consisting of two iterative loops.

The long-term outer loop contains four collaboration points over time, where team members have reciprocal interdependence. First, staff reflect on a child's behavioral data to understand the needs of the child and determine an appropriate intervention. Second, multiple staff members may be involved with an intervention. Reflecting on child data together helps staff apply the intervention consistently, for example, by comparing child responsiveness and immediate progress with different staff members, or by sharing successful strategies for applying the intervention and working with that child. Third, staff evaluate the effects of an intervention by reflecting on the child's data over time. Fourth, staff disseminate information on the child's progress to others on the team, to providers not on the team, or to caregivers or family members.

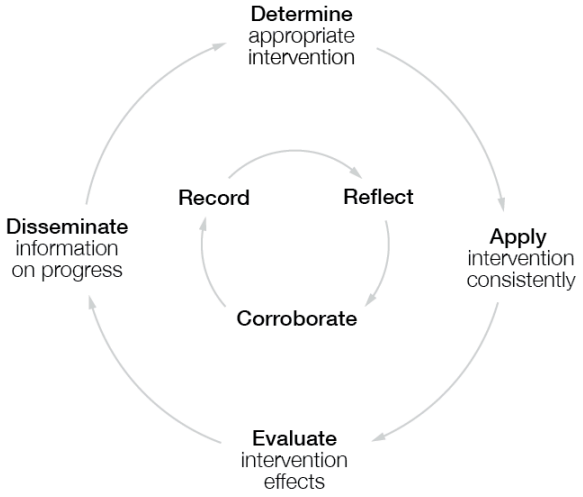

Figure 4. The collaborative reflection process, consisting of a short-term inner loop and a long-term outer loop.

The short-term inner loop shows how interdependent team members work together everyday to develop a shared understanding, which they draw on to make ongoing treatment decisions. Team members record data, reflect on the data both individually and collaboratively, and corroborate interpretations of the data with others.

3.4.1. When collaborative reflection is not data-driven

The use of two loops in Figure 2 helps to illustrate what we saw happening when this process was not data-driven. The short-term loop exists because of the records that staff are required to create, whereas the long-term loop exists because of the services staff are providing to the children. Ideally, these two loops inform one another in the following way. At each stage of the long-term outer loop, teams draw upon the collective knowledge they have developed within the inner loop. As team members contribute

individual knowledge to recording and reflection, this integration of knowledge, and the process of corroborating knowledge and evidence (inner loop), enables the team to interpret data collaboratively and use their collective knowledge to make treatment decisions over time (outer loop).

However, the realities of how challenging it is to record, manage, and use data – reported in Chapter 2 – result in a disconnect between the two loops. Staff may be required to record certain data, but when applying interventions and making decisions about a child it was easier for them to rely on intuition and face-to-face coordination, rather than the data. Figure 2 helps to identify where in the process I can pinpoint, based on the findings from Chapter 2, practices that were not data-driven. In the following chapter, I discuss how I applied this perspective to the design of a prototype, Lilypad, aimed at making practices more data-driven.

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Chapter 4

What is needed for coordination to be data-driven?

With an explanation of why paper persists in the use of data for coordination (Chapter 2), and having observed the process of collaborative reflection that occurs when coordination is data-driven (Chapter 3), my next phase of fieldwork focused on understanding what it takes for coordination to be data-driven. The findings reported in this chapter come from 81 hours of fieldwork conducted over 11 months at two of the seven organizations I began with. I first used the construct of collaborative reflection to conduct more focused fieldwork investigating the gap between the short-term and long-term loops, which causes processes to be less data-driven. I then generalized my fieldwork findings by comparing them to the literature, to understand what themes were common across different health service settings. These themes determined the main functionality of a prototype, Lilypad, designed to support data-driven coordination based on the process of collaborative reflection. The full design of Lilypad is described in Chapter 5.

4.1. Three barriers to data-driven practices

I observed many instances where coordination among staff was not driven by data that they had recorded. The informants themselves sometimes discussed, unprompted, the shortcomings of the data or their challenges with using it to inform interventions. I observed one such conversation during a regular meeting at one of the organizations, which I will call Monet, in which team members trying to make sense of a child's paper-based records to reflect on his progress over the past several weeks:

> Psychiatrist: *"He seems to be doing better based on this data, and the brief moments I've seen him in the classroom and hallway. He seems less irritable."*
>
> Behavioral specialist (record keeper): *"This is an example of how our record system doesn't work for someone like him, because it's showing something else … it should be telling us, when he is supposed to be on task, is he?"*
>
> Mental health therapist: *"The data may be accurate but it's not reflecting how he's really doing. I'm wondering if we can separate that behavior out and record that separately."*
>
> Behavioral specialist (record keeper): *"That would be hard." [Laughs nervously]*

Mental health therapist: *"I'm just thinking, if an auditor came in here and looked at the numbers, it would not be reflected that he's really where he is … how can we better reflect that he still needs to be in this program? Somebody from the outside may think, oh he's doing great, why is he still here?"*

This vignette illustrates the three critical problems that emerged in my fieldwork: record keepers have difficulty capturing representative records, decision makers do not have adequate access to informative records, and intuition and face-to-face communication are more prevalent drivers than data. This chapter illustrates how data is currently not representative and informative enough to drive the process of collaborative reflection.

4.1.1. Record keepers have difficulty capturing representative data

During the conversation above, the psychiatrist, who had a large caseload and thus little contact with each child, was misled to believe that a child had improved based on the records presented to her and her own anecdotal evidence. Two other members on the team, who saw the child more regularly, jumped in to explain that the records were not actually representative and the psychiatrist was making a misguided conclusion.

This scenario exemplifies how teams at Monet used paper-based records and anecdotal reports to coordinate among themselves. I heard many accounts of failed attempts to adopt HIT for the task of recording and analyzing behaviors. One comment from a mental health therapist summed up attitudes at Monet, especially toward one EHR they had tried using: "You've probably heard all about [redacted name of a system]; that was horrible, not user friendly at all, and we had to go back to paper". In addition to the problem of user friendliness, it was clear during observations and interviews that the flexibility required for coordination at Monet could not be provided by existing HIT.

Providers responsible for manually capturing data and managing records were consistently overburdened, and the unpredictability of their environment further complicated their responsibilities. If a provider was busy responding to an incident and intervening, he or she would not be able to create the record until later. Recording accurate data in the moment was challenging, and staff adopted unique practices to help them accomplish their work as conveniently as possible, in a way that worked for them. Freeform annotations and note taking, such as jotting down notes on the margins of a piece of paper or on a post-it note, were common. Staff even wrote on their hands during a critical incident when they did not have access to paper. No HIT had been able to provide nearly this much flexibility, explaining why paper persisted out of necessity.

HIT only came into play when it was required for reporting data to other agencies for billing and auditing purposes. Staff were frustrated with their lack of usability and how cumbersome it was to manually transfer data from paper to multiple reports and graphs. Complicating the task of creating records was that staff members (and especially record keepers) were responsible first and foremost for children's safety and behavioral intervention. Many informants spoke about the logistical impossibility of balancing all of the tasks they were responsible for: "there is no clerical time within the 40 hr work week, you do billing and paperwork on your own time". There were some efforts to incorporate use of Microsoft Excel and specialized iPad apps into this process, but they were not successful.

I found that supervisors tended to have unrealistic expectations that an incident be recorded in the moment, or immediately thereafter. However, the accuracy and timeliness of a record depended on the provider's availability to create the record. The gap between what was expected and what was possible was a significant issue during design work—some supervisors at Monet were unaware of this gap, and all of them were unsure of how to address it. I saw frustration among the record keepers expected to create and manage records without adequate support or tools, and their frustration grew with each passing month.

One record keeper recounted a conversation with his supervisor during which he was once again asked to record more data, without additional support. Having tried different ways to ask for support, he suggested to his supervisor: "we should do time studies to figure out how long all of these recording activities will take". The supervisor rejected the idea, saying, "this isn't a factory". The record keeper's reaction was "yes, it is"—revealing his disappointment that the demands of records were intervening with the human aspects of his job working with children. This record keeper often shared his feelings with us, typically using his sarcastic humor to express his frustration with supervisors' unrealistic expectation that he manage both clerical work and providing behavioral intervention to multiple children: "they're turning this into an office job—inside a petting zoo!"

4.1.2. Decision makers do not have adequate access to informative data

The earlier vignette showed how records informed treatment decisions by communicating progress both internally and externally. External decision makers included auditors who license organizations like Monet so that they can provide services, and parents who decide which organization and treatment is best for their child.

In order to help treatment teams reflect on cases collaboratively and make sense of a child's behaviors, Monet had developed four school-wide categories of behavior on which to base records. All students (save for a few classrooms dedicated to lower functioning students who were working on developing verbal behavior) were asked to follow four rules, described in Table **:** be safe, use kind words, complete work, and follow directions. These rules drove positive behavioral reinforcement and the parallel activity of recording behaviors. For example, providers would respond to violence toward a peer or property destruction by reminding a student to be safe, physically and verbally intervening, and then recording the incident on a paper data sheet.

Rule	**Example behaviors in violation of rule**
Be safe	Violence toward peers, providers, or self; property destruction
Use kind words	Swearing; bullying peers; back-talking to providers
Complete work	Frustration with assigned task; distraction or avoidance
Follow directions	Nonresponsiveness to prompts; leaving the room or area

Table 1. Monet's four school-wide behavioral rules.

A record of an incident could be as simple as adding to a running tally of the number of times a behavior had occurred that day. A record could also include details such as the timed duration of the behavior, names of peers involved, or the antecedent event right before the behavior occurred, which could provide insight into the psychological trigger of the behavior. The amount of detail in a record varied across providers, based on their workload and personal work style, due to the subjective nature of data. Standardization was avoided because it would not enable individualized and adaptive services, but a tradeoff was an unavoidable amount of inconsistency from one child's data to another—which typically affected those team members with larger caseloads, such as psychiatrists and clinical supervisors. The four behavioral categories also included some overlap (*e.g.*, a student who is not completing his work is probably also not following directions). Monet used training and inter-rater reliability checks to maintain data reliability as much as possible.

I also discovered conflicting information needs across decision makers, which helped to explain the unrealistic expectations for recording practices, and why these tensions remained unresolved. Insurance companies required specific information for billing purposes, such as detailed logs of work hours and activities. Each provider was required to justify their work with each child, sometimes down to the minute, to be assured their regular pay. Monet administrators passed down these instructions to their employees, sometimes with specific software to be used for reporting records for billing. Insurance companies requested daily narratives to be written for each child, outlining their treatment and progress. These narratives were to be entered into a poorly designed and time-consuming piece of software. Audits were common, sometimes once a year, adding to the pressure of having to create detailed and accurate records so as to not create problems for oneself or the organization. Administrators were in a difficult position, having to adhere to requirements from insurance companies, and passing these down to their employees. Meanwhile, providers were more concerned with the nuances of carrying out a treatment plan, rather than reporting out progress so regularly. Providers were driven to record data that would help with sensemaking and reflection for making treatment decisions. They were therefore frustrated when records needed to be created for mere logistical purposes, and took up a significant amount of the time they had with the children. The day before an audit, for example, some providers who typically worked full time in a classroom had to take time completely away from their regular jobs in order to find a quiet place to sit at a computer and work on records. Even more frustratingly, last minute requests for more data continued to come in from their supervisors.

