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Sean P. Mikles

No Wrong Door: Designing Health Information Technology to Support
Interprofessional Collaboration Around Child Development Work

Sean P. Mikles

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Reading Committee:

Anne M. Turner, Chair

Julie A. Kientz

Debra Lochner Doyle

Program Authorized to Offer Degree:

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University of Washington

Abstract

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Sean P. Mikles

Chair of the Supervisory Committee:
Anne M. Turner
Biomedical Informatics and Medical Education

Child development refers to children gaining the skills they need to succeed in life, consisting of abilities in overlapping domains such as speech, motor, social, and cognition. Developmental disabilities are chronic delays in gaining such skills, and if they are not addressed in a timely manner, a child can experience negative outcomes throughout their life. Responsibilities for identifying and treating developmental delays and disabilities are spread across many stakeholders in the community, including not only parents but an interprofessional collection of service providers such as pediatricians, early educators, childcare providers, providers of home visiting services, and community groups. Regardless of who is involved in a child's care, there must be

“no wrong door” into the ecosystem of development support services. Unfortunately, these stakeholders operate in silos, resulting in a fractured system of services that parents struggle to navigate. This often leads to delays in the receipt of necessary services and uncoordinated care. Various researchers and policy leaders, such as the American Academy of Pediatrics, have suggested that health information technology (HIT) could be an important tool to help stakeholders collaborate in a child’s care management.

Current biomedical informatics literature, however, provides little practical guidance on how to design HIT systems to support such interprofessional collaboration. This dissertation presents four studies that aim to address this design gap by drawing upon the extensive body of literature on collaborative practice and the user-centered design framework. These studies demonstrate the use of qualitative methods in conjunction with theoretical concepts to assess the needs of a heterogeneous collection of stakeholders in regard to collaborative work with the goal of deriving design implications for future creators of collaborative HIT systems. The first study demonstrates the utility of using concepts from collaboration literature to uncover actionable design implications for collaborative systems using previously collected interview data from an interprofessional collection of stakeholders. The second and third studies utilize the methods of the first study to explore interprofessional work processes and interprofessional trust, respectively, with original interview data. Building upon the third study, the last study provides practical guidance for designing interprofessional collaborative systems to support the creation of trust between stakeholders of heterogeneous backgrounds. This is achieved through eliciting the information that people use to judge trustworthiness, and then creating and testing prototype webpages listing the noted information. This research will provide concrete methodological

guidance for designers of future systems to support collaborative work, as well as provide concrete design implications for such systems.

TABLE OF CONTENTS

Chapter 1. Introduction and Approach.....	1
1.1 Child Development Background.....	1
1.2 Collaborative Health Information Technology.....	5
1.3 Research Purpose.....	11
1.4 Dissertation Overview	13
Chapter 2. Research Background.....	16
2.1 Child Development Support Services.....	16
2.1.1 Healthcare Barriers to the Adequate Receipt of Services.....	20
2.1.2 Connections Between Healthcare and Other Service Providers.....	23
2.2 Interprofessional Collaboration	28
2.2.1 Review of the Collaboration Literature	28
2.2.2 Health Information Technology to Support Collaboration.....	33
2.3 User-Centered Design.....	36
Chapter 3. Concept-Based Needs Assessment to Design Collaborative Health Information Technology	39
3.1 The Collaboration Space Model	39

3.2	Research Methods	40
3.2.1	Data Collection	40
3.2.2	Data Analysis	42
3.3	Results.....	44
3.3.1	Process	44
3.3.2	Work Context.....	48
3.3.3	Technology	49
3.3.4	Awareness	50
3.3.5	Common Ground	50
3.4	Discussion.....	51
3.5	Conclusions.....	55
Chapter 4. Deriving Health Information Technology Design Implications From a Community- Wide Workflow Analysis		
4.1	Introduction.....	56
4.1.1	Work Processes in an Interprofessional Space	57
4.1.2	Work Context in a Collaborative Space.....	60
4.1.3	Child Development Support Work and Processes	62
4.2	Research Methods.....	65

4.2.1	Recruitment.....	65
4.2.2	Data Collection	66
4.2.3	Data Analysis	66
4.3	Results.....	68
4.3.1	Workflow Diagrams.....	73
4.3.2	Workflow Descriptions	74
4.3.3	Work Context Factors	80
4.4	Discussion	86
4.5	Conclusions.....	96
Chapter 5. A Thematic Analysis of Trust and Sharing Between Child Development Support		
	Services	98
5.1	Introduction.....	98
5.1.1	Trust Background.....	99
5.1.2	Trust and Health Information Technology	102
5.1.3	Trust Between Collaborators Who Support Child Development	105
5.2	Research Methods	107
5.3	Results.....	109
5.3.1	Assessing the Trustworthiness of Entities	109

5.3.2	Additional Themes Related to Trust	113
5.4	Discussion	119
5.5	Conclusions	123
Chapter 6. Designing User Interface Prototypes to Support Trust Between Child Development Stakeholders		
		125
6.1	Introduction	125
6.2	Trust Based on Social Transparency and Social Presence.....	126
6.3	Research Methods	130
6.3.1	Recruitment.....	131
6.3.2	Demographic Questions.....	132
6.3.3	First Survey Questions and Analysis	133
6.3.4	Prototype Design.....	135
6.3.5	Second Survey Questions and Analysis.....	135
6.4	Results	136
6.4.1	First Survey Results	138
6.4.2	Prototype Designs	150
6.4.3	Second Survey Results.....	153
6.5	Discussion	155

6.5.1	Information Indicating Trust.....	155
6.5.2	Statistical Analysis Results.....	157
6.5.3	The Dark Side of Trust	159
6.5.4	Limitations	161
6.6	Conclusions.....	161
Chapter 7. Conclusion.....		163
7.1	Introduction.....	163
7.2	Contributions.....	164
7.3	Important Empirical Findings	165
7.4	Limitations	167
7.5	Future Work	170
7.6	Concluding Remarks.....	175
Bibliography		177
Appendix A: Factors that affect collaborative practice from the literature		224
Appendix B: Major Research Findings and Design Implications Considering the Collaboration Space Model.....		243
Appendix C: Interview Guides for Chapters Four and Five		247
Appendix D: Detailed child development support workflow maps.....		281

Appendix E: Survey Collecting Information Child Development Stakeholders use to Assess Trustworthiness	286
Appendix F: Survey Evaluating Prototypes to Generate Trust.....	299
Appendix G: Cumulative Rank Scores for Information Categories	303

List of Figures

Figure 1. Best practices algorithm for supporting child development defined by the AAP.	19
Figure 2. Representation of the UCD cycle.	37
Figure 3. Overall workflow connecting best-practice child development support activities defined by the AAP.	74
Figure 4. Prototype depicting a doctor with information portraying competence, benevolence, and integrity.	153

List of Tables

Table 1. List of interviews in the pilot analysis by data source and role. Three parents and one childcare provider reported having multiple roles.	41
Table 2. Quantitative analysis of process-related codes.	45
Table 3. Summary of interview participants by their associated child development support role and related information, and basic demographics.....	69
Table 4. Summary of design implications for creating collaborative HIT to support child development.	87
Table 5. Themes around assessing the trustworthiness of entities in a collaborative space.	110
Table 6. Additional themes related to trust assessment and the effects of trust on the use of shared information	113
Table 7. Aggregate demographics for study participants, split by recruitment group and survey answered.	136
Table 8. Trust factors considered most important, split by respondent background and trustee background.....	138
Table 9. Multinomial logic regression model results. Statistically significant findings at a significance level of 0.05 are bolded.	139
Table 10. Information categories and encompassing themes. Categories are accompanied by specific descriptors used by respondents, split by descriptors used for doctors, those used for teachers, and those used for both.	141
Table 11. Information categories that were leveraged, and how they were operationalized for the prototypes.....	152

Table 12. Results of the cumulative logits model listing log-odds of having a higher level of agreement with statements related to trust. The table contains parameter estimates, standard errors, and p-values. All factors are significant at a level of 0.05.	154
Table 13. The dimensions of the MoCA and how they are expressed in the domain of child development work.....	173

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DEDICATION

This work is dedicated to the families who were willing to share their stories with me throughout
this research.

Chapter 1. INTRODUCTION AND APPROACH

1.1 CHILD DEVELOPMENT BACKGROUND

Child development is the process by which children gain the skills they need to succeed in school and in life (National Governors Association, 2005). Development encompasses a wide range of interrelated skill domains, including language, motor, social, and cognitive abilities (National Governors Association, 2005; Shonkoff & Phillips, 2000). The seminal report “From Neurons to Neighborhoods” notes that a child’s development proceeds at its fastest pace between birth and five years of age, defining these ages as a critical period for identifying and addressing any delays in a child’s development (Shonkoff & Phillips, 2000).

If a child does not gain certain skills at an expected age, they are considered to have a *developmental delay*, and if this lack of physical or mental abilities is chronic and inhibits daily activities, then the child is considered to have a *developmental disability* (Council on Children With Disabilities, 2006). Developmental disabilities are a broad, heterogeneous collection of conditions encompassing both clinically defined diagnoses, such as attention deficit hyperactivity disorder (ADHD) and cerebral palsy, as well as general collections of conditions, such as learning disabilities, sensory impairment, communication delays, or maladaptive social behaviors (Malone, McKinsey, Thyer, & Straka, 2000). When defining developmental disabilities that require treatment, modern United States legislation, most recently encapsulated in the Individuals with Disabilities Education Act (IDEA), is less concerned with specific diagnoses or categories of illnesses and more oriented toward functional abilities around major life activities such as self-care, language, learning, mobility, self-direction, and capacity for independent living (Malone et al., 2000). Children with developmental disabilities comprise a

subset of children with special healthcare needs (CSHCN), defined as children who require more health services than most children due to developmental disabilities or medical conditions such as diabetes (L. S. Anderson, 2009).

Research estimates that approximately 5.76 to 15.04% of children aged 3-17 in the United States have some form of developmental disability (Boyle et al., 2011; Zablotsky, Black, Maenner, Schieve, & Blumberg, 2015). Bio-behavioral attributes acquired early in life can persist throughout a person's entire life (Halfon & Hochstein, 2002). Research has identified many negative long-term effects stemming from untreated developmental delays and disabilities, such as decreased school readiness (Lloyd, Irwin, & Hertzman, 2009), lower educational attainment (Campbell et al., 2012; Reynolds, Temple, Robertson, & Mann, 2001), increased need for specialized medical and care services (Boulet, Boyle, & Schieve, 2009), increased medical expenditures (Newacheck & Kim, 2005), and increased risk for abuse and neglect (Shannon & Tappan, 2011).

"From Neurons to Neighborhoods" notes that human development is shaped by "a dynamic and continuous interaction between biology and experience" (Shonkoff & Phillips, 2000). Researchers have found that a combination of many influences, including genetic, family, psychosocial, cultural, and health system factors, affect a child's development (Halfon & Hochstein, 2002). Prior research especially highlights the importance of environmental threats and early childhood caregiver relationships in shaping a child's development (Shonkoff & Phillips, 2000). The environmental factors associated with developmental disabilities are varied, including factors such as food and housing insecurity, parental education, and parental substance use (K. P. Marks, Page Glascoe, & Macias, 2011). Delays in critical events in a child's life, such

as entry into school, can also have a significant negative impact on a child's development (Halfon & Hochstein, 2002; Shonkoff & Phillips, 2000).

Research studies have also uncovered racial and socioeconomic disparities in the risk factors for developmental delays experienced by children, and also in the identification and treatment of developmental disabilities. A study of National Health Interview Survey data found that children in lower income families were more likely to have a developmental disability (Boyle et al., 2011). A review of pediatric health disparities found that African American and Latino children had higher odds of having a developmental delay than white children, and that they were less likely to receive a diagnosis for ADHD (Flores, 2010). When receiving a diagnosis, African American children were diagnosed on average 1.4 years later than white children (Flores, 2010). This indicates the existence of a significant social component to the genesis, identification, and treatment of childhood developmental disabilities.

Effective interventions provided in early childhood can lead to more adaptive outcomes throughout a child's life (Shonkoff & Phillips, 2000). Programs aimed at supporting young children not only improve all domains of functioning in children, but they can improve family functioning as well (Duby, 2007). Clinical trials have shown that early childhood services, though varied in practice, provide benefits to children who face both biological and environmental risks to developing a developmental disability (Guralnick, 2011). Early childhood development programs have positive effects on cognitive function and school readiness (L. M. Anderson et al., 2003), and bestow long-term benefits to children, such as improving rates of college graduation and gainful employment, decreasing the need for public assistance services, decreasing juvenile arrest rates, and increasing positive health behaviors (Campbell et al., 2012; Palfrey et al., 2005; Reynolds et al., 2001).

While the effectiveness of individual early childhood programs has been established, many families of children with developmental disabilities never effectively engage needed services. Many children with developmental delays and disabilities do not receive the services for which they are eligible (Rosenberg, Zhang, & Robinson, 2008). Studies have found that many families of children with chronic developmental disabilities feel they have unmet needs, with families of children who have the greatest needs experiencing the greatest disparities (Bitsko et al., 2009; Inkelas, Raghavan, Larson, Kuo, & Ortega, 2007). Beyond the receipt of services, many families of children with special needs also report dissatisfaction specifically with the provision of family-centered care and care coordination (Bitsko et al., 2009). There are also significant disparities in the receipt of adequate care management services for children with developmental disabilities based on a child's race and ethnicity, economic status, and the nature of the disability (Adams & Tapia, 2013; Park et al., 2014; Raphael, Guadagnolo, Beal, & Giardino, 2009; Rosenberg et al., 2008; Sheldrick & Perrin, 2010).