4.1.3. Intuition and face-to-face communication are more prevalent drivers than data

Coordination at Monet needed to be flexible because the responsibility of maintaining a safe environment and providing all of the children the support they needed was dispersed across all staff in the organization. The nature of behavioral and mental health services required Monet's staff members to support one another and jump in to fulfill responsibilities. Regardless of whether staff held roles such as teacher, therapist, or supervisor, to ensure the safety and wellbeing of children and staff alike, all staff members were trained to respond to behavioral incidents, and did so at a moment's notice when the need arose.

For example, when a child grew frustrated and left the classroom, at least one staff member would follow him into the hallway (or outside) to ensure his safety, talk him through managing his emotions, and generally wait him out until he was able to calm down and move on. This process could take minutes or hours. Meanwhile, the remaining staff members in the classroom needed to continue the

current activity with the rest of the children, and ensure record keeping continued. A staff member from outside of that classroom, such as a therapist or supervisor, sometimes filled in if additional support is needed during this time period. As such episodes were unpredictable and could accumulate across multiple children at any given moment without warning, staff members were always ready to diffuse responsibility at a moment's notice.

The social aspects of this diffusion generally ran smoothly because the staff were well trained and prepared to use their instincts and work together. Staff members were able to ask for support through several established social channels such as gesturing to a team member, making a request to any staff member in the hallway, or calling their assigned supervisor who was always on call and would answer their mobile phone even during meetings. However, despite how effective these social channels were, the records were not effective for coordination. The paper-based records acted as a mechanistic system, thus not matching the need for an organic way of keeping all team members informed and adapting to each situation. When records were not representative or informative enough, staff relied on anecdotal evidence and their intuition—as the psychiatrist in our earlier vignette did in the context of a formal meeting.

4.2. Standardization and the unfulfilled promise of health information technology

The three problems that I observed are not unique to the setting that I studied. Comparing my findings to health informatics literature, I saw a common theme surrounding the standardization of formalized, structured workflow through HIT, which conflicts with the reality of informal, unpredictable workflow that takes place in health services.

Standardized processes are a stark contrast to the process of collaborative reflection that I observed. Similar to my findings, others have revealed the inadequacy of tools that aim to increase standardization, for example with handoffs in hospitals (Cohen & Hilligoss, 2008). Historically, the design of HIT has focused heavily on standardization of practices (Kimble, 2014; Berg, 2003). An increasing amount of literature shows that the promise of HIT – reducing human error and cost, while improving coordination, best practices, and efficiency – remains largely unfulfilled (Kimble, 2014; Berg, 2003). As a result, the focus on standardization is now being called into question.

The introduction of information systems has been plagued by unintended consequences—many of which actually undermine communication and coordination (Stoller, 2013). These unintended consequences are being attributed to design toward standardization: "information technology is seen by many to be

[the solution], yet the standardization of health care work that this requires may render this 'solution' to be fatally contradictory to the nature of health care work and information" (Berg, 2003, p. 79). Mentis, too, calls out the "a lack of understanding how medical workers realistically coordinate and share information" (2010, p. 3).

A focus on standardization has let to the design of HIT that tends to overemphasize structure, and not support informal documentation and communication (Harrison, Koppel, & Bar-Lev, 2007; Park, Pine, & Chen, 2013; Weibel, Emmenegger, Lyons, Dixit, Hill, & Hollan, 2013). Informal practices tend to be overlooked in the design of HIT. In striving for standardized and perfect accounts, research shows that HIT actually undermines accuracy in records (Pine & Mazmanian, 2014). In an increasingly complex health care system, there is an "unprecedented requirement for adaptability" (Schön, 1983, p. 15), which HIT is not currently designed for. Studies have revealed that HIT misrepresents communication as information transfer, and misrepresents collective, interactive work as linear, predictable workflow (Harrison *et al.*, 2007).

According to Berg (2003), "technology development still all too often tends to be considered as an autonomous or neutral process" (p. 38) – yet HIT is "thoroughly social" (p. 37). A focus on standardization has resulted in what Diana Forsythe refers to as HIT that "delete the social" (1992, p. 111). Her extensive fieldwork in medical settings showed that because HIT is "designed, built, and evaluated according to procedures that 'delete the social' and mute the voice of users, most of these systems remain 'on the shelf,' a fact which is hardly surprising" (1992, p. 111). The design limitations that caused the low adoption rates Forsythe observed in the 1990s continue to cause the unintended consequences reported today. Rates of adoption have naturally increased given the prevalence of information technology, yet "despite the fact that similar systems had been used outside healthcare for a number of years, definitive evidence of their success in the healthcare domain remains elusive" (Kimble, 2014, p. 1).

The design of HIT continues to not match social practices, and higher adoption has led to a higher incidence of unintended consequences. Design problems also plague consumer health applications, which have low rates of adoption and impact, despite the pervasiveness of smart phones and the high availability of health applications aiming to empower patients (Bebinger, 2013; Shute, 2013). Although they target both providers and consumers of health services, information technologies are not improving coordination in health services.

4.3. Changing focus from standardized practices to social practices

In this thesis, then, I take an alternative approach to one that prioritizes standardization and risks a result that will "delete the social". Instead I begin with the social, and then explore how much standardization is appropriate. My design work is based on Berg's (2003) idea that "'flexible standardization' is not a contradiction in terms" (p. 79). I am ultimately concerned with determining how information technology can support realistic coordination despite the amount of unpredictability and subjectivity involved in health services. I investigate the social aspects of coordination by looking at coordination at the organizational level. Using an organizational lens provides a complementary perspective to approaches such as cognitive psychology (*e.g.,* activity theory, distributed cognition), by showing the realistic, logistical, and subjective aspects of HIT implementation that occur at the organizational level.

4.3.1. Sensemaking and reflection in organizations

The term sensemaking has been commonly applied to the organizational process of interpreting and acting on data by applying knowledge, experience, and available resources (Weick, 1995). Sensemaking plays a key role in health services (Paul & Reddy, 2010). Weick (1993) famously described the enactment of sensemaking, describing how the process plays out through the actions of individuals within an organization—including what happens when the process breaks down.

While some studies focus on sensemaking in a lab setting, I am concerned with the naturalistic enactment of sensemaking in the real world, which is called macrocognition. Macrocognitive models of sensemaking include Klein, Moon, and Hoffman's (2006) Data/Frame Theory, which describes the active process of framing and interpreting data. Frames are used to "shape the data (for example, a house fire will be perceived differently by the homeowner, the firefighters, and the arson investigators)" and they also "change as we acquire data" (p. 1). Through a bidirectional process, frames "shape and define the relevant data, and data mandate that frames change in nontrivial ways" (p. 1). The frame metaphor captures the unpredictable nature of sensemaking in the real world.

Others have described this unpredictability as improvisation, comparing it to the actions of skilled jazz musicians (Miner, Bassoff, & Moorman, 2001; Schön, 1983). During improvisation, skill and memory is applied to unexpected, non-routine events. Miner *et al.*'s (2001) field study found that this process was embedded in collective processes: "the distinct competencies in improvisation did not appear to reside in specific individuals; rather, they flowed from broader organizational routines, cultures, and collective

capabilities" (p. 327). Other studies have also shown how sensemaking is enacted in organizational coordination and culture (Bardram & Bossen, 2005; Orlikowski, 2002).

Another relevant aspect of sensemaking processes in organizations is that they are focused on long-term outcomes. Miner *et al.* (2001) describe how long-term processes are informed by short-term and situational actions. Short-term improvisation can "serve as a 'trial' in long-term trial-and-error learning", and long-term learning occurs "after outcomes of action have been experienced, and new actions or inferences arise, specifically based on the consequences of completed action" (2001, p. 321). I similarly use the term collaborative reflection in this thesis (Chapter 3) to illustrate this process within health service settings. Short-term activities comprise of recording data, interpreting data, and corroborating interpretations with others. As individuals contribute these activities on a daily basis, the integration of knowledge long-term creates a collective knowledge base that an organization draws upon over time for treating complex and unpredictable chronic conditions.

Schön (1983) uses the term reflection as I did in Chapter 3, to connote the "complexity, uncertainty, instability, uniqueness, and value conflicts" (p. 14) involved in professions like medicine, management, and engineering. Increasing complexity in these fields "resists the skills and techniques of traditional expertise" (p. 14), requiring instead what Schön refers to as reflection-in-action. There is an unprecedented adaptability required of individuals in these professions: "85 percent of the problems a doctor sees in his office are not in the book" (p. 16). Through reflective practice, a practitioner frames and reframes the problem, applies past experience to the unique situation, and rigorously experiments in the moment. Reflection-in-action enables what Erikson (1985) calls "disciplined subjectivity" when a lack of standardization, structure, or predictability prevent objectivity.

Given the amount of improvisation, reflection, and subjectivity required, how can information technology support sensemaking? Weick asserts that information technology can make the sensemaking process more susceptible to breakdowns because people "act less, compare less, socialize less, pause less, and consolidate less when they work at terminals than when they are away from them" (1985. p. 56). In clinical settings this effect has been called electronic siloing, or the discouraging of spontaneous interaction in clinical workflow (Stoller, 2013). Weick argues that unintended effects can be reduced through the use of mobile technologies in the field, which can make people better problem solvers because they are "able to use different forms of data and test their hunches with triangulation" (1985, p. 62). Similarly, Bardram and Bossen's concept of mobility work highlights the spatial aspects of problem

solving in clinical settings, for which they prescribe "systems architectures for more *ad hoc*, peer-to-peer based interaction" (2005, p. 157).

4.3.2. Organizational features can dictate the design of appropriate HIT

My fieldwork also revealed the importance of understanding how an organization functions in order to design appropriate HIT – most importantly, what features enable an organization to provide the services they provide. Organizational science scholars define the contrast between loosely and tightly coupled organizations (see Table 2). A focus on standardization of practices adheres to the needs of tightly coupled organizations. The organizations I studied were primarily loosely coupled, because they needed to be flexible and adaptable in order to provide individualized and ever-changing treatment for each child. A loosely coupled organization lacks rigidly defined roles and formal ties; collaboration predominantly happens informally as needed to serve the needs of its clients; events are usually unpredictable; and as a result of these qualities, technology tends to be unavailable or problematic for supporting services (O'Looney, 1993; Weick, 1976).

Table 2. Loosely coupled organizations match organic systems, and tightly coupled organizations match mechanistic systems. Characteristics adapted from O'Looney (1993) and Harrison (1994).

Loosely coupled organization	**Organic system**
Adaptive to individual and environmental needs	Roles and responsibilities are diffuse, flexible, and change through use
Inductive services, customized for individual needs and malleable over time	Coordination through flexible plans, changing goals, and evaluation over long periods of time
Standardization is avoided in order to respond to individual needs and environmental pressures	Multidirectional communication and multilevel contacts with outside agencies
Problems are difficult to define, so technology is unavailable or problematic	Democratic focus on task, team, organization; expertise and knowledge grant authority
Tightly coupled organization	**Mechanistic system**
Less adaptive	Roles and responsibilities are specialized, clearly defined
Deduces individual needs based on an assessment and delivers services according to protocol	Coordination based on standard procedures; evaluation based on clear objectives, standards
High potential for diffusing innovation once it is standardized, but rigidly defined roles stifle innovation	Hierarchical communication with top-down emphasis; top management has key outside contacts
Problems and technology are well defined	

My observations of Monet as a loosely coupled organization, and its adoption of HIT as problematic, suggests that HIT tend to support the type of workflow that exists in tightly coupled organizations—

those with formal ties that prescribe coordination and collaboration (see Table). Sociotechnical information systems that are a good fit for tightly coupled organizations are mechanistic: they involve standard procedures and objectivity; they are hierarchical in their communications, with top management making outside contact; and they are based on loyalty to superiors, with position and experience granting authority (Harrison, 1994). Problems are well defined in tightly coupled organizations, and therefore services are able to follow a protocol by using deductive logic to determine individual needs. They can deliver services more quickly and efficiently by following a standardized process. Emergency rooms, trauma teams, and acute care services are more likely to be tightly coupled because they are designed to respond quickly to time-critical events. Technology can be well defined for this kind of organization, and can increase efficiency and safety—for example, decision support systems help with deductive logic, and HIT helps with standardization.

When a mechanistic system is used in a loosely coupled organization, however, this creates the type of unintended consequences that have been well documented with HIT (Harrison *et al.*, 2007; Marcu, Tassini, Carlson, Goodwyn, Rivkin, Schaefer, Dey, & Kiesler, 2013; Mentis, 2010; Park *et al.*, 2013; Pine & Mazmanian, 2014; Stoller, 2013). Sociotechnical information systems that are a good fit for loosely coupled organizations are organic (see Table 2): they involve roles and responsibilities that are diffuse, flexible, and change over time; they coordinate through flexible plans and changing goals; their communication is multidirectional and there are multilevel contacts with the outside; and they operate democratically, with a focus on the task, team and the organization, and expertise and knowledge granting authority (Harrison, 1994).

Monet's persistent use of paper-based records, and struggles to transition to HIT, illustrate a lack of appropriate organic systems to fit their coordination practices. My findings suggest that unintended consequences of HIT are caused by a mismatch between their design as largely mechanistic systems, when the organizations that use them, and the broader healthcare context of these organizations, are not always tightly coupled. For Monet, as with many organizations, this resulted in a reliance on paper records, and minimal and problematic use of HIT.

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Chapter 5

The Lilypad prototype: How can a system support data-driven coordination?

Coordination practices are often organic by nature, especially in a loosely coupled organization that provides health services through individualization, adaptability over time, and flexibility for unpredictable events. Evidence of unintended consequences of HIT suggests that many of these systems share a fundamental flaw in their design, which makes them unable to fit an organic workflow. In the final portion of my thesis, I discuss how HIT can be designed to more effectively support coordination by using what I learned in my fieldwork about (a) the process of collaborative reflection, and what makes it data-driven, and (b) the need for organic systems that fit existing workflows. I designed a prototype, Lilypad, through continued immersion in the practices of the Monet school. I involved staff in participatory design over the course of 11 months, and then studied the use and impact of Lilypad in a five-month field study at Monet.

The design of Lilypad was informed by formative fieldwork in seven organizations providing behavioral and mental health services for children, which identified data-driven coordination as a problem (Chapter 2); focused fieldwork in two of these organizations, which provided the theoretical construct of collaborative reflection to describe what is needed for coordination to be data-driven (Chapter 3); and a comparison of this fieldwork to the literature to ground this work in broader themes that apply to health services in a variety of organizations (Chapter 4).

My approach in the design of Lilypad was to address the three problems I found to be barriers to data-driven coordination (see Chapter 4):

- record keepers need support for capturing representative data,
- decision makers need access to informative data, and
- data needs to complement intuition and face-to-face communication.

In this chapter I describe how the design of Lilypad targeted these three problems. Chapter 6 then presents findings from the field deployment that demonstrate how those design decisions resulted in Lilypad functioning as an organic system.

5.1. Design process

The design process I used is best characterized by the new interdisciplinary term *design anthropology* (Clarke, 2010; Gunn, Otto, & Smith, 2013). Combining immersive ethnographic fieldwork and design work, I studied the use of data for coordination, and the meaning of the data, interactions, and artifacts involved in workflow. This design work culminated in the development and evaluation of a first prototype, Lilypad. Following user testing that included a think-aloud study, I launched a 5-month field deployment study (Siek, Hayes, Newman, & Tang, 2014) to engage an organization in a transition to HIT and study the impacts of the design decisions behind Lilypad. The deployment was modeled after the recent trend of "in the wild" studies, to examine the use of the prototype *in situ*, rather than in the lab (Bonsignore, Quinn, Druin, & Bederson, 2013; Johnson, Rogers, van der Linden, & Bianchi-Berthouze, 2012; Marshall, Morris, Rogers, Kreitmayer, & Davies, 2013; Messeter & Molenaar, 2012).

Lilypad was designed for, and with, the Monet school. A team of 9 developers, user experience designers, and ethnographers engaged the staff in participatory design for 11 months. All team members interacted with Monet and its employees through a subset of the following activities throughout the design process: observation, contextual inquiry, design workshops, and user studies. We involved members of the organization in the design of a solution to their problem, in the spirit of action research (Hayes, 2011), and in response to Schön's (1983) assessment that "professionally designed solutions to public problems have had unanticipated consequences, sometimes worse than the problems they were designed to solve" (p. 4). We, as the design professionals, practiced Schön's reflection-in-action ourselves by framing and reframing the problem together with the organization. We engaged the professionals at Monet in reflection-in-action while we conducted participant observation and contextual inquiry to reflect on their existing workflow together, and used participatory design to iterate together many times on ideas and mockups for a solution.

5.2. Designing Lilypad to support data-driven coordination

With existing paper-based systems for collecting data on a child, the data were stored in the form of hard-to-read scatter plots or overly abstract monthly reports. Data stored in heavy binders were not easily accessed or shared. Sometimes one staff member would be the keeper of the data and responsible for transferring information from data sheets to graphs or reports for others to use, making human error difficult to avoid, and making staff dependent on one person's interpretation and handling of data.

Similar findings have been reported in other settings—*e.g.*, Bardram & Bossen, 2005; Mentis, 2010—demonstrating that what we observed was not domain specific.

To alleviate these problems, the Lilypad system is designed as a network of handheld tablets enabling treatment team members to record and share behavioral data. Each team member logs into the system through a personal tablet to record and view data. The Lilypad system facilitates coordination by giving each team member access to visualizations of aggregate data that has been collected by all team members. Yuill, Rogers, and Rick's (2013) study comparing the use of paper and iPads in a collaborative activity suggests that social work can be transitioned from paper to tablets, which are able to "sustain individual and shared actions at different stages in the creative process" (p. 1). Their study illustrates how a tablet-based information system has the potential to support collaborative reflection by enabling both the individual and shared aspects of reflection with data.

The informants in the organizations I studied specifically and repeatedly requested that they use iPads for managing behavioral data. Although some of their opinions might have been influenced by the popularity of the iPad, my design team and I agreed that handheld tablets could enable the ad hoc peer-to-peer based interaction prescribed by Bardram and Bossen (2005) for supporting mobility work. Yuill *et al.* (2013) argue that tablets could play the role of Weiser's scrap computers (*i.e.,* mimicking scrap paper) because they can "readily flip between being personal and being shared, potentially enabling more fluid transition between individual and group working" (p. 949). During my fieldwork I observed many examples of the spontaneous use of scrap paper alongside formal data sheets, generally caused by the unpredictability of the environment.

Figure 1. Examples of informal documentation—writing on one's hand (left) and on a piece of scrap paper (right)—alongside formal documentation such as a computer keyboard and mouse, and a data sheet on a clipboard (right).

The images in Figure 1 are two examples of scrap paper captured *in situ*. The photograph on the right was taken of a record keeper's desk in the middle of the day, and was not staged. It shows a piece of scrap paper with a pencil lying among (from left to right) a computer keyboard, mouse, paper calendar, data sheet on a clipboard, and an iPad in the top right corner. All of these tools were actively being used throughout the day, demonstrating the lack of an adequate and streamlined information system. The photograph on the right shows how a different record keeper made do when she was in the hallway with a child who had left his classroom – she kept track of his behaviors by writing with a pen on the back of her hand.

The informal concept of scrap computers can support record keepers who capture the data by enabling the flexibility to adapt to this type of unpredictable environment. In addition, this type of system could improve the social aspects of the work of treatment teams (*i.e.,* collaborative reflection). Yuill et al.'s study (2013) compared the use of paper and iPads for collaborative work (via a game of co-creation). They found that iPads afforded similar social behaviors and coordination as paper, and improved group creativity – suggesting that Lilypad could be designed to maintain some of the affordances of paper that other HIT have not been able to achieve.

5.2.1. Record keepers need support for capturing representative data

Figure 1 shows the main Lilypad interface for recording data. Record keepers manage one child's data on his or her unique screen (in Figure 2, a student with the pseudonym Benedict D.). The system enables quick switching between the individual screens of children under a provider's care (the left navigation pane in Figure 2). In a classroom setting, providers are often working with multiple children at a given time, and must track all of their behaviors as immediately as possible. The recording features were designed to mimic the existing practice of carrying a clipboard with a data sheet for all of the children and all of the day's activities for one classroom. Therefore, the ease with which users could flip back and forth between students and activities was a key part of the design.

On multiple occasions during the design process, inconsistencies were uncovered in the implementation of data recording practices. Most of the time I found contradictions between supervisors, who tried to enforce ideal recording practices, and behavioral specialists working in the classroom, who recorded data as they could in the moment. Sometimes informants were unaware of their contradictions, and sometimes I acted as a mediator to find a compromise between the ideal and the realistic. The process of

designing a novel system became a means for the informants, together with our design team, to uncover and resolve such inconsistencies.