One significant reason for this disparity in the receipt of services is due to the disconnection between separate programs that support child development. The overall system of developmental services in the US has been described as highly fragmented, with confusing structures and multiple points to entry that can be difficult to navigate (American Academy of Pediatrics Council on Children with Disabilities, 2005; Shonkoff & Phillips, 2000). Development support services can be provided by many different sectors in the community, including healthcare, early education, childcare, community nonprofits, and various therapists and specialists. Adding to this complexity, the mix of providers supporting a specific child and family over time will vary depending on a range of factors, such as the age and abilities of the

child and the family's socioeconomic status (American Academy of Pediatrics Council on Children with Disabilities, 2005).

Both medical and educational leadership in Washington State aim to support a “no wrong door” policy whereby children are connected to the developmental services they need regardless of who is involved in their care. Unfortunately, these separate programs do not adequately communicate or collaborate in the support of children with developmental needs. To address this problem, experts have called for better connections between the child's medical home, and developmental support services such as referral tracking systems or better tools for care coordination and management (Adams & Tapia, 2013).

1.2 COLLABORATIVE HEALTH INFORMATION TECHNOLOGY

Health information technology (HIT) has received increased attention as a potential means to support care that crosses institutional boundaries (C. Kuziemyky & Reeves, 2012; Ohno-Machado, 2018). HIT has the capability to bolster care coordination across fragmented services and providers (Hillestad et al., 2005; C. Kuziemyky & Reeves, 2012; Marchibroda, 2008), and information exchange across healthcare organizations has been shown to decrease healthcare costs and improve care quality (Menachemi, Rahrurkar, Harle, & Vest, 2018). The use of HIT, such as electronic health records (EHRs), personal health records (PHRs), and telemedicine systems, is suggested as a means to connect various service providers in the care of chronic health issues (Eikey, Reddy, & Kuziemyky, 2015; R. J. King et al., 2016; Melby & Hellesø, 2014; S. M. Smith, Cousins, Clyne, Allwright, & O'Dowd, 2017). Additionally, the lack of interoperable computerized documentation systems has been identified as a significant barrier to chronic care management (Bodenheimer, 2008).

HIT is being increasingly used to support communication between clinical, home care, and community settings for complex pediatric patients (Abowd, Hayes, Kientz, Mamykina, & Mynatt, 2006; Gentles, Lokker, & McKibbin, 2010). Policymakers suggest that HIT such as EHRs and health information exchange (HIE) could provide valuable support for early childhood health programs, including developmental screening and intervention (Council on Clinical Information Technology, 2011; Downing, Zuckerman, Coon, & Lloyd-Puryear, 2010; Hinman, Eichwald, Linzer, & Saarlal, 2005; Hinman, Saarlal, & Ross, 2004). The American Academy of Pediatrics (AAP) recognizes the use of HIT as a promising approach to supporting a medical home for children with special needs by helping to both identify developmental disabilities and also track a child's health and progress over time (Adams & Tapia, 2013; Council on Clinical Information Technology, 2011). Findings from qualitative studies of interprofessional care coordination for children with medically complex chronic conditions have also shown that many respondents express strong support for an interprofessional electronic platform for sharing information such as contact information, clinical records, and personal data among the entire care team (Horsky, Morgan, & Ramelson, 2014; Quigley, Lacombe-Duncan, Adams, Hepburn, & Cohen, 2014).

Unfortunately, current literature indicates that many existing HIT systems do not adequately support collaborative work (Eikey et al., 2015). Poorly designed HIT that does not consider the complex contexts that encompass interprofessional work can inhibit collaborative practice (C. Kuziemyky & Reeves, 2012). For example, Kuziemyky and Reeves note the failure of the UK's National Health System to create an effective system-wide EHR system, blaming the implementation failure on inadequate consideration of the complex workflows and interplay between interprofessional cultures inherent in the underlying healthcare system (C. Kuziemyky

& Reeves, 2012). A review of the biomedical informatics literature concerned with collaborative work by Eikey, Reddy, and Kuziemyky found many examples of HIT systems that caused misunderstandings and impeded communication (Eikey et al., 2015).

Chronic care management is a collaborative endeavor, and HIT systems to support collaboration need to consider the complex characteristics of such work, such as supporting teams of users with diverse backgrounds, services being located in different locations with infrequent or inconsistent contact, and issues of data security and privacy (Abowd et al., 2006). The necessity of care management activities in supporting child development indicates that bidirectional communication and the synthesis of multiple viewpoints could prove beneficial to providing needed care. Beyond simple communication between parents and service providers who support child development, collaboration is needed to ensure that all stakeholders' opinions and expertise are considered in the management of a child's developmental care.

For the purpose of this dissertation, the term "collaborative HIT" will be used to denote an HIT system meant to support the collaborative work of parents and multiple service providers to address complex health conditions. Collaboration is a broad and complex topic that presents many challenges to the HIT system designer. Collaboration, however, also has a broad base of literature spanning many academic traditions that could provide guidance for the design of HIT systems meant to connect disparate professions and organizations. Experts in collaborative work have posited that the design of effective collaborative HIT systems requires the consideration of theoretical and empirical findings from the deep well of past research, along with the views of all system users (C. Kuziemyky & Reeves, 2012). Unfortunately, many studies of HIT systems that support collaborative work do not consider the concept explicitly (Eikey et al., 2015).

Researchers have noted that many interventions designed to support interprofessional

collaboration do not utilize concepts from collaboration literature in their designs (Reeves et al., 2011; Weir et al., 2011), indicating a missed opportunity to create more effective collaborative HIT systems. Literature on collaboration, however, notes a wide number of factors as fundamental to collaborative practice, arranged into a vast collection of models and theories (D'Amour, Ferrada-Videla, San Martin Rodriguez, & Beaulieu, 2005; Eikey et al., 2015; Lemieux-Charles & McGuire, 2006; Mulvale, Embrett, & Razavi, 2016; Patel, Pettitt, & Wilson, 2012). The literature will be discussed further in the following chapter, but a summary of collaboration literature is in **Appendix A**, which includes technical, organizational, social, and process factors. This overwhelming complexity may explain why few systems incorporate features from the collaboration literature into their designs, and why many studies of collaborative work only consider only two collaborators.

Some studies describing systems to support collaboration in child-health-related work fail to describe the processes for defining end-user needs or evaluating whether these needs are met. For example, a report about the Tennessee Child Health Profile (TN-CHP) system aimed at supporting work with CSHCN outlines organizational linkages and provides technical specifications with a special focus on data security and standards, but does not provide details on how the system design supports specific user workflows and goals (Lozzio et al., 2005). A report on the technical architecture for a system to share newborn screening test results omitted details on how the flow diagrams, system functions, and technical architectures were configured to meet users' needs (S.-H. Hsieh et al., 2010).

Other studies that describe the assessment of user needs in a collaborative space tend to be narrow in scope and not reflective of the full complexity of interprofessional communications. Such work may only consider the perspectives and work of one or two collaborators and not the

whole spectrum of caregivers and service providers. Bergman, Beck, and Rahm describe the use of the online Child Health and Development Interactive System (CHADIS) to improve collaboration between parents and healthcare providers (Bergman, Beck, & Rahm, 2009). An initiative reported by Radis, Updegrove, Somsel, and Crowley focuses on granting school nurses access to various electronic database systems to support care management for students (Radis, Updegrove, Somsel, & Crowley, 2016). A study by Silverstein et al presents an EHR-based intervention to support referrals between primary care and Head Start programs (Silverstein et al., 2004). A paper by Abowd et al describes three separate systems meant to support children with autism spectrum disorder by easing data collection by therapists, caregivers, and educators (Abowd et al., 2006), but does not detail the complex collaborative work that would be involved in sharing such information across professional boundaries. Similarly, Baby CROINC (Ben-Sasson, Ben-Sasson, Jacobs, & Saig, 2017) and Text4Baby (Evans, Wallace, & Snider, 2012; Whittaker et al., 2012) are focused on improving caregiver documentation and knowledge. BabySteps (Kientz, Arriaga, & Abowd, 2009; Kientz et al., 2007; Suh, Porter, Hiniker, & Kientz, 2014; Suh, Porter, Racadio, Sung, & Kientz, 2017) is a system focused on empowering caregivers to regularly perform developmental screening tests on their children. By limiting the scope of work and the perspectives involved in the design of these interventions, these systems may not adequately support the full complexity that comes with having many different groups involved in collaborative development support work. The implementation of any HIT system incurs tradeoffs between pre-implementation and post-implementation workflows, and considering only a portion of collaborators may lead to workflows that are optimized for one group of users at the expense of other groups (C. E. Kuziemy, 2015a).

None of these projects explicitly reference the vast literature on collaboration, but supporting research has inductively discovered factors that are also prevalent in collaboration literature. The previously referenced study by Radis et al to connect school nurses to various existing data systems focuses on describing the policies and thought leadership needed to make these connections, and not the creation of new electronic systems (Radis et al., 2016). The study by Silverstein et al describes an intervention where a referral packet is automatically printed by an EHR and then subsequently mailed to Head Start providers due to a lack of electronic communication mechanisms between these organizations (Silverstein et al., 2004). Factors related to policies and technological resources have been identified by multiple models from collaboration literature (Lemieux-Charles & McGuire, 2006; Mulvale et al., 2016; Patel et al., 2012), therefore suggesting that an *a priori* consideration of those models would have aided in the design of these interventions.

The work undertaken to design BabySteps also strongly suggests the importance of considering a wide range of technical and social factors from collaboration literature in the design of a child development support system. The work by Suh et al (2017) takes deeper steps into considering interprofessional collaboration by specifically engaging Latino parents, health care providers, and Latino community health advocates. This work explored cultural factors regarding use of technology and constraints placed on screening activities based on the family's home environment. Based on these factors, the BabySteps team explored the use of both text messaging and Twitter along with a web portal to spur more system engagement (Suh et al., 2014, 2017). The "Grow and Know" study by Kientz et al drew upon ethnographic research performed with parents and providers, using considerations related to factors such as motivations, relationships, and data reliability to guide the design of future systems (2007). An

evaluation of the BabySteps system explicitly considered increased parent-provider engagement as an outcome, discovering complexities in how parents and providers view engagement over time (Kientz et al., 2009). This highlights the importance of work context and social factors that have been previously discussed in collaboration literature (D'Amour et al., 2005; Eikey et al., 2015), and, furthermore, demonstrates how consideration of these factors can lead to HIT design implications that encourage more efficient and effective system usage.

Due to these overall limitations, current research in the biomedical informatics field lacks guidance on how to create and implement a wide-reaching HIT system that would support the extent of child development support work with multiple professional groups. Grounding design work in the existing literature describing interprofessional collaborative work has the potential to guide designers through the complexity of collaboration to find concrete implications for system designs. The use of these concepts could also allow researchers to widen the scope of which collaborators are considered in needs-assessment research while considering each collaborating group in a comprehensive, systematic way. The research presented in this dissertation will test the utility of using existing collaboration literature in system designs, while also discovering concrete implications for creating an HIT system to support professional collaboration in a child's development.

1.3 RESEARCH PURPOSE

The purpose of this study is to provide guidance to HIT system designers who aim to build new systems to support interprofessional collaboration in a complex space such as child development. To consider multiple steps of the design process, starting with needs assessments and proceeding through the testing of prototypes, this research is guided by three main research questions:

RQ1. How can existing literature be leveraged to derive design implications for collaborative HIT systems?

RQ2. What are the unique considerations for designing HIT to support interprofessional collaboration in the space of child development?

RQ3. How can these considerations impact system designs and design artifacts?

To answer these questions, this dissertation will focus on how existing concepts from literature can be used to discern design implications for HIT systems to support collaborative work, and further demonstrate how these implications can be leveraged to create and test system designs. Within the user-centered design framework, this dissertation will address the first question by testing the use of deductive qualitative methods in conjunction with concepts from collaboration literature to analyze existing interview data. This will then address the second question by deriving actionable design implications from original needs assessment data, focusing on two concepts from the literature: work processes and trust. The third question will be addressed by taking design implications related to the consideration of trust to guide the creation and evaluation of prototypes for a collaborative HIT system. Based on the noted research questions, the research described herein has four main aims:

Aim 1: To demonstrate the effectiveness of a deductive qualitative analysis method, leveraging concepts from collaboration literature to uncover design implications from previously collected interview data from a heterogeneous collection of child development stakeholders. [Addresses **RQ1**]

Aim 2: To leverage the method from Aim 1 to analyze and diagram child development support workflows and accompanying work contexts to derive implications for HIT system designs. [Addresses **RQ2**]

Aim 3: To leverage the method from Aim 1 to explore how trust is expressed in the interprofessional space of child development support work and how interprofessional trust affects the sharing of information. [Addresses **RQ2**]

Aim 4: To design and test user profile prototypes for a hypothetical child development support system to support the creation of trust within an interprofessional care team to deepen an understanding of how trust is expressed in the child development space. [Addresses **RQ3**]

1.4 DISSERTATION OVERVIEW

This dissertation consists of seven chapters. Chapter 2 will present background needed to understand the child development space and the research approach in following chapters. It includes a discussion of child development services and the challenges stakeholders face in collaborating to support a child's development, a high-level description of the concept of collaboration and its attendant academic literature, and how concepts from the literature can be used within the user-centered design framework.

Chapter 3 presents the results of a study piloting the use of concepts from collaboration literature. The analysis uses concepts from a collaboration model to guide the analysis of data from multiple child development stakeholders collected by prior research initiatives. The results of this study demonstrate the relevance of these concepts, and how they drove the creation of implications for designing collaborative HIT systems.

Chapters 4 and 5 use the method piloted in Chapter 3 to explore the concepts of “workflow” and “trust,” respectively, in more detail using interview data. Chapter 4 discusses the results of a qualitative study to explore workflows across child development stakeholders and the

environmental contexts within which this work is performed. Information on workflow and environment was gathered through semi-structured interviews with a wide range of child development stakeholders, including parents, pediatricians, home visitors, specialized early intervention providers, early educators, social workers, and a community nonprofit group. The results of this study demonstrate the complexity of an interprofessional space, and present workflow diagrams and a set of design implications for a collaborative HIT system to manage the care of children with developmental delays and disabilities.