I approached such design challenges by using a balance of structure and flexibility, evidence and intuition – inspired by what Berg (2003) calls "flexible standardization", and what Erikson (1985) calls "disciplined subjectivity". Whereas some structure was used to produce reliable records, significant flexibility was maintained in other areas of the system, for example, requiring a form to be completed in a particular way but allowing subjective notes to be added.

Three data types were the focus of Lilypad's recording interface. These were based on the common practices for recording behavioral incidents, which emerged across the organizations I had observed: all of them tended to use frequency, duration, and qualitative details such as antecedents. These three data types enable record keepers to adapt use of Lilypad in order to capture representative data.

Frequency

The top half of the record screen features counters to track the frequency of several types of behaviors. The Lilypad is customized with four counters for Monet's behavioral rules (see Figure 2).

Duration

The bottom half of the screen features a reverse-chronological log of duration-based behaviors such as time outs. Users select an incident type from a custom list (*e.g.,* time out, physical aggression), and enter a start time and end time (which are used to calculate and display the duration of the behavior and the period/activity during which the behavior occurred). Figure 3 is a comparison of how this data was recorded on paper, and how the same data is displayed on Lilypad – the second column from the right displays the duration of the incident, calculated from start time and end time entered.

Qualitative comments

Each time a duration-based behavior is recorded, the user can type a comment such as an antecedent, or names of other children or staff involved. Each comment is therefore associated with a behavior, to support the identification of long-term trends. Figure 3 shows how paper data sheets (left) were appropriated with qualitative comments added on the side, and how Lilypad (right) enables users to enter a qualitative comment for each individual incident, in the rightmost column.

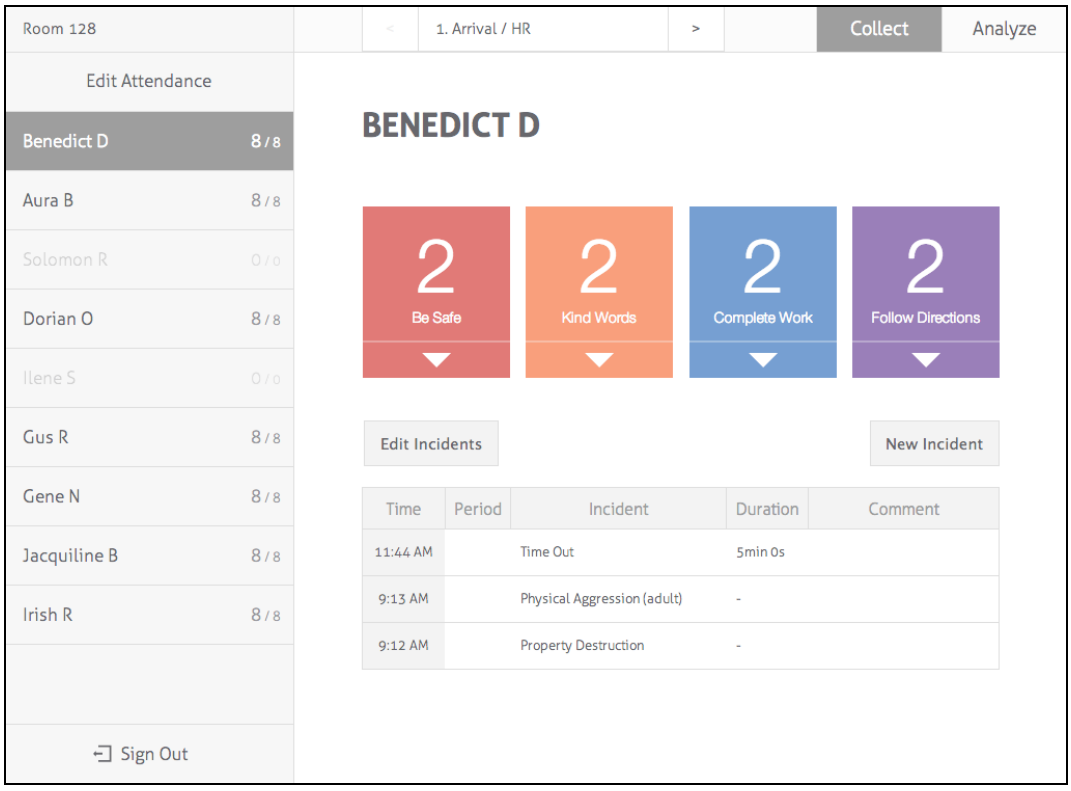


Figure 2. Screenshot of Lilypad system interface for manually recording behavioral data.

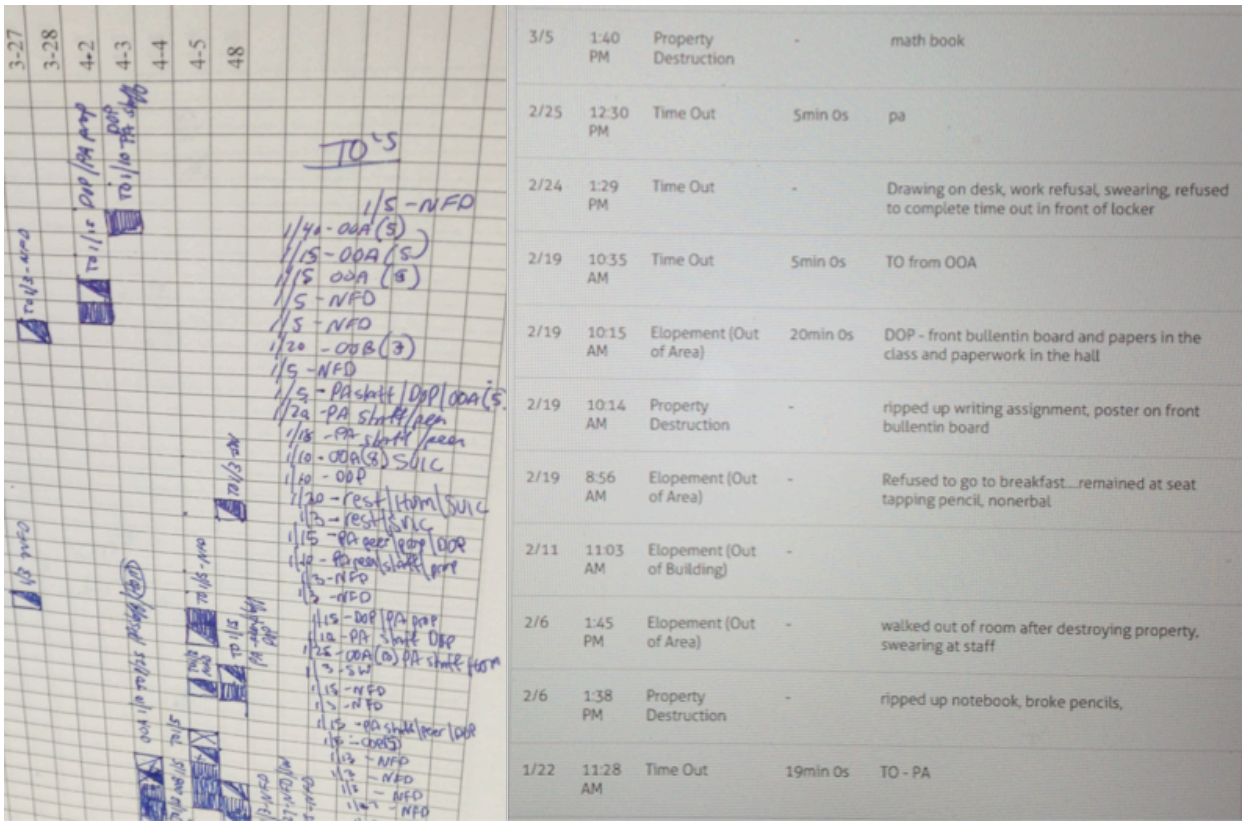


Figure 3. Duration data and qualitative comments, recorded on paper (left) and on Lilypad (right).

5.2.2. Decision makers need access to informative data

Monet administrators had developed four school-wide behavioral rules to give some consistency to the data that decision makers were reviewing. However, a drawback of the system was the need to fit specific behavioral issues of each child within these rules, and then use the abstracted data to determine progress on the specific behavioral issue. It seemed that even with the flexibility of paper-based records, their system had still become too mechanistic, and the standardization of the way behaviors were recorded caused limitations for use of the data. The goal of Lilypad was therefore to create an infrastructure that the organization as a whole could use as a foundation for coordination, while allowing behaviors to be easily changed for each child, and adjusted during the course of treatment. Such adjustments were not accommodated by their current system due to the challenges of updating and reprinting paper data sheets.

Paper-based data stored in binders was also difficult to share and review. Long-term data in particular was not very accessible. In one meeting, I observed a record keeper attempting to examine how a child's data had changed over time. She struggled to look at enough data at once to be able to make such a determination, at one point folding over a data sheet to be able to see the next set of data (Figure 4), and ultimately relied on her intuition to report to the rest of the treatment team an estimation of the child's progress.

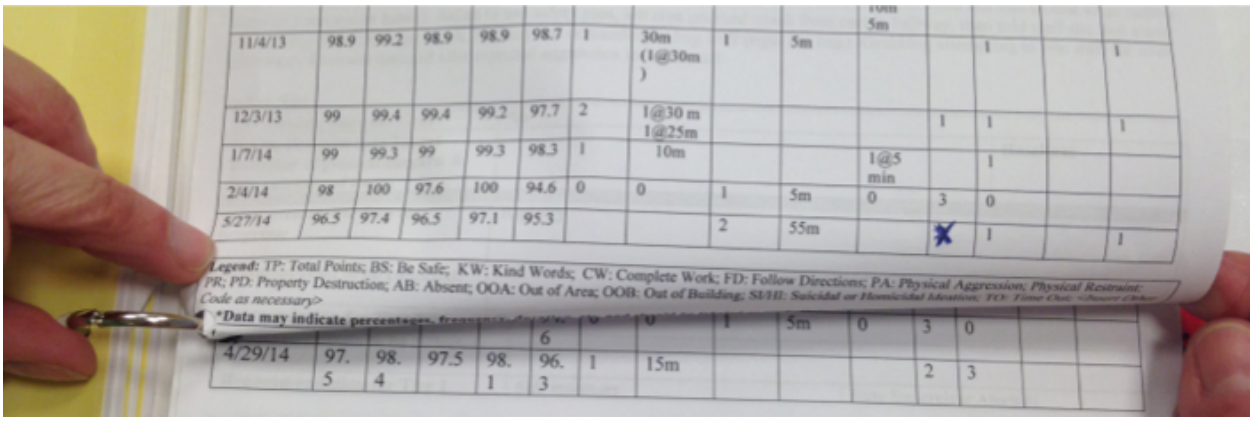


Figure 4. Paper-based data stored in binders was difficult to review. In one meeting, this record keeper was trying to determine long-term trends by folding over a data sheet to see the next set of data.

Monet reported the progress of a child, both internally and externally, in two primary ways. To reflect on daily and weekly data, record keepers drew line graphs by hand using tallies of behaviors on each day (Figure 5, top). To reflect on monthly data, record keepers calculated performance metrics based on quantified behavioral goals set every 20 days (Figure 6, top). Lilypad generates these metrics

automatically and displays real-time visualizations (Figure 5, bottom, and Figure 6, bottom). Existing paper-based line graphs showed only approximately two weeks' worth of data each, and were stored in binders where they were not easy to review. By enabling the instantaneous viewing of data at various levels of detail, such as day, week, month, or year, Lilypad introduces the capability to reflect on long-term data so teams can identify trends and patterns in behavior.

Team members discussed quantitative behavioral data in one of two ways: by absolute points earned (20/40) or percentage of points earned (50%). Different team members were discussing data based on their personal preference for one of the two representations. Over time, during the participatory design discussions, they realized that each of the two representations revealed different aspects of a child's progress. This information was used in the design of Lilypad's visualizations. Percentages helped them review data long-term because percentages accounted for variations in points possible (for example, due to a half day or a student arriving late for school). Absolute points were harder to reflect on long-term because the denominator could change, but absolute points gave a more complete picture of a particular day or short-term period.

Improving treatment teams' ability to review and reflect on data is a main area where Lilypad has the potential make a real and positive impact. However, achieving an entirely positive impact without unintended consequences was nontrivial due to the complexity of workflow. Each simple feature could cause a tremendous shift in workflow. The challenge of designing new visualizations was to not change workflow too much. The design process therefore involved the team balancing our ideas about what could be ideal if we were starting with a blank slate, with what would be closest to the existing practices of the organization. The resulting designs for visualizations (see bottom of Figures 5 and 6) were purposefully safe and attempted to usher users gently into new ways of reflecting on their data.

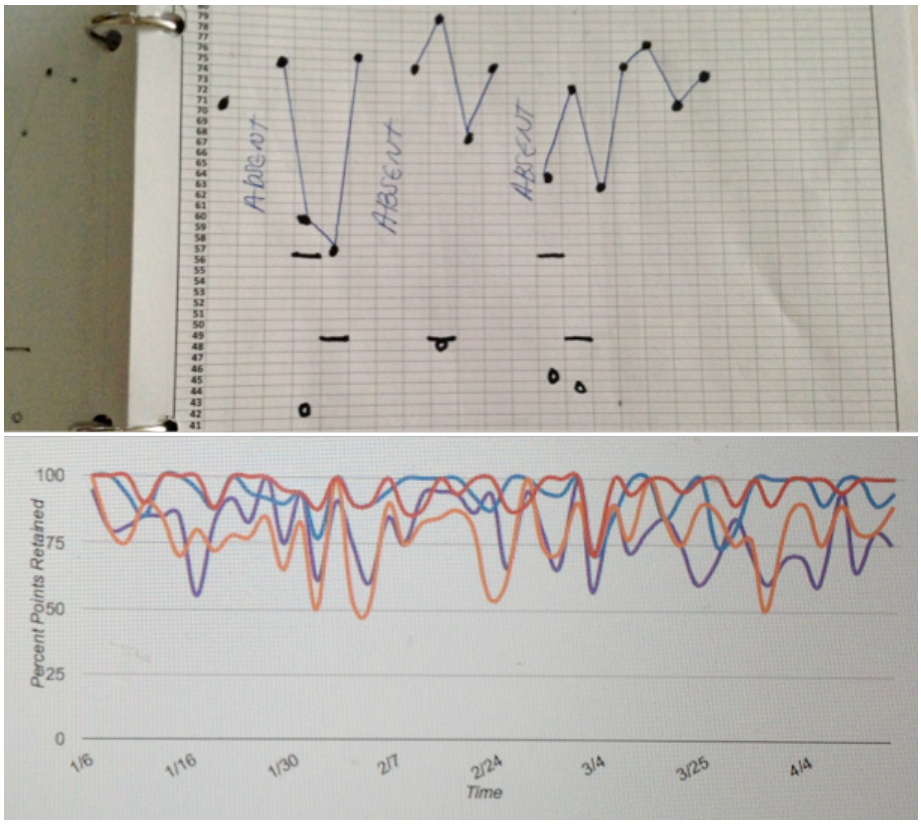


Figure 5. Manually created graphs on paper (top), and the same data automatically graphed on Lilypad's interface (bottom).

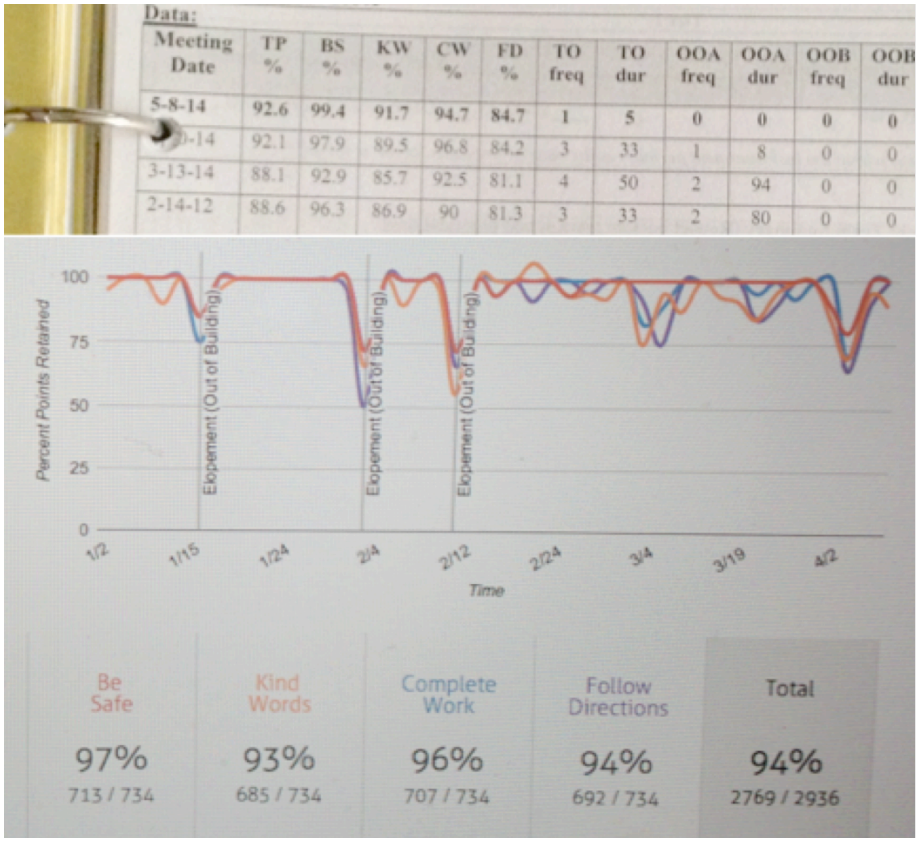
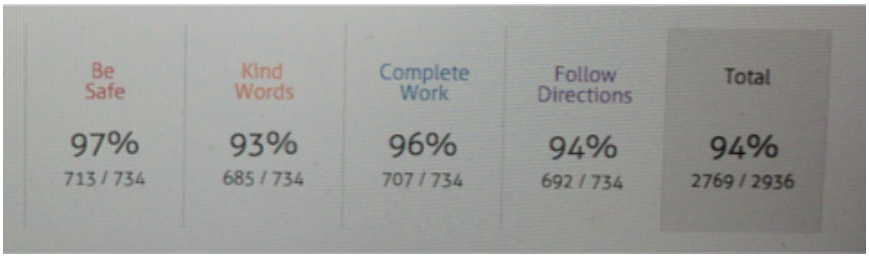


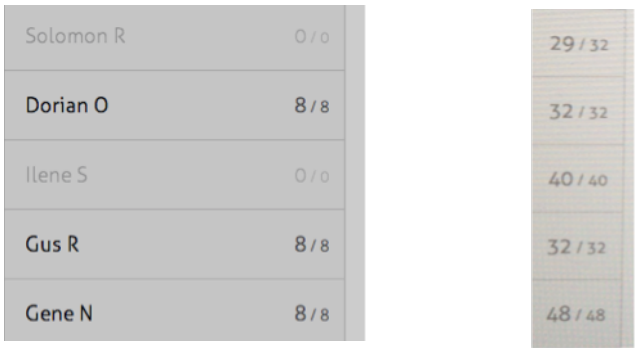
Figure 6. Manually calculated performance metrics presented in a summarized report (top), and the same metrics calculated automatically and displayed in real time on Lilypad's interface (bottom).

5.2.3. Data needs to complement intuition and face-to-face communication

Record keepers were so burdened by the amount of data they were required to record, graph, and transfer repeatedly, that they felt like mindless data entry workers. This effect was evident in their comments comparing their responsibilities to factory work and mere clerical duties, when in fact these individuals play a key role in the collaborative reflection process. One design goal behind Lilypad was to reduce the burden on record keepers and increase their active involvement in sensemaking and reflecting on data as part of the team. Achieving this goal would also result in more detailed and reliable data being made available to the rest of the team members via the record keepers. To this end, Lilypad streamlines administrative logistics through automation where possible. Four examples are illustrated below, with photographs of the interface taken *in situ* while the system was in use (with the exception of those showing names, which have been changed for confidentiality).



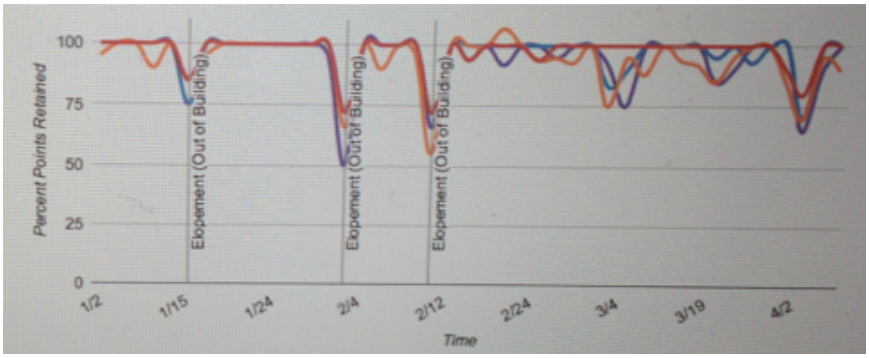
Feature 1. Calculates performance on monthly goals.



Feature 2. Displays real time point tally, and takes attendance data into account in calculations (*i.e.,* a child who arrived late to school cannot earn as many points as a child who arrived on time).