In Chapter 5, the interviews gathered for Chapter 4 are reanalyzed to explore how the expression of trust can affect sharing information in the interprofessional space of child development services. The results identify factors that can affect the judgment of trust within an interprofessional group of stakeholders, as well as how trust or distrust affects the sharing of data and the use of shared data. These results highlight the importance of perceptions of competence, benevolence, and integrity in assessing the trustworthiness of others, and that stakeholders use certain characteristics of people and “indicators of trust” to form trust judgments.

Building upon the design implications uncovered in Chapter 5, Chapter 6 takes identified factors that affect judgments of trust between stakeholders and aims to 1) define how a general population sample of parents, healthcare providers, and educators operationalize these factors in everyday life; 2) create prototype informational webpages for a hypothetical collaborative system using those factors; and 3) test whether the prototypes support the generation of trust in an unknown stakeholder. The results of this study indicate that information related to the trust-related factors identified in Chapter 5 was able to generate trust in unknown entities, demonstrating the value of considering propositions from collaboration literature in the creation of concrete system designs.

Chapter 7 will discuss the overall implications of this research in terms of supporting child development and interprofessional collaboration in general, as well as the methodological guidance it provides for designing future collaborative HIT. This chapter will also discuss the limitations of this research and directions for future inquiry. Overall, this research contributes to the literature by demonstrating the value of leveraging existing collaboration literature in the design of collaborative HIT systems.

Chapter 2. RESEARCH BACKGROUND

Chapter 1 outlined the rationale for this research into the design of collaborative HIT systems to support child development. This chapter presents background in three areas to support an understanding of the following chapters. The first background area is the complex web of services available to families to support child development. This background will provide a justification for framing subsequent work in terms of collaboration, and for involving more than two stakeholder groups in the following needs assessment research. The second background area is that of collaboration, which will demonstrate the complexity of the concept and the need to consider multiple facets of collaboration in HIT system designs. The third background area is in user-centered design, which is the framework used to guide all subsequent research.

2.1 CHILD DEVELOPMENT SUPPORT SERVICES

Due to the importance of adequately supporting child development, an extensive array of programs has arisen to support children with special needs, involving a diverse collection of service providers. Pediatricians and family practice physicians who see children are two key groups of providers in the ecosystem of child development services. The early identification of developmental delays is considered an integral part of the primary care medical home (Council on Children With Disabilities, 2006), and has been given significant attention by the American Academy of Pediatrics (AAP), which has released multiple statements related to the detection of developmental delays and disabilities (K. P. Marks et al., 2011).

Many services related to evaluating the nature of a developmental disability or providing therapeutic and care coordination services are provided outside of the primary care provider's office. Pediatricians, family physicians, and families commonly need to collaborate with many

different professionals, such as pediatric subspecialists, early intervention programs, childcare providers, preschool teachers, social workers, mental health providers, allied health professionals, and providers of after school programs, in order to support a child with complex needs (American Academy of Pediatrics Council on Children with Disabilities, 2005; Duby, 2007; K. P. Marks et al., 2011; L. Myers, 2014).

The funding for two important sets of programs that support children with developmental delays is established in the federal Individuals with Disabilities Education Act (IDEA), originally passed as the Education for All Handicapped Children Act (EHA) in 1975. Part C of IDEA establishes specialized community-based, family-centered, and multidisciplinary early intervention (EI) services to support children with delays and disabilities from birth to three years of age and their families, and Part B establishes grants to support special preschool education services for children ages three to five (Adams & Tapia, 2013; American Academy of Pediatrics Council on Children with Disabilities, 2005; Department of Education, 2018; Duby, 2007; Trohanis, 2008). Federal law mandates that available services in the community must include early identification, screening, assessments, care coordination, special instruction, and a wide array of therapeutic services as well as social work and family counseling services (Duby, 2007). Services can encompass a variety of therapies for eligible children, including speech, physical, and occupational therapies along with family education, psychological counseling, nutrition services, and assistive technologies (L. Myers, 2014). Other programs that support early childhood development are Head Start and Early Head Start programs (Hillemeier, Morgan, Farkas, & Maczuga, 2013; Love, Chazan-Cohen, Raikes, & Brooks-Gunn, 2013; Nelson et al., 2013), Nurse Family Partnership (Olds, 2006) and similar home visiting programs, community Help Me Grow programs (Bogin, 2006), and various private childcare and therapy programs. In

the state of Washington, public programs to support development are administered by multiple state agencies such as the Department of Social and Health Services (DSHS), the Department of Health (DOH), The Department of Early Learning (DEL), the Office of the Superintendent of Public Instruction (OSPI), and the newly established Department of Children, Youth, and Families (DCYF) (Hills, Doyle, & Zarate, 2014).

A child's developmental care requires effective management to coordinate care across settings, track progress over time, and change care plans when necessary. The AAP recommends the establishment of a medical home to support children with complex needs, which requires: a plan of care driven jointly by the physician, child, family, and others involved in the child's care; a centralized record or database containing all pertinent information from all settings; appropriate referrals and data sharing between providers; linking families to family support resources; and coordination of plan of care between all care settings, including schools and community organizations (American Academy of Pediatrics Council on Children with Disabilities, 2005). A review of studies investigating the effects of interventions congruent with the medical home model of care for children with special needs suggests that such interventions can improve health status, timeliness of care, family centeredness, and family functioning (Homer et al., 2008). The increasing number of children with special needs and the increased complexity of those needs make care coordination an integral pillar of the medical home model for children with developmental delays or disabilities (American Academy of Pediatrics Council on Children with Disabilities, 2005). The AAP suggests that the primary care provider's role in care coordination should be flexible, and leadership of the care coordination team should be determined by the needs of a specific child and specific family (American Academy of Pediatrics Council on Children with Disabilities, 2005).

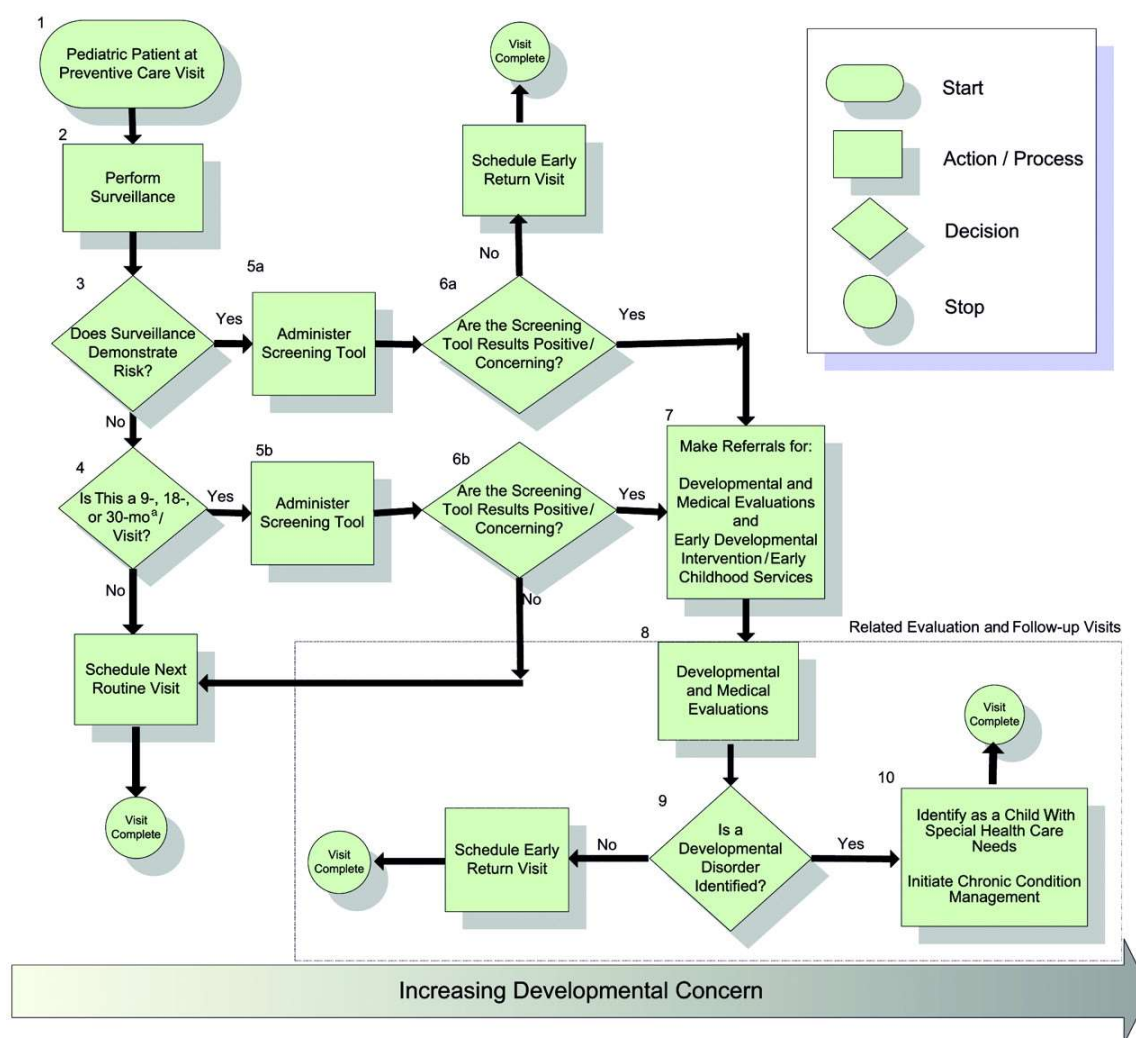


Figure 1. Best practices algorithm for supporting child development defined by the AAP.

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In 2006, the AAP defined a general algorithm presenting best practices for pediatricians to follow in order to detect potential delays and disabilities during well-child visits and refer families and children to further services in a timely manner (Council on Children With Disabilities, 2006). This algorithm, reproduced and described in **Figure 1**, depicts multiple activities that are necessary to adequately support child development. These activities include:

“surveillance” to monitor for developmental delays, the administration of standardized research-based “screening” instruments to identify probable developmental disabilities, “referrals” to further services, in-depth “assessments” to determine the nature of a disability, treatment “services” to address delays and disabilities, and “care management” activities to ensure that the child is receiving needed care over time. While this algorithm provides a useful blueprint for community-wide child development support services, the algorithm focuses on activities performed by pediatricians during well-child visits and does not provide enough detail to support the design of HIT systems to manage information around these activities.

2.1.1 *Healthcare Barriers to the Adequate Receipt of Services*

2.1.1.1 Identification of Delays and Disabilities

Biomedical literature has noted many barriers faced by pediatricians to the effective identification of developmental delays and disabilities. Monitoring for developmental disabilities through clinician judgment alone has poor sensitivity (Sheldrick, Merchant, & Perrin, 2011) and is greatly enhanced by the use of standardized, research-based developmental screening tests. Such tests have been shown to improve rates of delay identification, increase referrals to developmental services (Guevara et al., 2013; Jee et al., 2010; Schonwald, Huntington, Chan, Risko, & Bridgemohan, 2009), and decrease time to identification (Guevara et al., 2013). Unfortunately, surveys of pediatric practice have found that many pediatricians do not regularly use screening instruments (Radecki, Sand-Loud, O'Connor, Sharp, & Olson, 2011; Sand et al., 2005). A project in North Carolina to improve developmental screening rates found that only 34% of recommended well-child screenings were carried out at baseline (Earls, Andrews, & Hay, 2009).

Research has identified a number of barriers to screening, such as: a lack of time to administer instruments, lack of reimbursement to perform screening, lack of training in the use of screening tools, discomfort with reporting abnormal screening results, unfamiliarity with and a lack of trust in screening instruments, and a lack of confidence in the ability to effectively manage identified delays or disabilities (S. G. Allen, Berry, Brewster, Chalasani, & Mack, 2010; Honigfeld & McKay, 2006; Morelli et al., 2014; Pinto-Martin, Dunkle, Earls, Fliedner, & Landes, 2005; Tanner, Stein, Olson, Frintner, & Radecki, 2009; Weitzman & Wegner, 2015). There exists a wide range of screening instruments with overlapping goals, making the selection of the correct tool potentially difficult (Drotar, Stancin, & Dworkin, 2008; Glascoe, 2005; Weitzman & Wegner, 2015). Research has, however, indicated that if screens are completed by parents before a well-child visit, they can help providers organize their conversations during the visit (K. P. Marks et al., 2011; Schonwald et al., 2009) and mitigate problems with observing representative child behaviors in the doctor's office due to children being uncooperative during the visit (Kientz et al., 2007). While screening tests aid in the identification of delays and disabilities, the results of screening tests are regularly overridden by a clinician's "intuition" (K. P. Marks et al., 2011). Referral to IDEA Part C EI by a pediatrician is therefore more likely for delays that are easier for a doctor to observe in an office setting, such as gross motor abilities, than those that are less apparent in an office setting, such as social issues (K. P. Marks et al., 2011).

2.1.1.2 Referrals to Assessments and Services

While the identification of potential delays and disabilities is a necessary step in providing adequate developmental care, proper care also requires referrals to treatment and diagnostic services, receipt of care, and coordination between providers (Talmi et al., 2014). A review of

AAP policies on developmental screening by Marks, Glascoe, and Macias suggest that clinician-initiated referrals to services are the “weak link” in the chain to connecting children to services, and advocate for “system-wide care coordination programs” to support clinicians in this endeavor (2011). Children with suspected delays are not reliably linked to recommended services due to provider reluctance to refer, parent reluctance to follow up on a referral, or poor communication between the medical home and other services in the community (Guevara et al., 2013; K. P. Marks et al., 2011; Morelli et al., 2014). A nine-month pilot program to implement the AAP’s 2006 algorithm found that only nine of the 17 pilot pediatric primary care clinics attempted to track referral outcomes, and only six succeeded in implementing such a tracking system, reporting that the process was time- and labor-intensive and difficult to maintain (T. M. King et al., 2010). Sites qualitatively reported that many families never followed through with recommended referrals, with families often not understanding why a referral was made (T. M. King et al., 2010).