2/24	1:29 PM	Time Out	-	Drawing on desk, work refusal, swearing, refused to complete time out in front of locker
2/19	10:35 AM	Time Out	5min 0s	TO from OOA
2/19	10:15 AM	Elopement (Out of Area)	20min 0s	DOP - front bullentin board and papers in the class and paperwork in the hall
2/19	10:14 AM	Property Destruction	-	ripped up writing assignment, poster on front bullentin board
2/19	8:56 AM	Elopement (Out of Area)	-	Refused to go to breakfast....remained at seat tapping pencil, nonerbal

Feature 3. Generates reports for internal and external use.



Feature 4. Generates statistics and graphs for long-term analysis, juxtaposing multiple types of data.

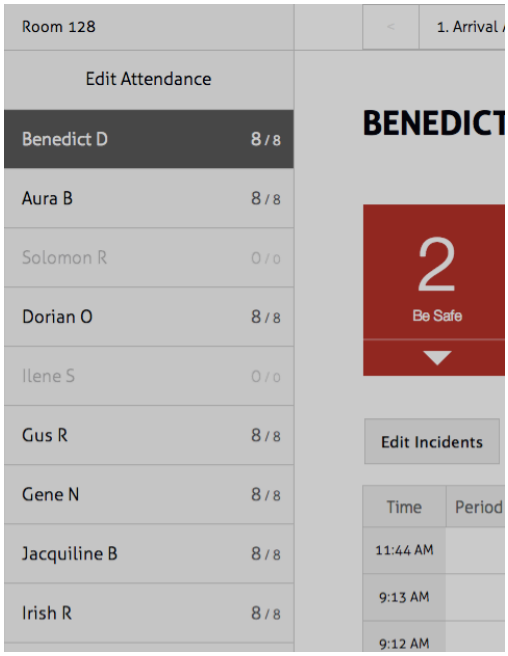
The aim of these features is to (a) enable the record keepers to focus on recording representative data and then taking part in reflection with the rest of the team, rather than spending a large portion of their time transferring data and manually creating reports, and (b) make more informative data available to decision makers, without them having to wait for a record keeper to provide or interpret it, so that they can reflect on the data themselves. Lilypad gives more people direct access to representative and informative data, so that the data can be more easily combined with intuition and face-to-face communication. Existing coordination was largely based on anecdotal evidence in the form of firsthand knowledge, intuition, and secondhand reports. Lilypad was designed to improve access and exploration of data in order to complement the use of important anecdotes and expert intuition with data-driven practices.

The disconnect in the process of collaborative reflection, which caused practices to not be driven by data, was between the short-term loop of recording the data, and the long-term loop of utilizing it to reflect on

a child's progress. During everyday coordination, I saw team members often share knowledge by exchanging anecdotal accounts and second-hand evidence. Collaborative reflection took place primarily during everyday informal interactions, when data might not be at hand, as during a conversation between two teaching aides across the room while they were working with different children, or in a discussion when two staff members ran into one another in the hallway.

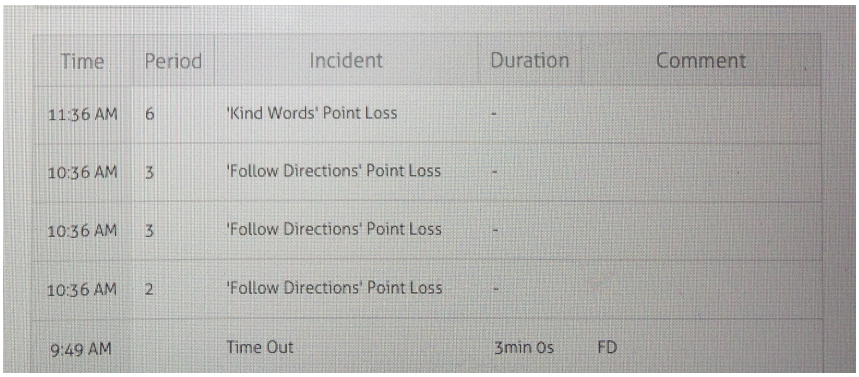
Lilypad makes data accessible in this kind of context with functionality described below, so that discussions can involve first-hand interpretations of data. When team members have different areas of expertise and different perspectives, converging their interpretations of the same data can be challenging. By making it easier for teams to access and review data together, Lilypad addresses the barriers to data-driven coordination by aiming to increase opportunities for team members to share their interpretations of data.

Provides access to aggregated data and updated statistics for team members in real-time



This staged interface shows, clockwise from top left: currently viewing data from classroom 128, for the first period of the day ("1. Arrival"), with a log of behavioral incidents thus far today (three, at 9:12am, 9:13am, and 11:44am), and current point standing for each child in the classroom.

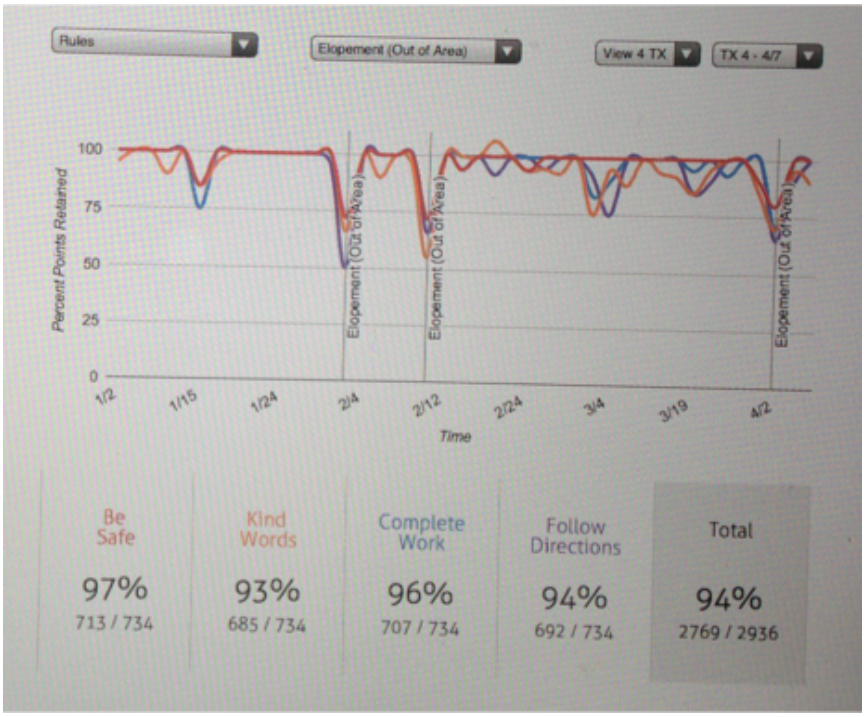
Visualizations show multiple metrics together



Time	Period	Incident	Duration	Comment
11:36 AM	6	'Kind Words' Point Loss	-	
10:36 AM	3	'Follow Directions' Point Loss	-	
10:36 AM	3	'Follow Directions' Point Loss	-	
10:36 AM	2	'Follow Directions' Point Loss	-	
9:49 AM		Time Out	3min 0s	FD

This sample behavior log shows, from left to right: time stamp, period during which the behavior occurred, incident type, duration (if applicable), and optional qualitative comment.

Visualizations show data in multiple ways (*e.g.*, graphs and tables, abstract and detailed).



The main interface for reviewing quantitative data, with the following features, from top to bottom: drop down menus for selecting a time period and isolating data to be viewed, an aggregated line graph and critical incidents overlaid with vertical lines, and for each type of behavior tracked for that child (at Monet, their 4 rules), percent of points earned and actual points earned out of total possible.

Provides visualizations on an interface that can be shared or projected at any time for discussion

This photograph was taken during a regular meeting, and illustrates the amount of technology being underutilized: iPads and a laptop used to review reports that had been manually prepared and posted on a shared Dropbox account, and a wall mounted display connected to an Apple TV that I never saw being used for meetings.

5.3. Lilypad within the process of collaborative reflection

Treatment teams I had observed drew upon their shared understanding of a child's progress to make decisions over time. The outer loop of the process of collaborative reflection shows four long-term collaboration points at which team members were especially interdependent. Lilypad is designed to provide the infrastructure to enable team members to connect at these points in time to make decisions for the course of treatment.

Determine appropriate intervention

Reflecting on a child's progress with treatment over time enabled staff to understand how a child responded to various interventions. Identifying and predicting trends over time with Lilypad could inform and empower decision-making about interventions going forward. Lilypad's visualizations and automated analytics could make the identification of trends much simpler, and allow team members to collaborate on assigning meaning to the trends.

Apply intervention consistently

With the ability to view aggregated data that have been collected by multiple team members, treatment teams could monitor the application of interventions and ensure consistency. The effects of an intervention are closely tied to providers' ability to apply it consistently across time and context. For example, behavioral interventions need to be generalized across contexts in order for a child with special needs to adhere to the new behavior consistently. Lilypad could help all relevant team members reflect on the agreed-upon intervention, and could also be used to verify the consistency of its application.

Evaluate intervention effects

Staff often followed their intuition, based on their expertise and human judgment, to understand how a child was responding to an intervention and to adjust the intervention accordingly. This intuition is critical and cannot be mimicked or replaced, but it could be supported with data. Lilypad makes a child's data more accessible anywhere and anytime, helping team members test their intuition against data, and present them to others on the team for corroboration.

Disseminate information on progress

Team members I observed spent a lot of time updating one another on activities and progress someone may have missed, because everyone needed to be included before discussion and decision-making could happen. Some staff reported not learning about important updates or changes to treatment plans until weeks or months later. Lilypad gives all team members access to the same data and intervention information and allows them to easily connect with one another, helping the teams disseminate information more effectively.

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Chapter 6

Lilypad in the wild: A field deployment validating Lilypad as an organic system

I modeled a field deployment (Siek, Hayes, Newman, & Tang, 2014) for Lilypad after the growing trend of "in the wild" studies (Bonsignore, Quinn, Druin, & Bederson, 2013; Johnson, Rogers, van der Linden, & Bianchi-Berthouze, 2012; Marshall, Morris, Rogers, Kreitmayer, & Davies, 2013; Messeter & Molenaar, 2012), to examine the use and impacts of the technology *in situ*, with real world social scenarios and constraints, rather than in the lab. The features of Lilypad were rolled out gradually, in order to study the effects of their use. The goal was not a full and complete transition from paper records to HIT. Instead, I took a long-term view and treated the deployment as an attempt to carry out a transition in the real world, without a required outcome. This enabled me to realistically validate the design of Lilypad, including its feasibility, limitations, and impacts. My goal was to determine Lilypad's impact on workflow at Monet, as well as user adoption, acceptance, and attitudes.

6.1. Methods

Lilypad was deployed at Monet for 24 weeks. During that time, I conducted 76 hours of participant observation in 48 total visits, averaging 4.5 hours per week. I attended 27 confidential treatment team meetings with consent from parents. 24 staff informants were compensated with $20 per week through the course of the deployment.