2.1.1.3 Care Management

After referrals to services are made, children and families also face barriers to the establishment of a medical home to coordinate care. While the medical home concept can be invaluable to the support of a child with complex needs, implementing the tenets of the medical home may prove difficult for many pediatricians when the services supporting a child are distributed across different organizations and professions. A study investigating the provision of medical care for CSHCN found that only 53% of children with special needs received care congruent with all principles of the medical home, with 22% facing problems with obtaining referrals, and 60% lacking effective care coordination when needed (Strickland et al., 2004). Another study assessing parental satisfaction with services for their CSHCN found that a majority of parents

were dissatisfied with the ability of their pediatrician's office to connect with resources outside of the pediatric office (Wood et al., 2009). The current medical system has built natural barriers to the communication necessary for care management, such as physicians' inaccessibility, difficulties with sharing medical records across settings, lack of reimbursement for communication activities, time delays inherent to using paper documentation, and chronic condition management not being a prevalent model for outpatient care (C. J. Stille, 2009; C. J. Stille, Frantz, Vogel, & Lighter, 2009). Access to healthcare services in general can also provide a significant barrier to children receiving needed services. Previous research has discovered that the identification of developmental disabilities are affected by well-child visit compliance rates (K. Marks, Hix-Small, Clark, & Newman, 2009). Many children in Washington State do not attend recommended well-child visits, and thus miss the opportunity for pediatricians to be involved in developmental care in any capacity (Washington Health Alliance, 2017).

2.1.2 *Connections Between Healthcare and Other Service Providers*

2.1.2.1 Addressing Healthcare Gaps

Due to the inconsistencies inherent in relying solely on pediatric practices and primary care providers to be the gateway to developmental services, other community services are needed to fill these gaps and ensure that children receive needed services (K. P. Marks et al., 2011). Many other services, such as early education and childcare programs (Hillemeier et al., 2013; Nelson et al., 2013; Trohanis, 2008), local health departments (National Association of County and City Health Officials, 2017), social workers (Malone et al., 2000), and community groups (Bogin, 2006) also monitor for developmental delays, perform developmental screening tests, and coordinate care. Since children spend substantial time in caregiver settings outside of the home,

such as schools or childcare centers, links between these settings and the medical field are of increased importance (American Academy of Pediatrics Council on Children with Disabilities, 2005). The overlap in responsibilities between service providers indicates that there are many opportunities outside of the doctor's office to identify children at risk for poor developmental outcomes and connect families to needed services. Integrating services outside of the healthcare field into developmental care has the potential to improve the overall effectiveness and efficiency of the ecosystem of child development support services.

2.1.2.2 Barriers to Communication

The integration of multiple child development support services requires that lines of communication are opened and maintained between organizations and members of different professional fields. Communication is a pillar of the medical home model and is necessary to provide high-quality care for children with special needs (American Academy of Pediatrics Council on Children with Disabilities, 2005; C. J. Stille, 2009; C. J. Stille et al., 2009). As the number of providers in a child's care team increases, however, there is potentially a geometric increase in the number of lines of communication needed to adequately connect all relevant stakeholders (Bodenheimer, 2008; C. J. Stille, 2009). Care coordination also requires specific types of communication to support co-management that may not be a part of regular medical practice, such as negotiating a care plan and responsibilities for care, and the coordination of activities and care approaches (C. J. Stille, 2009).

Communication between primary care providers (PCPs) and other providers of early childhood services is a challenging endeavor. Exchanging health information across organizational boundaries can be a complicated and time-consuming process (Horsky et al., 2014), and poorly designed or implemented mechanisms for care coordination can waste

significant resources and money (Antonelli, Stille, & Antonelli, 2008). A study of communication between PCPs and a pediatric specialty hospital found multiple barriers to effective communication between providers, such as parents not identifying their PCPs when they present at a specialist location, PCPs receiving infrequent information with insufficient detail for co-management, and some specialists thinking that communication with PCPs was outside their scope of practice (C. J. Stille et al., 2009). A report on a North Carolina project to improve developmental screening and referral rates noted that public and private agencies struggle to communicate with one another (Klein & McCarthy, 2009). A similar initiative in Illinois found that PCPs did not adequately engage parents to ensure that referral appointments were completed, only discovering that referrals were not completed at the next well-child exam (Hinkle & Rosenthal, 2011).

Professionals in school settings such as school nurses struggle to access medical information held by a child's PCP (Radis et al., 2016). Communication between EI service providers and PCPs are hindered by time constraints, difficulties reaching pediatricians by phone, and the use of different professional languages between the healthcare and education fields (Ideishi, O'Neil, Chiarello, & Nixon-Cave, 2010). A study of the dynamics between education, medical, and social worker professionals found misunderstandings about each other's roles and work processes and negative perceptions of each other's abilities and demeanors (Widmark, Sandahl, Piuva, & Bergman, 2016). For example, social service providers thought that school professionals did not adequately identify psychosocial needs, and mental health providers felt that school providers had unrealistic expectations for the amount services they could provide (Widmark et al., 2016). For children with special needs, defining who is even part

of their care team can be challenging (Ranade-Kharkar, Weir, et al., 2017), making it difficult for service providers to know who they should engage in care management activities.

2.1.2.3 Parental Responsibilities in Supporting Communication

When channels of communication between providers are not well established, parents generally have to facilitate such communication, which can be a significant burden (L. S. Anderson, 2009; Henry, 2016; Ideishi et al., 2010; C. J. Stille et al., 2009). Parents of CSHCN need to cope with worrisome diagnoses, process large amounts of medical information, and manage complex care plans (Christopher J. Stille, Primack, McLaughlin, & Wasserman, 2007). A study of communications between parents, PCPs, and medical specialists found that approximately one third of parents were not comfortable being the primary conduit of communication between providers, with some providers showing discomfort with parents playing that role as well (C. J. Stille et al., 2009). Parents face additional difficulties when trying to coordinate care between professionals in medical and education fields. In a study of parent experiences with coordinating school-based care for CSHCN, mothers reported a lack of communication between schools and medical resources and little knowledge of what communication occurs without their involvement (L. S. Anderson, 2009). Mothers also reported that coordinating activities between healthcare and education providers took significant time and effort, and that parental expertise on their own children was not always recognized by service providers (L. S. Anderson, 2009).

Parents have varying levels of health literacy, defined as the ability to understand basic health information and services in order to make appropriate health decisions (Yin et al., 2009), and therefore differing levels of ability to facilitate communication between professionals. An estimated 29% of parents in the US have basic or lower health literacy (Yin et al., 2009).

Differences in health literacy are associated with lower education, low English proficiency, low

income, and race and ethnicity (Yin et al., 2009). Low literacy is also a predictor for having an uninsured child in the household (Yin et al., 2009). Parents with lower health literacy tend to have poorer health behaviors regarding their children, such as inaccurately dosing their child's medications (DeWalt & Hink, 2009), and research has found that lower caregiver health literacy is related to poorer child health outcomes in regard to diabetes and asthma care (Keim-Malpass, Letzkus, & Kennedy, 2015; Sanders, Federico, Klass, Abrams, & Dreyer, 2009).

Studies indicate that parents with lower educational attainment have difficulties understanding the medical information they have been provided (Davis, Jones, Logsdon, Ryan, & Wilkerson-McMahon, 2013), and that many pediatricians have experiences with parents who do not adequately understand medical information (Turner et al., 2009). These results are reflected in child development literature. A study of care coordination between parents, physicians, and specialized care coordination staff found that extensive interpretation of medical findings was necessary to help parents navigate the medical system (Horsky et al., 2014). A study of parental beliefs around autism spectrum disorder found that parents with lower educational attainment and lesser economic means were more likely to consider their child's condition to be a mystery and less likely to believe that they had the power to help their child's condition (Zuckerman, Lindly, Sinche, & Nicolaidis, 2015).

2.2 INTERPROFESSIONAL COLLABORATION*

Chronic care management is a collaborative endeavor (Abowd et al., 2006). Due to the wide range of providers who can be involved in a child's developmental care and the necessity of repeated interactions between them for adequate care management, *interprofessional collaboration* is fundamental to the space of child development services.

2.2.1 *Review of the Collaboration Literature*

An international collection of policymakers such as the National Health Service in the United Kingdom, the National Academy of Medicine in the United States, and the World Health Organization have suggested that teamwork and collaboration in healthcare are necessary to provide quality patient care (Reeves, Pelone, Harrison, Goldman, & Zwarenstein, 2017; Xyrichis & Lowton, 2008; Xyrichis & Ream, 2008). The formation of joint action around health issues has become ubiquitous in the United States, with the acknowledgement that complex health issues cannot be addressed by individual people or organizations working alone (Lasker, Weiss, & Miller, 2001). Interprofessional collaboration between wildly diverse people also has the potential to lead to more comprehensive solutions to complex problems due to the combined breadth and depth of knowledge across collaborators (Mitchell, Parker, Giles, & White, 2010). Research on collaboration and teamwork has shown positive effects from supporting collaboration in healthcare, including enhanced access to health services, increased quality of

* Portions of this section have been adapted with permission from a paper published in the *Journal of Biomedical Informatics* (Mikles, Suh, Kientz, & Turner, 2018).

patient care and patient satisfaction, improved organizational efficiency and cost containment, decreased duplication and fragmentation of care, and increased job satisfaction for health professionals (Gocan, Laplante, & Woodend, 2014; Mitchell et al., 2010; Petri, 2010; World Health Organization, 2010; Xyrichis & Ream, 2008). Alternately, a lack of collaboration can cause medical errors due to inadequately reported information or information misinterpretation (O'Daniel & Rosenstein, 2008). Diverse health professionals, who could potentially collaborate to address complex health issues, have traditionally not worked together due to factors such as time and resource restraints or differing approaches to work, leading to the inefficient use of resources and a diminished impact on health outcomes (R. J. King et al., 2016).

While the value of collaboration is widely acknowledged, supporting collaboration in practice presents many difficulties. Recent reviews, while noting the importance of collaboration, have found mixed evidence as to the effectiveness of specific interventions meant to support collaborative practice (Reeves et al., 2017; Schepman, Hansen, de Putter, Batenburg, & de Bakker, 2015). One review noted that many interventions to support collaboration are “complex” and have multiple elements, hypothesizing that the lack of positive outcomes for collaborative care may be due to improper or incomplete implementation of such interventions (Schepman et al., 2015). HIT is also underexplored as a means to support collaborative practice. Another recent Cochrane review exploring shared care between primary care and specialist practices found that only 24% of interventions had a technological component (S. M. Smith et al., 2017).

As described in the previous chapter, a potential barrier to creating effective collaborative care interventions is that collaboration is a broad area with an extensive base of research, indicating many factors to consider when designing systems to support collaborative work. Collaboration has been studied in many academic fields such as healthcare (Bookey-Bassett,

Markle-Reid, Mckey, & Akhtar-Danesh, 2017; D'Amour et al., 2005; Gocan et al., 2014; Lasker et al., 2001; Légaré et al., 2011; Lemieux-Charles & McGuire, 2006; McDonald, Powell Davies, Jayasuriya, & Fort Harris, 2011; Modin, Tornkvist, Furhoff, & Hylander, 2010; Morgan, Pullon, & McKinlay, 2015; Mulvale et al., 2016; Petri, 2010; San Martin-Rodriguez, Beaulieu, D'Amour, & Ferrada-Videla, 2005; Suter et al., 2009; Xyrichis & Lowton, 2008; Xyrichis & Ream, 2008), health informatics (D. Dorr et al., 2007; Eikey et al., 2015), public health (Axelsson & Axelsson, 2006; R. J. King et al., 2016; Roussos & Fawcett, 2000; Varda, Shoup, & Miller, 2012; Walter & Petr, 2000), social work (Bronstein, 2003), engineering (C. P. Lee & Paine, 2015; Patton-Lopez et al., 2015), and administration (Bryson, Crosby, & Stone, 2006; Chi & Holsapple, 2005; Daley, 2008; Dawes, Cresswell, & Pardo, 2009; Nylén, 2007; Syväjärvi, Stenvall, Harisalo, & Jurvansuu, 2005; Thomson, Perry, & Miller, 2007). Collaboration has received many definitions, such as: “planned or spontaneous engagements between individuals or teams” where information is exchanged (Eikey et al., 2015); an ongoing partnership with “shared objectives, decision-making, responsibility, and power” that works together to solve problems and provide services (Morgan et al., 2015; Petri, 2010); or a sense of sharing and collective action built on harmony and trust (D'Amour et al., 2005). Many definitions highlight the notion that collaborative work often involves people of different professional backgrounds (Eikey et al., 2015; Morgan et al., 2015; Petri, 2010), or emphasize the importance of shared sensibilities, goals, and information among collaborators (Weir et al., 2011).

A review of biomedical informatics literature by Eikey, Reddy, and Kuziemy (2015) notes that collaboration effectively encompasses related constructs such as cooperation, coordination, and communication. The definitions of all of these terms describe interactions between individuals, with communication relating to the exchange of information; coordination

referring to the management of people, activities, and resources; and cooperation referring to production in a shared workspace (Eikey et al., 2015). Collaboration requires all three constructs in order to establish rules of engagement and a shared understanding of how work is to be carried out in a shared space. (Eikey et al., 2015)

Multiple terms have been suggested to describe different types of collaboration, such as “interdisciplinary” collaboration between comparable health professionals, and “interprofessional” collaboration between completely different professions (Retchin, 2008).

Thylefors, Persson, and Hellström (2005) define three types of “cross-professional teams” from the literature: multiprofessional, interprofessional, and transprofessional. In a multiprofessional environment, different team members work relatively independently, and in a transprofessional environment professional boundaries are dissolved as professions undertake the responsibilities of other professions (Thylefors et al., 2005). In an interprofessional setting, however, goals can only be achieved through interactive efforts and the contributions of all involved, requiring a high level of collective planning, decision-making, and responsibilities (Thylefors et al., 2005).

Collaboration in an interprofessional setting adds layers of complexity beyond collaboration within an organization or amongst professionals with the same background. Different professions are socialized through their training to view their work through discipline-specific frameworks and adopt profession-specific practices and values (P. Hall, 2005), and are granted access to separate professional jurisdictions that may historically be seen as competitive (D’Amour et al., 2005). Professionalization establishes boundaries between closely held areas of expertise, which can cause conflict in interprofessional environments where professional responsibilities overlap (Fox & Reeves, 2015). Professionalization confers social identities upon different professional groups, leading to potentially adversarial “in-group” and “out-group”

dynamics between professions (Mitchell et al., 2010) that can decrease trust between potential collaborators. When there is an implicit hierarchy of power between professional groups, barriers to collaboration such as boundary infringements, lack of role understanding, and limited communication can occur (Fox & Reeves, 2015). This is pronounced when considering the healthcare field since the history of professionalization in medicine places physicians in a privileged position relative to other professions (P. Hall, 2005). An understanding of the group dynamics between different professions is necessary to encourage interprofessional collaboration (Braithwaite, 2015). To be effective, collaboration also requires a shared “mental model” on how to reason about health issues (Patel et al., 2012; S. W. Smith & Koppel, 2013) and a shared knowledge base and language (Coiera, 2000; C. E. Kuziemyky & O’Sullivan, 2015; Weir et al., 2011), which can be difficult to establish in an interprofessional setting.

A review of the collaboration literature yields a large number of factors hypothesized to encourage or inhibit collaborative work, including some well-supported factors that regularly appear in the literature, such as work processes, trust, power, and role definitions. **Appendix A** contains a listing of 47 empirical and review articles in the literature concerned with collaboration, and a brief synopsis of the constructs they theorize to be relevant to collaboration (Axelsson & Axelsson, 2006; Bookey-Bassett et al., 2017; Bronstein, 2003; Brown, Dennis, & Venkatesh, 2010; Bryson et al., 2006; Chase et al., 2014; Chi & Holsapple, 2005; Daley, 2008; D’Amour et al., 2005; D’Amour, Goulet, Labadie, Martin-Rodriguez, & Pineault, 2008; Darlington & Feeney, 2008; Darlington, Feeney, & Rixon, 2005; D. A. Dorr, Jones, & Wilcox, 2007; Eikey et al., 2015; Fewster-Thuente & Velsor-Friedrich, 2008; Gaboury, Bujold, Boon, & Moher, 2009; Gocan et al., 2014; Horsky et al., 2014; Karunakaran, Reddy, & Spence, 2013; Körner et al., 2016; C. E. Kuziemyky & Peyton, 2016; Lasker et al., 2001; M. Y. Lee et al., 2012;

Légaré et al., 2011; Lemieux-Charles & McGuire, 2006; McDonald et al., 2011; Modin, Tornkvist, Furhoff, & Hylander, 2009; Modin et al., 2010; Morgan et al., 2015; Mulvale et al., 2016; Nylén, 2007; Odegard, 2006; Patel et al., 2012; Petri, 2010; Retchin, 2008; Roussos & Fawcett, 2000; San Martin-Rodriguez et al., 2005; Schmied et al., 2010; Sloper, 2004; Supper et al., 2015; Suter et al., 2009; Syväjärvi et al., 2005; Thomson et al., 2007; Varda et al., 2012; Walter & Petr, 2000; Xyrichis & Lowton, 2008; Xyrichis & Ream, 2008).

2.2.2 *Health Information Technology to Support Collaboration*

Due to the difficulties parents face in being the prime resource driving care coordination for their children, new tools to support direct communication and collaboration between different professionals may be an important way to improve the quality of care for children with developmental delays and disabilities. Researchers have also recommended that communication channels that are “efficient, concise, and automatic” are desirable, and that information in communications must be focused on providers’ needs (C. J. Stille, 2009). Experts have defined principles and requirements for electronic systems to meet child health goals: minimizing duplicate data entry, notifying parents and guardians when information is entered or shared, using data only for intended purposes, role-based and context-sensitive support to data access, ability for “push” communications, feedback to users when data changes and client data verification, and not using data for discriminatory purposes (Hinman, Atkinson, et al., 2004; Hinman, Saarlal, et al., 2004). The AAP recommends that to support a child’s medical home, HIT needs to support longitudinal tracking of chronic health issues, support co-management of CSHCN, and support patient care transitions (Council on Clinical Information Technology, 2011).

Outside of expert consensus on needed system functions, biomedical informatics research has also explored HIT system functionality and its effects on collaborative work. There is a growing body of work investigating the use of HIT tools to support collaboration in both primary care (Dendale Paul et al., 2014; D. A. Dorr et al., 2007; S. A. Smith et al., 2008) and hospital settings (Cohen, Blatter, Almeida, Shortliffe, & Patel, 2006; Collins, Bakken, Vawdrey, Coiera, & Currie, 2011; Feufel, Robinson, & Shalin, 2011; Gurses & Xiao, 2006; Morrison, Fitzpatrick, & Blackwell, 2011; Reddy, Dourish, & Pratt, 2001). A review of HIT to support collaborative work by Eikey, Reddy, and Kuziemy (2015) identified features in current HIT systems that may support collaboration, such as allowing communications between distant collaborators, alerting multiple caregivers when emergent events happen, or removing communication barriers inherent in hierarchical organizational structures. Unfortunately, most current HIT was designed to support care coordination within a single care location, and not between care settings (O'Malley, Grossman, Cohen, Kemper, & Pham, 2010). While HIT has the potential to facilitate collaborations in support of child development, poorly designed HIT can impede collaborative work as well. Current HIT systems have inhibited collaboration when separate documentation tools are not integrated, HIT workflows disrupt normal work processes, information is de-contextualized when shared, and HIT does not support the building or maintenance of relationships (Eikey et al., 2015).

Existing data standards focus on the work of individual clinicians and not the unique needs of team-based care (D. A. Dorr et al., 2007; Melby & Hellesø, 2014). Many EHRs used in clinical settings are not configured to adequately interface with other systems, including EHRs in other clinics (O'Malley et al., 2010). EHRs may not store information fundamental to collaborative practice, such as the composition of the patient's care team (Vawdrey et al., 2011)

or referrals and consultation reports (O'Malley et al., 2010; Talmi et al., 2014). Research has also noted that current HIT lacks functionality deemed to be important for collaborative care, such as managing care teams, supporting planning and monitoring, managing care transitions, and helping parents navigate the healthcare system (Bates & Bitton, 2010; Ranade-Kharkar, Weir, et al., 2017). In the field of child development, EHRs tend to lack mechanisms for supporting communication and care coordination between pediatricians and other professionals who may be involved in their care (Jensen, Chan, Weiner, Fowles, & Neale, 2009). Other types of HIT, such as PHRs, may help to fill these gaps in EHR functionality, but still require more design work to ensure they meet the needs of everyone involved in a child's care (Bourgeois, Taylor, Emans, Nigrin, & Mandl, 2008). Most EHRs also do not adequately support complex security and patient consent functionality needed for data sharing arrangements that cross organizational boundaries (van der Linden, Kalra, Hasman, & Talmon, 2009). Aside from the lack of functionality related to the storage and sharing of data fundamental to collaborative work, the use of HIT can also create barriers to collaborative work by impacting social dynamics in unexpected ways. For example, an e-messaging system between homecare providers and general practitioners in Norway decreased face-to-face communication between providers, thus degrading interpersonal relationships (Melby & Hellesø, 2014). Another study of a telehealth system to support interprofessional work found that clinicians experienced a shift in their perceived care roles and professional identities (Segar, Rogers, Salisbury, & Thomas, 2013).

Due to the inability of current HIT systems to adequately support collaboration and the patient-centered medical home, researchers have called for further work exploring the creation or implementation of collaborative systems (D. Dorr et al., 2007; Fitch, 2009; Young et al., 2007). A recent study of the use of HIT to support care coordination activities within a patient-centered

medical home found significant inconsistency between different tools in the percentage of necessary activities supported by HIT (Morton et al., 2015). A recent study of the use of EHRs and HIEs to support a patient-centered medical home found many barriers to care coordination using existing tools, with many respondents using separate, home-grown systems to bypass those barriers (J. E. Richardson, Vest, Green, Kern, & Kaushal, 2015). The biomedical informatics literature indicates that new work is needed to design collaborative HIT.

2.3 USER-CENTERED DESIGN

The end goal of IT research is the creation of usable artifacts, indicating the importance of design to the informatics field (Hevner, March, Park, & Ram, 2004). The American Medical Informatics Association (AMIA) recognizes the importance of applying social and behavioral sciences in the field of biomedical and health informatics (BHI) to design systems that best support the users of biomedical information (Kulikowski et al., 2012). Accordingly, BHI researchers have noted the critical importance of involving end users in the design process, and that a lack of user input can lead to systems not meeting user requirements, poor user adoption, and ineffective system usage (Berg, Aarts, & van der Lei, 2003; De Vito Dabbs et al., 2009; Johnson, Johnson, & Zhang, 2005; Kushniruk & Nøhr, 2016; Rinkus et al., 2005). The effectiveness of an HIT solution cannot be disentangled from the physical, cognitive, and social needs of users and the context within which they operate (Lawler, Hedge, & Pavlovic-Veselinovic, 2011).

User-Centered Design (UCD) presents a useful framework for designing HIT systems. UCD is a time-tested framework for design that actively involves potential users in all steps of the design process (Maguire, 2001). Key principles of UCD are involving users to understand user and task requirements, the iteration of design solutions, and a collaborative design process

(Maguire, 2001). The UCD process uses an iterative cycle, as depicted in **Figure 2**, of understanding the users' needs and context of use, specifying system requirements, and then creating and testing a design solution with users (Maguire, 2001). A UCD approach should not only focus on user-friendly interfaces, but must also consider appropriate functions, tasks, and facets of the users themselves (Zhang, Patel, Johnson, Malin, & Smith, 2002). Discussions of integrated child health systems recognize the importance of considering all end user perspectives in system design, implementation, and evaluation (Council on Clinical Information Technology, 2011; Downing, Zuckerman, Coon, & Lloyd-Puryear, 2010; Hinman, Eichwald, Linzer, & Saarlal, 2005; Hinman, Saarlal, & Ross, 2004).

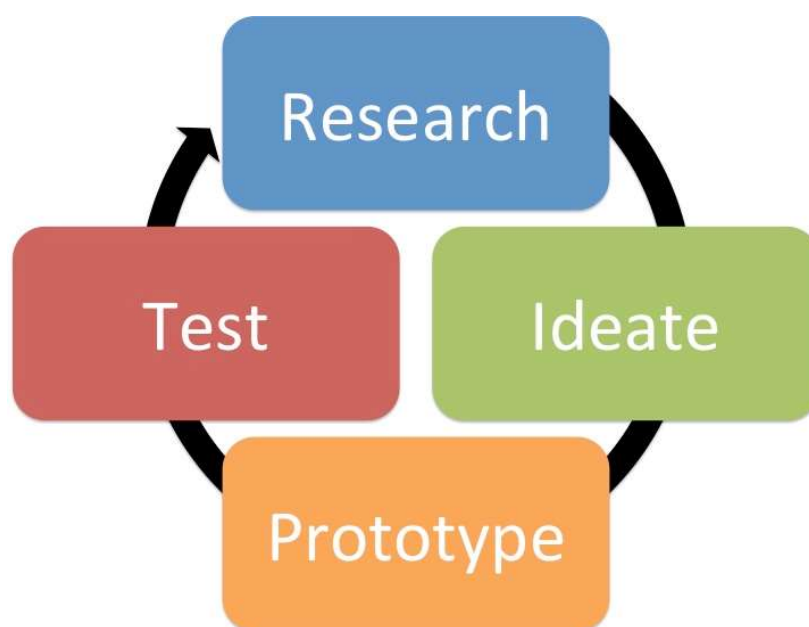


Figure 2. Representation of the UCD cycle.

The use of constructs in the literature that are theorized to affect collaborative work could play an important role in a UCD process by allowing designers to simultaneously leverage previous theoretical work while also using empirical end-user data (Hekler, Klasnja, Froehlich, & Buman, 2013). Studies of user needs generally utilize qualitative data such as observations or

interviews (Maguire, 2001; Zhang et al., 2002). When qualitatively analyzing text, audio, or video data, two major approaches to analysis are the use of inductive methods, where the meaning is derived solely through collected data, or deductive methods, where important concepts are defined before the analysis and then identified within the data. A fully inductive approach to qualitative data analysis risks the researcher unnecessarily missing important themes that have been uncovered through past research, whereas a deductive method can be used to build upon existing theory if available for the domain under consideration (H.-F. Hsieh & Shannon, 2005). Constructs from the literature could be used to guide deductive analysis of qualitative data, focusing the researcher on important factors related to the support of collaborative work (Halverson, 2002). In domains such as collaboration that have a large body of prior research, a deductive method is an appropriate approach since it “makes explicit the reality that researchers are unlikely to be working from the naïve perspective” that is seen as crucial to an inductive approach (H.-F. Hsieh & Shannon, 2005).

Deductive analysis methods have the potential to provide concrete guidance to HIT system designers. In their paper “Mind the Theoretical Gap,” Hekler et al. (2013) discuss methods for using theory during the design process, noting studies where theoretical constructs derived from the literature are used during HIT evaluations to focus end user responses. They suggest that conclusions reached using theories alone without the use of empirical data should be treated more as “design hypotheses” than as design implications (Hekler et al., 2013). This indicates that a research approach which combines theoretical constructs from the literature with a UCD process that elicits the needs of multiple groups of users is needed to guide system designs.