Fieldwork during the deployment investigated the recording of data in three classrooms at Monet, and followed how that data was shared and used across the rest of the organization. The three classrooms served 2nd to 6th grade students. Each classroom had 4 to 5 staff members working with 4 to 9 children. Treatment teams serving each of these students were made up of individuals across all levels of the organization (*e.g.*, classroom staff, therapeutic staff, psychiatrists, and clinical supervisors). Fieldwork focused on 7 treatment teams composed of 24 staff.

Student diagnoses, skills and needs varied within each of these classrooms—some students were functioning one or two grade levels below their age, and some had progressed enough during several years at Monet that they were in the process of gradually transitioning to a typical school. Despite the range of special needs, the services provided to all of these students were a similar combination of behavioral reinforcement, cognitive behavioral therapy, and potentially psychiatric medications. These services were driven by the collaborative use of behavioral data by the treatment teams.

Organizational change is a large part of transitioning to HIT. I therefore worked with the entire organization to support a transition from paper-based records to HIT. I met with administrators and supervisors throughout the study to update them on the progress of the transition, interview them for their attitudes, and work to maintain their buy-in. I spent most of my participant observation with record keepers, who used the Lilypad system most frequently as the gatekeepers of the data. I also used guerilla interviewing to reach staff across all levels of the organization.

6.2. Findings

Lilypad was designed as an organic system in order to fit Monet's loose coupling. Findings from the deployment show that Lilypad was able to fit into the workflow of treatment teams, and help their coordination be more data-driven. In this section I describe this evidence within four categories, by referencing the four characteristics of organic systems (O'Looney, 1993) that were particularly relevant for Monet: diffuse roles and responsibilities, flexible coordination, authority based on knowledge rather than position, and multidirectional communication.

6.2.1. Diffuse roles and responsibilities

Team members had particular roles and contributed unique expertise and backgrounds to the treatment of a child (*e.g.*, therapist, record keeper, family liaison), but these roles were not rigid. Their daily roles and responsibilities needed to be diffuse in order to adapt to individual needs and situations. Lilypad facilitated diffuse roles and responsibilities by making it easier for more stakeholders to be involved with recording and reviewing records, and providing access to aggregated records in real-time. An intuitive and collaborative interface helped team members coordinate around the data.

One important goal for Lilypad was to reduce the burden on primary record keepers, because their responsibilities were unrealistically split between creating records, and providing *in situ* behavioral intervention to children to ensure their safety and progress. The record keepers' ability to learn to use it quickly, combined with their attitudes toward Lilypad, demonstrated a perceived reduction of burden which enabled them to better manage their responsibilities. Record keepers learned to use Lilypad on the job. For their first 3 days of use, we conducted 3-4 hours of participant observation, thereby making ourselves available while they were learning to use Lilypad. However, Lilypad's design closely mimicking existing paper-based records made this transition smooth. The record keepers needed little guidance while learning to create records using Lilypad. By the second week of use, Olivia was upbeat about

having already adjusted to Lilypad in her daily practices, saying: "it's nice that this [system] is becoming a part of my day".

When Olivia was preparing for maternity leave, the record keeper who replaced her spent about two weeks shadowing her in order to transition into her role. The new record keeper picked up Lilypad as part of this transition within three days, without our support. Lilypad was transitioned from one individual to another naturally and smoothly as part of the whole process, indicating that it had become an integral part of the record keepers' workflow.

During the sixth week, team members working closely with record keepers like Olivia began helping them create records on Lilypad. I had not encouraged or trained these individuals to use Lilypad. Instead, they were intrigued by watching the record keepers use it, and jumped in as users themselves in order to diffuse the responsibility of creating records. As an interesting counter example to this trend, when a record keeper was absent one day no one used Lilypad in his place, choosing to try to maintain record keeping using the familiar paper-based method instead. This incident suggests that despite the diffusion of responsibility, team members are not willing or able to handle an undue burden associated with someone else's role. Taking over the use of Lilypad for a day on their owne likely felt like a higher commitment than making some notes on a piece of paper—an attitude which would also suggest that staff placed weight on the utility and role of Lilypad within workflow. Overall, the voluntary participation of more and more staff members, and their ability to quickly learn to use the interface, showed how Lilypad's design was appealing, intuitive, and able to facilitate the diffusion of roles and responsibilities.

6.2.2. Flexible plans and changing goals

Chapter 2 describes the persistence of paper due to the challenges of incorporating HIT to support the unpredictable and individualized services provided by organizations like Monet. Lilypad was designed as an organic system to address the tendency of HIT to overemphasize structure and standardized practices. A marked moment of success during the deployment was therefore when I asked the record keepers if they still needed to rely on paper, during the fourth week, and they told me that Lilypad met all of their needs. They had adapted to using Lilypad to record all quantitative and qualitative types of data they had been recording on paper.

The design of Lilypad's recording interface and data structures, with flexible ways of recording multiple types of data, enabled users to adapt it to their needs. Claire was overwhelmed on a daily basis and not

always able to record data in the moment. Lilypad enabled her to catch up at a later time on all of the children's data, as she had done on paper. Jonah was meticulous with data, and Figure 1 shows how he had the ability to add details of behavioral incidents that would help the team reflect on the data later.

3/5	1:40 PM	Property Destruction	-	math book
2/25	12:30 PM	Time Out	5min 0s	pa
2/24	1:29 PM	Time Out	-	Drawing on desk, work refusal, swearing, refused to complete time out in front of locker
2/19	10:35 AM	Time Out	5min 0s	TO from OOA
2/19	10:15 AM	Elopement (Out of Area)	20min 0s	DOP - front bullentin board and papers in the class and paperwork in the hall
2/19	10:14 AM	Property Destruction	-	ripped up writing assignment, poster on front bullentin board
2/19	8:56 AM	Elopement (Out of Area)	-	Refused to go to breakfast....remained at seat tapping pencil, nonerbal
2/11	11:03 AM	Elopement (Out of Building)	-	
2/6	1:45 PM	Elopement (Out of Area)	-	walked out of room after destroying property, swearing at staff
2/6	1:38 PM	Property Destruction	-	ripped up notebook, broke pencils,

Figure 1. Lilypad gave Jonah, who tended to be very detailed in his record keeping, the flexibility to add a qualitative comment to each entry, without enforcing this level of detail on the other record keepers.

Figure 1 shows some of the data Jonah recorded with Lilypad during the course of the deployment – he tended to include a qualitative comment with almost every each entry, which was unusual. He noted specific details of a behavior, for example qualifying a Property Destruction incident with "ripped up notebook, broke pencils"). He noted the antecedent to a behavior, for example an Elopement Out of Area incident occurred when the child "walked out of room after destroying property, swearing at staff".

These details were not easy to record on paper, especially in a consistent way across multiple staff members, and they were even more difficult to transfer and review later. With their paper-based system, Monet reviewed data at a very abstracted level, and mostly reviewed quantitative data. With Lilypad, staff members added qualitative details at their convenience, which were then immediately available for review by other team members, without the added effort of creating graphs or preparing reports.

In the vignette presented in Chapter 4, I had observed a conversation among team members about what adjustments might lead to capturing records that are more representative. The record keeper, Claire, laughed uncomfortably at the suggestion of changing her recording practices on paper, saying it would be too difficult. The limitations of paper-based records led to these types of dead ends during reflective conversations. These observations suggest that more flexibility in the management of their data would enable the process of collaborative reflection to be more data-driven. The flexibility provided in Lilypad's recording interface, which allowed Claire to catch up when she was able to, and Jonah to add additional details, could have significant implications long-term as teams iteratively record and use the data for decisions about interventions.

Long-term, Lilypad could also enable members of a team to compare and discuss how they are recording data. Teams might develop some common structure to their data, improving consistency, by providing the flexibility and communication tools for team members to become aware of which elements of their individual practices work best. During the course of the deployment administrators mentioned to me that they were considering a change from the four school rules to individualized behavioral goals. They were reassured and pleased to learn that Lilypad had been designed to handle such a change, because of the primary focus on customizable frequency and duration data.

6.2.3. Authority based on knowledge rather than position

Monet followed a democratic service model (Bloom and Farragher, 2013), encouraging and valuing the involvement of all staff in treatment discussions and coordination. Team members were reciprocally interdependent, because they each contributed unique knowledge and experiences to coordination (Marcu, Dey, & Kiesler, 2014). As a result, hierarchy was not as valued as democratically sharing experiences, anecdotes, opinions and interpretations—the process that makes up collaborative reflection. Authority, in turn, was granted to those staff members who at that moment had the appropriate knowledge to contribute to the process of collaborative reflection. Lilypad fit this model by democratizing the use of HIT for coordination.

Chapter 5 discussed the frustrations of overburdened record keepers, and the observed tensions between them and the supervisors who sometimes had unrealistic expectations of them. These tensions were caused in part by the negative impact of the cumbersome paper-based system on the overall democratic process of collaborative reflection. Record keepers were dependent on their supervisors to provide data sheets, so they did not have much say in what data should be recorded or how. By the second week of