Chapter 3. CONCEPT-BASED NEEDS ASSESSMENT TO DESIGN COLLABORATIVE HEALTH INFORMATION TECHNOLOGY[†]

Chapter 2 established the rationale for using concepts from collaboration literature within a UCD process to design new collaborative HIT to support child development stakeholders in their work. The research in this chapter pilots this approach using previously collected data from child development stakeholders and concepts from the Collaboration Space Model (Eikey et al., 2015). This approach follows the suggestions of Hekler et al (2013) for designing through the use of theories by: 1) considering constructs hypothesized to affect collaborative work while 2) also considering empirical data from potential end users. A model consisting of multiple constructs was utilized to demonstrate that one construct alone cannot fully describe collaborative work, and that the use of multiple constructs can lead to a more robust set of design implications.

3.1 THE COLLABORATION SPACE MODEL

The Collaboration Space Model (CSM), defined by a review of the biomedical informatics literature (Eikey et al., 2015), provides a potentially useful model for guiding the design of collaborative HIT. The CSM contains technically focused constructs relevant to collaboration in healthcare while also moving beyond work that solely considers issues of data and process interoperability (D. A. Dorr et al., 2007; C. E. Kuziemyisky & Peyton, 2016) to also consider the

[†] Portions of this chapter have been adapted with permission from a paper published in the *Journal of Biomedical Informatics* (Mikles, Suh, et al., 2018).

social aspects of collaboration. The CSM contains four main concepts: processes, context, technology, and outcomes. The construct of “processes” refers to the workflows and communication that support collaborative work (Eikey et al., 2015). “Context” refers to the user roles, the work setting, and whether communication in this space is synchronous, asynchronous, or mixed (Eikey et al., 2015). “Technology” refers to the work role that is the focus of the design and the necessary functions of the HIT under consideration (Eikey et al., 2015). The “outcomes” of the CSM represent two goals that HIT should achieve in a collaborative setting: supporting “awareness,” and “common ground.” “Awareness” refers to collaborators having an understanding of “what is happening around them” (Eikey et al., 2015), and “common ground” is the shared understanding that collaborators need to allow communication to occur (Eikey et al., 2015). From an HIT design perspective, these factors can have implications for system features such as the use of structured versus unstructured documentation, the need for mobile technologies, and how information is aggregated across care settings.

3.2 RESEARCH METHODS

3.2.1 *Data Collection*

For the UCD needs assessment, data were collected from two initiatives (WA DOH and Grow and Know) that explored the use of technology to support child development. A secondary analysis of these interview data was performed, comprising a total of 44 interviews with various stakeholders including parents, early educators, and pediatricians.

WA DOH: The Washington State Department of Health (WA DOH) collected 23 interviews in March and April of 2015 from a convenience sample of service providers who were involved in a statewide initiative to support developmental screening. Interview questions

focused on the processes related to the administration of developmental screening tests, the use of developmental screening data, and processes around service referrals. Data from this initiative were in the form of typed notes.

Grow and Know: The Grow and Know initiative conducted 21 interviews with parents and caregivers with a focus on the use of technology to monitor a child's development (Kientz et al., 2007). Researchers recruited participants for this study in 2006 through Craigslist.org, mailing lists, and word of mouth. They specifically targeted new or expecting parents, experienced parents, and caregivers, and discussed how interviewees monitored developmental progress. Data from this initiative were verbatim transcripts of the interviews.

Four interviewees across these two sources held multiple roles as parents and service providers, leading to 48 distinct interview narratives. A full list of narratives by source and role is in **Table 1**.

Table 1. List of interviews in the pilot analysis by data source and role. Three parents and one childcare provider reported having multiple roles.

Role(s)	WA DOH	Grow and Know	Total
Parent	4	18	22
Primary Care Provider (PCP)	11	0	11
Childcare	2	4	6
Early Intervention Provider	1	0	1
Early Education	3	1	4

Role(s)	WA DOH	Grow and Know	Total
Community Support Group	2	0	2
Public Health Practitioner	1	0	1
Family Resources Coordinator	1	0	1
Total	25	23	48

3.2.2 *Data Analysis*

For the deductive analysis, the author created an initial codebook consisting of major constructs from the CSM: process, technology, context, and the outcomes of common ground and awareness. The definition of process included subcodes based on the best-practice child development support activities proposed by the AAP (Council on Children With Disabilities, 2006). The activities were categorized as “surveillance” to monitor for developmental delays, the use of standardized “screening” instruments, “referrals” to outside services, “assessment” of developmental disabilities, receipt of “services,” and “care management” (see **Figure 1** in Chapter 2). During coding, researchers noted both the role of the interviewee who reported an activity taking place and the role of the person performing the activity. Considerations of technology consisted of noting which stakeholders were currently using technology and how the technology was used to support child development. The definitions of context and awareness were taken directly from the CSM, while the definition of common ground was supplemented by further definitions in the literature defining common ground as “widely shared propositions” and a shared knowledge of available resources in the community (C. E. Kuziemsky & O’Sullivan, 2015; Weir et al., 2011).

Interview data were uploaded to Dedoose qualitative analysis software. The directed content analysis method (H.-F. Hsieh & Shannon, 2005) was used to apply codes from the codebook to text excerpts relevant to the codes. The author provided a research colleague with initial training on code definitions. Both the author and HS have experience with research related to child development services and qualitative analysis. The author coded all transcripts. To assess the reliability of the codebook, HS double-coded eight of the total transcripts (four from each source) and code applications between the author and HS were harmonized through in-person meetings. During the meetings, both researchers reviewed all of their code applications in Dedoose and any discrepancies were discussed and adjudicated. Throughout the analysis, no changes were made to the codebook and there was a high level of agreement between the two researchers.

Coded interview excerpts were analyzed using both quantitative and qualitative methods. Interviewees were organized into three groups: parent (n=22), PCP or pediatrician (n=11), and other service provider (n=15, encompassing childcare, early intervention, early education, community groups, public health practitioners, and family resources coordinators). Non-medical service providers were grouped together to provide a sample size comparable to the other groups. For the activities identified under the process construct, summary proportions were calculated to determine how often certain activities were performed by each role, recognizing that multiple people could be involved in performing a certain activity. For all constructs, qualitative descriptions provided by interviewees were used to elaborate on how each concept from the CSM was manifest in each narrative. Qualitative description is useful in the child development space due to the large variation in how collaborations between groups supporting child

development operate and how these variations might affect the design of a collaborative system (Sowa, 2008).

3.3 RESULTS

3.3.1 *Process*

Table 2 shows the results of the quantitative analysis of the AAP best-practice activities considered under the process construct (Council on Children With Disabilities, 2006).

Surveillance and referral codes were reported the most often. Screening and referral were mentioned most often in the DOH interviews, and surveillance was mentioned more often in the Grow and Know interviews, which is expected due to the different foci of the two underlying research projects. A majority of DOH interviews touched upon care management activities, while a majority of Grow and Know interviews talked about the receipt of developmental support services. Service providers aside from PCPs performed all assessments, though all stakeholder groups were involved with surveillance, screening, and referrals.

Table 2. Quantitative analysis of process-related codes.

			(A) % Narratives Reporting Activity by Source		(B) % Narratives Reporting Activity by Role			(C) % Activity Performed by Role		
Activity	Unique Activity Count	% Total Narratives Mentioned (n = 47)	% DOH (n = 24)	% Grow and Know (n = 23)	% Parents (n = 22)	% PCP (n = 11)	% Other Service (n = 14)	% Parents	% PCP	% Other Service
Surveillance	51	77	67	87	90	73	64	22	35	43
Screening	23	43	80	0	18	91	50	36	33	31
Referral	41	53	92	13	27	100	57	24	32	44
Care Management	34	40	63	17	23	64	57	24	15	62
Assessment	9	17	13	22	27	0	14	0	0	100
Development Services	26	39	25	52	55	18	36	23	8	69

(higher percentages are lighter, lower are darker).

(A) Percentage of narratives, by source, reporting activity

(B) Percentage of role narratives reporting activity

(C) Percentage of unique activity mentions split by performing role

The results of the qualitative analysis of the process construct are below, and are organized by the best-practice activities defined by the AAP:

Surveillance. For PCPs, surveillance generally took the form of asking questions around developmental milestones, whereas childcare providers generally collected observations of a

child's behaviors. Parents collected both types of information, including informal observations of things that "don't seem right." One parent reported the consideration of prenatal screening tests performed by medical specialists as well. Multiple parents reported difficulties with tracking their observations and their child's medical data over time.

Screening. All screening data were collected on paper with multiple service providers discussing double-documentation into electronic systems. Some PCPs provided parents with screening forms before a visit, requesting that completed forms be brought to the visit. Parents most often completed screening instruments, but only when directed to do so by a PCP or other service provider. Some early educators indicated that teachers or volunteers would sometimes complete screens during the day if parents were not available. One pediatrician noted a significant issue with delays in completing the screening forms: a parent may be given an age-specific screening instrument and fill it out later when the child is outside of the appropriate age range for the form.

Referrals. Referral processes varied significantly between narratives, and even differed from family to family within the practices of a single service provider. Communications between referral initiators and outside resources use many different modalities, such as faxes, paper and electronic forms, and phone calls, with the modality determined by the preference of the outside resource. A wide range of information is communicated through referrals, including demographics, medical history, standardized reporting forms, and screening test results. In many cases, "providing a referral" meant giving parents contact information for organizations, with the expectation that the parent would schedule necessary appointments. One pediatrician noted that the decision of whether to schedule referral appointments on behalf of the parents or only give the family referral information depended on the family's situation and preferences.

Service providers also discussed the need for getting feedback as to whether referral appointments took place, and the responsibility for gathering that feedback was inconsistent: it could be the parent, the outside resource, or the referral initiator. Pediatricians reported difficulties receiving feedback from early education groups. One early education site noted that their staff is heavily involved in referrals to school districts because the process is confusing, and referrals may need to be sent to multiple school districts.

Assessment. Early intervention programs and psychologists performed the majority of assessments for developmental disabilities, though in two cases medical specialists like neurologists were involved to perform medical imaging. In one case, an early educator helped a PCP assess a child for ADHD by filling out an ADHD checklist upon the doctor's request. Multiple parents reported that their children underwent several assessments for different developmental disabilities throughout the course of their care. When seeking services, one parent moved their child from provider to provider due to long wait times for scheduling services, and the child was assessed separately at each location.

Care Management. Parents reported difficulties with managing their children's developmental care over time, which was a barrier to sharing accurate information with all involved providers. One parent likened the difficulties they faced in organizing communications between service providers to a "juggling act." Transitions between care settings are a significant part of care management, and usually consist of transitions from specialized early intervention programs to the local school district. One parent noted that a standardized document created by the school system called an Individualized Education Program (IEP) helped with care management, though some early educators noted that the IEP is only shared with parents when

requested. Two parents noted difficulties with monitoring and altering medication regimens, as it required coordination between PCPs and school resources.

Developmental Services. Parents regularly reported that their children would receive developmental services from multiple providers at the same time. The nature of developmental services differed depending on the role of the person performing them. The few PCPs who provided services provided them in the form of educating parents on home-based support activities. Others provided at-home therapy services administered by professionals. Parents and childcare providers supported children mainly through developmental play, home-based therapy activities, and tools such as books, CDs, and DVDs.

3.3.2 *Work Context*

Many professionals are involved in child developmental care, including pediatricians, childcare providers, community groups, early educators, specialized early intervention programs, and public health programs. Pediatricians note that many different staff members could be involved in developmental screening and referrals, such as office staff, medical assistants, and nurses. Early intervention services also have separate therapists, who provide services, and care coordinators, who handle management activities. Children regularly receive services at multiple locations simultaneously.

Childcare and early education providers perform development support work in multiple types of environments, from home-based, to parent-teacher meetings, to classroom settings. Multiple parents commented that they trust observations made in home-based one-on-one settings more than classroom settings because it is difficult to monitor multiple children at once. Service providers reported that parents face many environmental factors that affect their ability

to pursue services, such as a stressful home environment. Many non-pediatrician service providers also noted a lack of work resources, leading to the limited availability of their programs and subsequently long waits for services.

Different work settings are also beholden to different laws and policies. Legislation such as the Health Insurance Portability and Accountability Act (HIPAA) and the Federal Education Rights and Privacy Act (FERPA) affect how healthcare providers and educators communicate information about a child. While the school system regularly requires parental consent in order to share information, most pediatricians assumed implied consent when making referrals. Also, while pediatric offices operate year-round, many early education services are tied to the school year, so special accommodations have to be made to support children during the summer.

Child development support activities use a mix of synchronous and asynchronous communication. Much information during referral processes is communicated asynchronously through faxing or using electronic or paper forms, and service providers rarely communicated synchronously with each other. Phone calls tend to be made on an *ad hoc* basis when one service provider had a specific question for another provider.

3.3.3 *Technology*

Many service providers in the child development space use existing electronic systems for documentation purposes. Pediatricians and PCPs reported documenting development support activities in EHR systems. Few practices store screening results as structured data; instead, they scan a copy of the paper screening into the EHR. Early educators reported the use of multiple systems to handle different activities. One uses a commercial system to perform surveillance activities and document the results of educational assessments. Another site uses an online

database managed by the state to document and report screening results. A public health practitioner reported entering screening data into a national database. No parents reported the use of existing electronic systems to perform child-development-related activities.

3.3.4 *Awareness*

Service providers regularly rely on parents to provide information on all of the services a child is receiving. This is usually a verbal report during medical well-child visits or parent-teacher conferences, though sometimes documentation from other service locations is requested. Many parents find it difficult to remember all pertinent information, especially if their child receives services in multiple settings. Parents and PCPs both rely on childcare providers and early educators to relay information about a child's behavior during the day. Parents generally receive this information informally, though some early education programs would also document behaviors in regular activity sheets or legally mandated documentation for children receiving services like the IEP or the Individualized Family Services Plan (IFSP).

3.3.5 *Common Ground*

The interviews suggest a wide variation in knowledge about available resources in the community and various aspects of child development. Service provider knowledge of resources ranged from only a couple of service providers, to extensive lists of services available in the community. One interviewee who worked at a community support organization noted that parents were often not aware of available services, and two pediatric practices report the use of specialized referral coordinators to help parents find services. Aside from knowing which resources exist, it was also important to know what service each resource provides, with one

pediatrician professing that they did not understand what exact services the school system provides.

Both parents and service providers reported that parents do not know how to identify delays or disabilities, do not know developmental milestones, and do not understand the purpose of developmental screening tools. Less often, service providers noted gaps in their own developmental knowledge. Childcare providers and early educators reported difficulty in understanding questions on screening tests, and noted the importance of training on screening instruments to get accurate results. A pediatrician recalled doing more research on autism spectrum disorders after missing a diagnosis. Different stakeholders also use common terms like “assessment” and “evaluation” to refer to different practices with different goals, which could cause potential conflicts in communication. Educators regularly assess a child’s school readiness, whereas medical providers focus on assessing medical diagnoses. Different stakeholders also use different screening tests that have different aims, which can cause confusion.

3.4 DISCUSSION

Leveraging the constructs defined in the CSM with deductive analysis of UCD-based interview data provided important insights into collaborative practice within the complex child development space. The results have practical implications for how a collaborative system should function to facilitate child development support work. These results suggest functionalities that different stakeholders should be able to access, the types of communication that need to be supported, and information that the system should store. See **Appendix B** for a full listing of design implications based on the findings.

Quantitative analysis of child development support activities indicated both differentiation and overlap in stakeholder responsibilities. Non-PCP providers were the only group to perform assessments, which is as expected since assessments often require the expertise of specialized professionals (Council on Children With Disabilities, 2006). However, the finding that all stakeholder groups performed significant surveillance, screening, and referral activities indicates that such activities are not solely within the purview of the pediatrician, and that all stakeholders must have access to related functionalities and data in the system. Previous research in collaboration has found that overlaps in role responsibilities may cause conflict (Gocan et al., 2014; Lasker et al., 2001), indicating that a collaborative HIT system might require functionality to clarify different stakeholders' roles in the child's care and adjudicate conflicts where roles overlap.

Descriptions of work processes uncovered inconsistent referral and care management processes that regularly relied on parents to perform needed communication. While the AAP algorithm for developmental screening (Council on Children With Disabilities, 2006) portrays a linear flow from the identification of developmental disabilities to care management processes, children regularly received multiple assessments over time, and received services from multiple providers simultaneously. This indicates that functionality is needed to share information between providers and possibly sort documentation based on the delay or disability being addressed. There was also a contrast in how PCPs and teachers approached monitoring child development, with teachers focusing on school readiness. This indicates that knowledge of the purpose and the practices behind different "assessments" needs to be communicated as well to ensure that all stakeholders can accurately interpret assessment results.

Services can be performed in multiple locations, meaning that the collaborative system needs to consider the unique constraints experienced by traveling service providers and services in group-based settings. This suggests the need for mobile solutions and possibly dashboard views that allow caregivers to easily document on multiple children simultaneously. Service providers usually relied on parents to provide situational awareness of a child's services. Previous work on the challenges parents face in facilitating communication suggests that facilitating provider-to-provider communication could lead to better care coordination. Parents had lower levels of knowledge about child development and available resources, indicating that a collaborative system should include educational resources to support common ground. Many service providers use existing electronic systems to document child development information, while parents reported no such system, suggesting that a collaborative system should provide documenting tools for parents and also interface to existing systems.

System implementation necessarily creates trade-offs between existing ways of work and new workflows introduced by new systems (C. E. Kuziemy, 2015a), which may be especially complex in a collaborative environment where many workflows must be reconciled. Providers who are presented with new information of unknown quality from other sources could experience information overload (C. E. Kuziemy, 2015a). Implementing structured documentation could be difficult in an interprofessional space where stakeholders have different conceptualizations of child development and care management goals (C. E. Kuziemy, 2015a). Also, the use of multiple systems could lead to a loss of information if people are confused as to when the different systems should be used (C. E. Kuziemy, 2015a).

This work provides insight into supporting collaboration in a non-acute community setting. Two previous studies also investigated the child development space from an informatics

perspective, but used more inductive qualitative methods (Horsky et al., 2014; Ranade-Kharkar, Weir, et al., 2017). Both studies conducted interviews with multiple stakeholders to understand information needs and usage in the support of children with complex health needs. These studies' results were congruent with constructs in the CSM, discussing the importance of situational awareness, activities related to care management, an overabundance of communication modalities in this space, and the vastness of a child's care network. This supports the relevance of constructs in the CSM to collaborative practice to support child development, and their potential value in focusing collaborative HIT system designers on important factors that will affect collaborative practice.

While the methods presented in this paper can provide rich, detailed information, they also have limitations. One significant difficulty is in operationalizing constructs with multiple definitions or that lack specificity in the literature, like "common ground" (Hekler et al., 2013). The use of one construct may require significant research to ensure that the construct is being considered adequately, and constructs may need to be split into smaller sub-constructs to aid in their identification during deductive coding.

Quantitative analysis provides a potentially useful set of results, but must be used carefully in a qualitative context. The use of semi-structured or non-structured data collection tools may decrease the comparability of responses across respondents, which decreases the believability of aggregated statistics. In this analysis, counts of activities performed were necessarily biased due to the different questions asked between the *WA DOH* and the *Grow and Know* data sets. Even if qualitative data collection precludes the use of statistical analyses and formal hypothesis testing, counts like frequencies and rank order comparisons may still be useful (H.-F. Hsieh & Shannon, 2005).

3.5 CONCLUSIONS

Design using existing constructs from the literature in a qualitative data analysis combines the benefits of considering a wide body of literature while utilizing data from end users. The concrete results of this study indicate that this is a useful method that will provide designers of collaborative HIT with actionable design implications to guide system prototyping and development. Future work is needed to synthesize the great number of collaborative work models in order to provide designers of collaborative HIT a holistic view of collaboration. Further exploration is also needed to characterize different collaborative work arrangements and better understand what functions of a collaborative HIT system are necessary in different situations. Clearly defining the characteristics and components of collaborations could lead to more focused work that identifies a library of collaborative HIT system components and the collaborative arrangements in which they are best applied.

This chapter demonstrated the utility of using constructs from collaboration literature to guide the analysis of qualitative data in order to formulate implications for design. The following two chapters in this dissertation will utilize the method described above with a larger, more varied collection of stakeholders to explore the work processes that stakeholders use to perform child development support work in more detail and discover how trust impacts the sharing of information in this space.

Chapter 4. DERIVING HEALTH INFORMATION TECHNOLOGY DESIGN IMPLICATIONS FROM A COMMUNITY-WIDE WORKFLOW ANALYSIS[‡]

4.1 INTRODUCTION

As described in Chapter 3, a consideration of “process” is one of the four major concepts in the CSM (Eikey et al., 2015). Considering factors related to work processes in that chapter uncovered important implications for the design of collaborative HIT, such as the significant overlap in tasks performed by different providers and the difficulties faced in supporting communication during service referrals. The work in this chapter looks to extend those findings by engaging more stakeholder groups and mapping the complex processes relevant to a family as they seek adequate developmental care.

The collaboration literature has regularly discussed the importance of “process” in supporting collaborative work (D’Amour et al., 2005; R. J. King et al., 2016; Lemieux-Charles & McGuire, 2006; Patel et al., 2012). The fields of computer-supported cooperative work (CSCW) and ergonomics have placed an emphasis on workflows in supporting collaborative work (Patel et al., 2012; Pratt, Reddy, McDonald, Tarczy-Hornoch, & Gennari, 2004), and task and functional analyses are fundamental methods in human-centered design (Maguire, 2001). The field of biomedical informatics recognizes that a consideration of work processes is fundamental

[‡] This chapter is adapted from a paper that has been submitted for publication to the *Journal of Interprofessional Care* (Mikles, Lordon, et al., 2018)

to creating usable and safe EHR systems (Middleton et al., 2013), as well as HIT meant to support collaborative work (Eikey et al., 2015; R. J. King et al., 2016). A review of the biomedical informatics literature by Eikey, Reddy, and Kuziemytsky discovered that existing technologies regularly have a negative impact on collaborative work by disrupting workflows or unexpectedly altering work practices (Eikey et al., 2015). HIT system features can be used to enforce necessary order of tasks, can break previously defined workarounds for exceptions to regular workflows, can make data entry onerously burdensome, and can affect how data can be leveraged for clinical and administrative needs (C. E. Kuziemytsky & Peyton, 2016).

Implementing HIT can have other unintended negative consequences such as communication issues, workload increases, or even medical errors, which can negatively impact patient safety (C. E. Kuziemytsky & Peyton, 2016; Unertl, Novak, Johnson, & Lorenzi, 2010). Issues can be caused by poor fit between functions and clinical workflows, differing needs between user groups, and the existence of both automated and manual system tasks (C. E. Kuziemytsky & Peyton, 2016). Considering existing workflows in the design of HIT can lead to the creation of systems that do not disrupt work, and also lead to the identification of inefficiencies in existing workflows that should be addressed.

4.1.1 *Work Processes in an Interprofessional Space*

A workflow refers to processes that coordinate activities of different entities to improve efficiency and support work success (Pratt et al., 2004), or a set of chronologically grouped tasks, and the people and resources needed to perform those tasks, undertaken to achieve a goal (C. Caine & Haque, 2008). When organizational workflows and the workflows assumed by HIT systems are not aligned, it can create a great burden on users who have to reconcile those

workflows themselves (C. Caine & Haque, 2008). Such disruption can lead to informal, unsafe workarounds, that bypass system safeguards (C. Caine & Haque, 2008). Poorly designed HIT may not be able to deviate from standard process for extraordinary cases, prompting system users to instead rely on alternate documentation methods such as paper charts, white boards, or phone conversations, which can cause confusion or degrade information as it is passed between mediums (C. Caine & Haque, 2008). HIT, however, can bring about positive process change with its ability to consolidate and display information to improve coordination and communication, though workflow analyses are needed prior to implementation to realize these benefits and reduce possibility that HIT disrupts workflow (C. Caine & Haque, 2008). In order to support work processes, HIT systems must be interoperable with the work processes they support, meaning that people must be able to share a common understanding across a network of systems, disparate systems must be interoperable, and tasks must be adequately coordinated (C. E. Kuziemy & Peyton, 2016).

When considering interprofessional collaborative work, a design approach that focuses not just on individual software applications aimed at specific users, but collections of such systems and their interactions, may be advantageous to addressing all aspects of collaborative care. There is increased recognition in biomedical informatics that workflow studies focusing solely on physicians are too limited in scope for the current healthcare climate, where cooperative work is essential to the provision of care (Ozkaynak et al., 2013). Ozkaynak et al propose a “patient-oriented” frame for workflow analyses that organizes work processes around the patient’s care, and use the patient’s perspective as the reference point for research (Ozkaynak et al., 2013). This patient-oriented frame includes all of the service providers involved in a person’s care. This allows designers to capture not only the individual tasks of separate

providers, but also the interplay of cooperative work between service providers. This frame also allows designers to explore the boundaries between the systems involved, workflows across organizations, and gaps between clinical and non-clinical practices (Ozkaynak et al., 2013). The patient-oriented perspective may lead to HIT tools that are consistent with cooperative work by “providing a broader understanding than clinician-specific models, assisting in capturing work across settings, and revealing emergent features such as variability” (Ozkaynak et al., 2013). This perspective is helpful for defining who should be considered in a collaborative workflow analysis, and eliciting patient workflows acknowledges the important role patients play in their own care. Further analysis to engage various groups of service providers would aid in understanding their separate processes, information needs, and work contexts.

Delineating HIT system requirements across stakeholders requires business process analyses to define the current state of work, a redesign of processes to address inefficiencies, and descriptions of how an information system can support the work (Public Health Informatics Institute, 2008). Unfortunately, taking a patient-oriented approach to workflow mapping can present many challenges in an interprofessional space, including: difficulties in conducting workflow research in both formal and informal settings, ensuring the validity of data due to high variability in data for complex settings, and contending with a larger scope for complex phenomena (Ozkaynak et al., 2013). Business process model and notation (BPMN) is a standard modeling language that provides visual flow diagrams depicting business processes (Object Management Group, 2011). While BPMN provides significant utility in modeling complex processes in an understandable way, it unfortunately is challenged in situations where there is overlap in roles performing a task, or a large number of roles involved in one workflow (Müller

& Rogge-Solti, 2011). This is due to the large amount of space required to give each role its own separate portion of the diagram.

4.1.2 *Work Context in a Collaborative Space*

While system design flaws and technological issues can lead to HIT implementation failures, many undesirable effects of HIT are also caused by the interactions between people, organizational culture, and technologies (C. E. Kuziemyky & Peyton, 2016). In recognition of this, consideration of work context, defined as factors that describe a work setting such as the physical space or social environment, figures prominently in workflow studies (Unertl et al., 2010). A consideration of context may play an especially important role when considering collaborative HIT (Eikey et al., 2015) due to the number of technical, organizational, and social factors that can affect how systems are used across workplaces and professional boundaries. Considering the contexts within which collaborative work is performed is a “first step” to designing new technologies to support such work (Eikey et al., 2015).