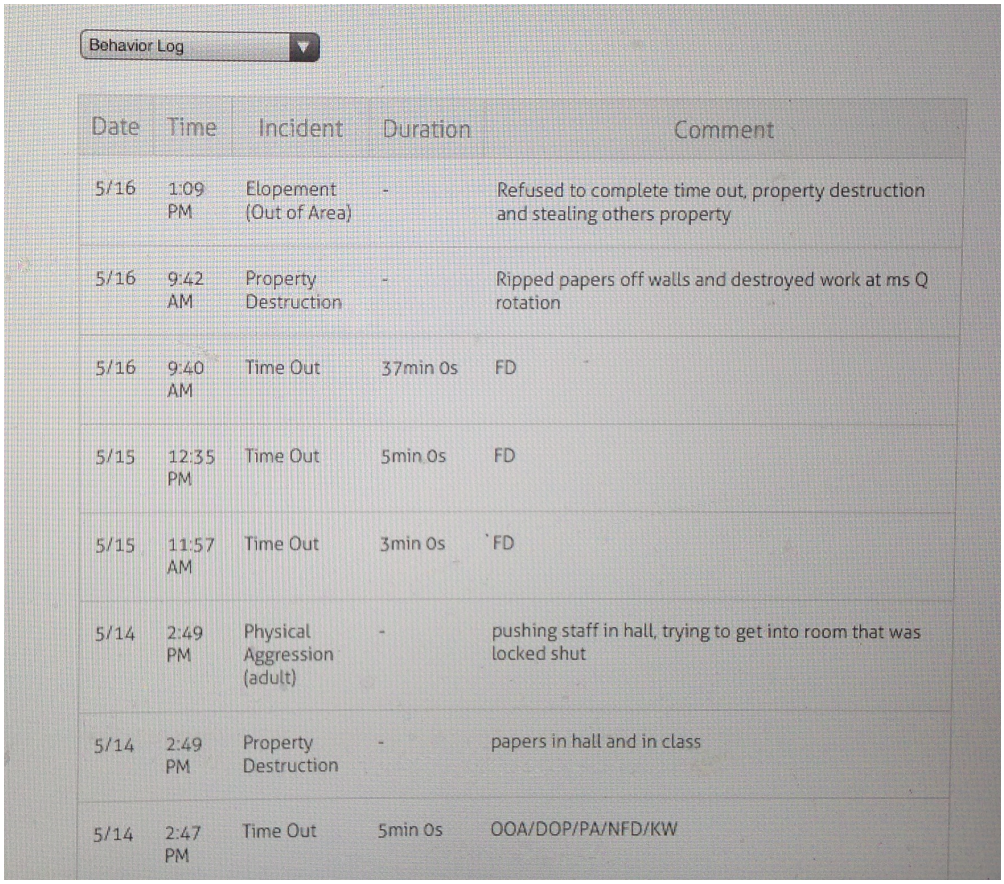
our deployment, one of the record keepers, Olivia, implied that Lilypad had the potential to address these issues. She referenced the tension with her supervisors: "this is great, I've been asking for something [to help me with records] for a while, and they wouldn't even let me use Excel." Olivia's comment suggests that the introduction of Lilypad began to empower record keepers like her. Lilypad was designed to have the flexibility to enable team members to record data in slightly different ways, so they could have the freedom to adjust their recording practices within the bounds of required data collection. I found that the balance of structure and flexibility gave those recording the data more of a voice in their practices and lowered their feeling of being constrained by the paper forms provided by their supervisor for recording data.

Within a month of beginning the deployment, I had built enough rapport that staff members were comfortable expressing their frustrations and speaking freely about tensions with their supervisors. Record keepers in particular shared stories about other staff members who had left or been fired, and thoughts about whether they themselves might leave the organization or the field. Fieldwork during the deployment focused mostly on the record keepers at first, because Lilypad's ability to support collaborative reflection depended on first and foremost enabling the capturing of records. The openness with which these individuals vented their grievances suggested that they were eager to be heard and supported. Their desire to be heard and empowered in their jobs drove the participatory design process, and my ability to build the closest rapport of all informants with the record keepers indicates that their involvement in design was meaningful and effective in driving organizational change.

Claire was the record keeper with which I had least rapport, and this did not surprise her coworkers. Claire was jaded after a decade of experience with her supervisors changing record keeping practices and tools. Already feeling overwhelmed with her job on a daily basis (even though she was not more burdened than her peers), she was unwilling to adapt to a new tool that, from her skeptical perspective, was likely to be taken away by her supervisors soon. Claire's reason for not wanting to adapt to Lilypad points to a lack of empowerment and an external locus of control. For a long time before Lilypad, staff members had been feeling that supervisors were enforcing practices a certain way and dictating how data should be managed. All of the record keepers other than Claire embraced Lilypad as a means to have more say and participation in how records are created, and those record keepers enjoyed using Lilypad and were enthusiastic to be a part of this work. The experiences of the record keepers show the importance of helping staff feel that they have a say in the design and use of a system, and overall organizational change, in order to match Monet's democratic service model.

6.2.4. Multidirectional communication

Because paper data sheets were not easily shared, coordination and discussion tended to be driven by the record keepers sharing anecdotes and answering questions by memory. With the use of Lilypad, record keepers participated more in discussions of data, and relied less on memory.



Date	Time	Incident	Duration	Comment
5/16	1:09 PM	Elopement (Out of Area)	-	Refused to complete time out, property destruction and stealing others property
5/16	9:42 AM	Property Destruction	-	Ripped papers off walls and destroyed work at ms Q rotation
5/16	9:40 AM	Time Out	37min 0s	FD
5/15	12:35 PM	Time Out	5min 0s	FD
5/15	11:57 AM	Time Out	3min 0s	FD
5/14	2:49 PM	Physical Aggression (adult)	-	pushing staff in hall, trying to get into room that was locked shut
5/14	2:49 PM	Property Destruction	-	papers in hall and in class
5/14	2:47 PM	Time Out	5min 0s	OOA/DOP/PA/NFD/KW

Figure 2. A child's behavior log using existing metrics such as timestamp and duration, and existing language such as elopement and property destruction. Aggregating this data and displaying it in the same place was new for users.

In one conversation I observed, team members were reviewing a child's data using Lilypad's interface projected via Apple TV. Although the line graphs resulted in minimal discussion in this case, once they turned to the log of incidents for this student, a mental health therapist made a comment about the screen in Figure 2. She noticed that three of the time outs over the course of several days happened subsequently to the child not following directions given by staff ("FD"). Interestingly, the child was not one of her cases, and she was just sitting in on this meeting to experience Lilypad. She asked the rest of the team if this might be a causal relationship, how the team might investigate this pattern further to find out, and what *in situ* intervention applied when the child has not followed directions might prevent

an escalation to a time out. The mental health therapist's insight, and the discussion that followed, exemplify data-driven coordination. This incident illustrates a distinct change from a prior tendency to use primarily intuition and anecdotal evidence. Instead, the process of collaborative reflection was driven by the use of data.

Team members also played different roles in maintaining external communication, each of which involved their own challenges: mental health therapists were the primary liaisons between home and school to support the course of treatment; psychiatrists would contact parents for medical information and external clinicians for medical histories; behavioral specialists would communicate with parents to compare and contrast daily behavioral trends between home and school; and supervisors would communicate with auditors and school districts in managing Monet's programs. Due to the limitations of paper-based records, these communications were not very data-driven. Much like the earlier vignette from a formal meeting, informal conversations tended to be based largely on anecdotal evidence and memory.

Various team members reacted positively to seeing visualizations on Lilypad, and comments reflected their respective roles in external communications. Mental health therapists, unprompted, stated how useful the visualizations would be for sharing with parents and keeping them informed about their child's progress. Several informants confirmed that the visualizations would be easier for parents to understand than existing paper reports. The roles of behavioral specialists (who were also record keepers) and supervisors sometimes contradicted, since the former was concerned with working closely with one classroom of children and getting to know their families, while supervisors were concerned with the wellbeing of the organization as a whole and its ability to pass audits. Lilypad seemed to create equilibrium by separating logistical needs that supervisors were concerned with, from the treatment needs that drove the everyday work of behavioral specialists. Supervisors were satisfied with the statistics being reported, while behavioral specialists had a variety of resources with which to explore a child's data.

Overall, the line graphs generated in real-time, performance metrics, and reports were highly valued. In contrast to the frustration record keepers felt when it came to requests from their supervisors for more paper-based records, they were willing put in the effort to adapt to Lilypad because they were motivated by the direct benefit they could experience in not having to transfer and manage as many reports. Claire, who was jaded and dragged her feet more than the others when it came to adoption, was more motivated after seeing the functioning graphs and experiencing that immediate and concrete benefit.

One informant joined the study when she was hired as a new mental health therapist at Monet. She had a very positive reaction when first introduced to Lilypad's visualizations, and was eager to be involved with the study despite still working to adjust to her new job. Based on her prior experience in the field, she told us Lilypad would be in high demand if it were offered as a product, suggesting that she viewed the design as filling an unmet need. She viewed Lilypad as an asset, requested to become a user, and enthusiastically asked questions about its features.

6.3. Conclusion

The promise of health information technologies has remained largely unfulfilled, and unintended consequences plague the introduction of these systems. This thesis builds on the growing body of literature identifying these problems. It provides a complementary perspective to the considerable literature on time-critical and acute care, by describing the nature of long-term chronic care. With a rise in the prevalence of chronic conditions that span time, organizations, and providers (e.g., autism, asthma, diabetes), team-based decision-making is becoming more common in health services.

I distinguish the focus of this thesis using the simplistic categories of organic and mechanistic systems. Mechanistic systems are more predictable and structured – with well-defined problems – and thus information technology is more straightforward to design and incorporate in these settings. I argue that the unintended consequences that have arisen with HIT involve a mismatch between an organization that operates organically, and HIT designed as a mechanistic system. I therefore designed and validated Lilypad as an organic system. It involves flexible coordination that enables individualized services—plans are flexible, goals change over time, and evaluation is subjective and long-term. It also avoids standardization to allow for the type of adaptability, or framing and re-framing, involved in the enactment of sensemaking and reflection.

The design of Lilypad as an organic system fit into existing workflow in an organization. Staff at Monet adapted to recording data with Lilypad, and their discussions referenced the data in ways they had not before. In addition, the Lilypad deployment seemed to reduce tensions among staff. In an organization where tensions already existed, introducing a tool that had the potential to increase accountability and supervision presented some risks. The use of Lilypad could have caused record keepers to feel even more pressure, and the ability of administrators to more closely oversee their actions could have created an even larger imbalance of power. Instead, Lilypad's design as an organic system empowered the record keepers. The deployment ended with Monet administrators asking for a full deployment across the

school for the following year – a request in which they appeared to draw from opinions of staff at all levels of the organization. Lilypad was designed and introduced organically by addressing the needs at various levels in the organization, and this united staff members who were sometimes at odds with one another due to competing demands.

The contributions of this thesis include both breadth and depth: fieldwork provided an understanding of day-to-day practices of coordination, with a focus on behavioral and mental health services; a combination of field sites and comparisons to literature grounded findings in broader impact across health services and organizational coordination. The concept of collaborative reflection emerged from both the breadth and depth of this work, and thus it can be applied to other types of organizations that use data to coordinate services.

Collaborative reflection can also further inform the design of organic systems, in ways that were out of the scope of this thesis. For example, I observed the use of email, cell phones, landline classroom phones, meetings, and ad hoc interactions in the hallway. HIT could provide additional means for team members to reach one another in order to corroborate interpretations of data. Examples include group messages with links to data, discussion forums around visualizations of data, and notifications based on automated analyses of data as they are recorded and aggregated. Multiple representations of data also could help members of a treatment team discuss the data in different ways. For example, data can be shown in a scatter plot or a bar chart, and data can be shown by week or by month. Looking at the data in different ways could help teams broaden discussions and possibly share more varying interpretations. Multiple views could therefore aid corroboration by helping team members to identify where there are diverging interpretations, and what should be discussed in order to develop a shared understanding as a team.

Further research is required to investigate the effects of a significant change in the representation of data. Existing paper-based data management enables little more than line graphs created by hand. The staff we observed did not have the means to perform statistical analysis even as simple as correlations, and few had appropriate training in data analysis. As a result, I expect new representations of their data to be a significant change in their practices. Understanding how this change will affect providers and their interpretations will inform the design of information systems for collaborative reflection.

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