This chapter considers a wider conceptualization for work context than what was presented in the previous chapter as a part of the CSM (Eikey et al., 2015). Work context has been broadly defined and encompasses many factors. Across the literature, context has been defined in terms of social factors, cultural factors, political factors, technology and workplace factors, policies and procedures, team-level factors, and individual psychological factors (C. E. Kuziemyky, Borycki, & Brasset-Latulippe, 2010; Lemieux-Charles & McGuire, 2006; Mulvale et al., 2016; Patel et al., 2012). Work context can also be defined on many levels of resolution. For example, the Integrated Team Effectiveness Model (ITEM) (Lemieux-Charles & McGuire, 2006) defines both organizational context and the larger social and policy context surrounding

the work organization. The social ecological “gears” model of collaboration proposed by Mulvale et al. includes factors defined at the “macro” policy or governmental layer, the “meso” organizational layer, the “micro” team level, and the individual level that can constrain collaborative action (Mulvale et al., 2016). High-level “meso” and “macro” factors such as inter-organizational structure and legislation can add complexity to collaborative work above and beyond work contained within a specific professional field or single organization. Factors such as the existence of a formalized governance structure between collaborators, or turnover between members, can alter the effectiveness of collaborative work (Bryson et al., 2006).

Within each level of resolution, there are collections of more granular factors that can affect collaborative work. This includes factors such as funding, training in collaborative practice, the ability to integrate electronic systems, the existence of formalized partnerships between entities, and the culture within an interprofessional team (Eikey et al., 2015; Gocan et al., 2014). The ITEM (Lemieux-Charles & McGuire, 2006) defines social and policy context around work, which includes organizational characteristics and resources, as well as the psychosocial traits of collaborating team members, such as norms and shared mental models.

Organizational factors such as incentives or disincentives for sharing information (Reddy, Shabot, & Bradner, 2008), or organization size, specialization, formalization, and managerial attitudes (Greenhalgh, Robert, Macfarlane, Bate, & Kyriakidou, 2004) can also affect the use of IT systems. Lee and Paine pose the Model of Coordinated Action (MoCA) as a framework that broadly defines the elements of CSCW that are relevant across many settings, considering factors such the synchronicity of communications, the physical distribution of actors, and the number of different communities of practice involved (C. P. Lee & Paine, 2015).

These contextual factors may have a significant impact on the effectiveness of HIT systems to support collaborative action. Within the field of biomedical informatics, factors such as organizational structure and policies can significantly affect the functions and data an HIT system should contain. For example, health systems with a measure of centralization in physician arrangements and insurance products tend to have higher levels of EHR interoperability (Holmgren & Ford, 2018), which facilitates sharing of information across organizations. Legislation such as the HIPAA can affect the technical specifications and functionalities that are necessary in HIT systems, such as the configuration of cloud computing resources (Schweitzer, 2012). HIT designs should be copacetic with the work contexts within which they will be used.

4.1.3 *Child Development Support Work and Processes*

The process that a child and family may undertake to pursue needed developmental care can be complex and difficult to traverse. As described in the previous chapter, families work with multiple professionals from different professional fields, necessitating the management of information from different sources. The professionals who form a child's care team also have their own separate processes for performing work and interacting with other professionals. This creates difficulties for the HIT system designer, who aims to design functions for a collaborative HIT system. Additional research is needed to define the study population of interest, decide the level of analysis, uncover interactions between the stakeholders involved, and determine how to connect workflows reported by disparate sources.

Prior research has discovered many complexities in the work performed to support child development, which involves families and networks of different professionals such as pediatricians, school nurses, therapists, and social workers (Horsky et al., 2014; Ideishi et al.,

2010; Radis et al., 2016; Ranade-Kharkar, Weir, et al., 2017; Widmark et al., 2016). For example, care coordinators in one study reported that children with three or more chronic conditions commonly see multiple specialists on a persistent basis, but with different frequencies (Horsky et al., 2014). These providers may be co-located and share an EHR, or may be spread across different organizations with different, non-integrated systems (Horsky et al., 2014). The use of multiple forms of communication between service providers is time consuming and could slow the pace of communication and require double documentation into electronic systems (Horsky et al., 2014). Providers aim to collect information from other providers to make informed care decisions, but oftentimes have difficulty identifying the key people to be contacted, or have to wade through pages of irrelevant information in long reports (Horsky et al., 2014).

Work context is also important in the child development space. The effect of legislation is highly pronounced in the child development environment, where multiple laws affect the sharing of information, such as the HIPAA for healthcare providers and the FERPA for educators. Reconciling these legislative regimes can be difficult and policymakers have had to define which professions and associated documentation fall under the purview of each law (Bergren, 2004). A failure to consider such factors in the design of an HIT system could have disastrous effects, such as prompting information exchange that could harm the patient and put the provider in legal jeopardy. The child development space also contains many different stakeholder groups with potentially conflicting social norms. Providers who want to build a dialog with other providers are regularly rebuffed (Ideishi et al., 2010). Maintaining a care plan can be difficult, since parents lack knowledge around medical terminology and health-related information, and providers lack knowledge of available services and service delivery systems

(Ideishi et al., 2010). Such interactions need explicit consideration to create effective collaborative HIT.

Experts recognize that the support of collaborative work around child health issues requires consideration of all potential users (A. Allen et al., 2014; Hinman, Atkinson, et al., 2004; Hinman et al., 2005; Hinman, Saarlal, et al., 2004; Public Health Informatics Institute, 2003; Saarlal et al., 2004), indicating that a focus on one user group is too narrow in scope. Unfortunately, little work has been done to map work processes that transcend professional boundaries or sectors of society in order to meet a shared goal. This provides little guidance for the domain of child development, where the activities that take place to support a child from birth through preschool age can potentially be distributed across many different service locations.

The aim of this chapter is to extend the process exploration in the previous chapter by performing a more in-depth workflow analysis to define the current state of child development support work. The goal is to generate design implications for the creation of HIT systems to support such work, and possible alterations of the work itself to improve efficiency and effectiveness of communication. This work will seek to engage a representative sample of all potential system users in the child development space and create “community-wide” process maps of the workflows that support children through the continuum of care. This research will also explore the contextual factors around child development support work to understand how they may affect this work.

4.2 RESEARCH METHODS

4.2.1 *Recruitment*

Data on work processes were collected through interviews with parents and service providers involved with either identifying or addressing developmental delays and disabilities in children under five years of age. Parents were recruited from the University of Washington (UW) Communication Studies Participant Pool and electronic newsletters managed by the Washington State Department of Early Learning and community nonprofit organizations. Parents were purposively sampled to select for experiences with a variety of developmental disabilities, including speech delays, autism spectrum disorder, and global delays. Service providers were recruited from a list of participants from a Washington State Department of Health initiative to support developmental screening.

New stakeholders were identified through snowball sampling by contacting potential participants referenced by existing participants during interviews using publicly available contact information or through e-mail introductions made by participants. Stakeholders were recruited throughout Washington State to gather experiences across multiple jurisdictions. Recruitment stopped after the primary researcher reached out to all relevant contacts on our initial participant lists and followed up on all potential leads provided during the interviews. Participants were provided with a written description of the research procedures and asked for consent to audio record the interviews. We offered participants a \$30 gift card. All study materials and protocols were reviewed by the UW Human Subjects Division, and the study was deemed exempt from human subjects review.

4.2.2 *Data Collection*

The primary author conducted semi-structured interviews with all participants, which included questions about child development workflows and communication between service providers. See **Appendix C** for the parent and service provider interview guides as well as associated questionnaires filled out by respondents. Interviews were one to two hours and conducted in person or over the telephone. Parents were asked how they monitored their child's development after birth, and asked about clinics, schools, daycares, and other service locations their children have attended. Discussions with service providers focused on tasks performed from the time a family initially engages the provider until the child leaves the provider's services.

4.2.3 *Data Analysis*

All interviews were audio-recorded. A professional transcription service provided verbatim transcripts, which were uploaded to Dedoose (dedoose.com) qualitative analysis software for coding. Interviews were analyzed using a deductive method piloted in a previous study outlined in Chapter 2 (Mikles, Suh, Kientz, & Turner, 2018). Prior to analysis, the primary author developed a codebook consisting of "work context" and activities gathered from the aforementioned 2006 AAP workflow: surveillance, screening, referral, assessments, developmental services, and care management (Council on Children With Disabilities, 2006). Work context was defined as the environment where users do their work, focusing on factors that could affect the use of electronic HIT systems. For examples of contextual factors, the primary author collected descriptions identified in previous literature (Eikey et al., 2015; C. E. Kuziemy, 2015b; C. P. Lee & Paine, 2015), such as the number of users and user groups

involved in collaborative work, physical setting, modality of communication, legislation, and social factors.

The primary author arranged a training session covering child development, the AAP workflow, and work context for the three research team members before assigning coding tasks. The primary author coded all transcripts and randomly assigned secondary reviews. While performing the qualitative coding in Dedoose, researchers also sketched diagrams of the workflows represented in the interviews on paper, focusing on tasks performed, order, and decision points. We used researcher triangulation to verify the reliability of the coding and reconcile workflow sketches (Unertl et al., 2010).

Overall, 46% ($n = 20$) of the 46 transcripts were independently coded by two or more researchers. Throughout the coding process, the team harmonized all code applications through in-person meetings. After coding, the initial author collected excerpts by activity to synthesize qualitative descriptions, and organized work context factors into themes. The primary author also synthesized the hand-drawn workflow diagrams into a single diagram encompassing all workflows using BPMN (Object Management Group, 2011) conventions in LucidChart. The diagrams were annotated to identify aspects of the workflows that have implications for system designs. Due to the large number of potential stakeholders involved in child development work and significant overlap in roles, we used a color-coding scheme to denote role-specific tasks (Müller & Rogge-Solti, 2011). A “workflow options” icon was used to denote branching paths based on individual or organization-specific differences in work practices as distinct from traditional diamonds where paths branch based on a specified input condition.

4.3 RESULTS

Forty-six participants were recruited from January 2016 through November 2017. **Table 3** provides a summary of participants, roles, and demographic characteristics. Of these respondents, there were 12 parents, 28 service providers, and six who were both parents and providers. Most of the respondents were of white race, with only four reporting another race. Parent experiences with delays ranged from having no experience to having children with global delays. Service providers worked with a wide population of children and families, ranging from high- and middle- to low-income families, families receiving public assistance, and families with limited English proficiency (LEP). Approximately 48% of the stakeholders lived in King County, with others living in Clark, Cowlitz, Franklin, Kitsap, Pierce, Skagit, Snohomish, Spokane, and Yakima counties.

Table 3. Summary of interview participants by their associated child development support role and related information, and basic demographics.

Role	Count	Gender (# female)	Age (range in years)	Yearly Household Income (range in thousands of dollars)	Ethnicity (# Hispanic or Latino)	Race (# non- white)	Number of Children with Delay or Disability (# range)	Identified Disabilities in Children	Service Population
Parent	12	12	31 - 53	<15 - 100+	1	1	0 - 3	Major depressive disorder, ADHD, motor delays, speech delay, autism spectrum, cognitive delay, global delay	N/A
Parent & Provider (early education, early intervention, medical specialist / therapist, community group, childcare)	6	6	27 - 53	15 - 75	1 (1 NR)	1	0 - 3	dyslexia, ADHD, autism spectrum, reactive attachment disorder, auditory processing delay, learning disabilities, global delay	Middle and high- income families, low-income families, LEP families, parents in child welfare system

Role	Count	Gender (# female)	Age (range in years)	Yearly Household Income (range in thousands of dollars)	Ethnicity (# Hispanic or Latino)	Race (# non- white)	Number of Children with Delay or Disability (# range)	Identified Disabilities in Children	Service Population
Pediatrician	4	3 (1 NR)	40 - 58 (1 NR)	100+ (1 NR)	0	0	N/A	N/A	LEP, insured, Medicaid eligible
Early Education (ages 3 - 5)	5	3	40 - 62	15 - 99	0 (1 NR)	0	N/A	N/A	High and middle- income families, homeless families, LEP families
Early Intervention (birth to age 3)	5	3 (2 NR)	41 - 61 (2 NR)	50 - 100+ (2 NR)	0 (2 NR)	0 (2 NR)	N/A	N/A	Children with developmental delays & disabilities, families on public assistance

Role	Count	Gender (# female)	Age (range in years)	Yearly Household Income (range in thousands of dollars)	Ethnicity (# Hispanic or Latino)	Race (# non- white)	Number of Children with Delay or Disability (# range)	Identified Disabilities in Children	Service Population
Medical Specialist / Therapist	4	2 (1 NR)	41 - 64 (1 NR)	50 - 100+ (2 NR)	0 (1 NR)	1 (1 NR)	N/A	N/A	No eligibility limits, children with behavioral and developmental issues
Nurse Home Visitor	4	4	30 - 64	50 - 100+	0	0 (1 NR)	N/A	N/A	First-time mothers, low- income families, families on public assistance
Social Work	3	2	36 - 53	50 - 99	0	0	N/A	N/A	Families where children have been removed from the home, families on public assistance, LEP families

Role	Count	Gender (# female)	Age (range in years)	Yearly Household Income (range in thousands of dollars)	Ethnicity (# Hispanic or Latino)	Race (# non- white)	Number of Children with Delay or Disability (# range)	Identified Disabilities in Children	Service Population
Community Group	2	0	24 - 29	35 - 99	0	1	N/A	N/A	Families seeking services in the community
Childcare	1	1	40	50 - 75	0	0	N/A	N/A	Teenage mothers, families on public assistance, LEP families

NR = number of respondents who did not respond to the question. N/A = responses not applicable to respondent. ADHD = attention deficit hyperactivity disorder. LEP = limited English proficiency.

4.3.1 *Workflow Diagrams*

Figure 3 depicts a broad overall workflow connecting the different AAP best practices activities. This figure highlights the non-linear and sometimes cyclical nature of child development support work. The activities around referrals, assessments, and developmental services are deeply intertwined with care management activities. Services and service locations regularly change along with changes in functional abilities, the child's age, time of year for programs based on the school year, or if the family moves. Detailed process maps of the best-practice activities from the AAP workflow are presented in **Appendix D**. The separate diagrams outline the tasks within each activity and how each activity connects to subsequent activities.

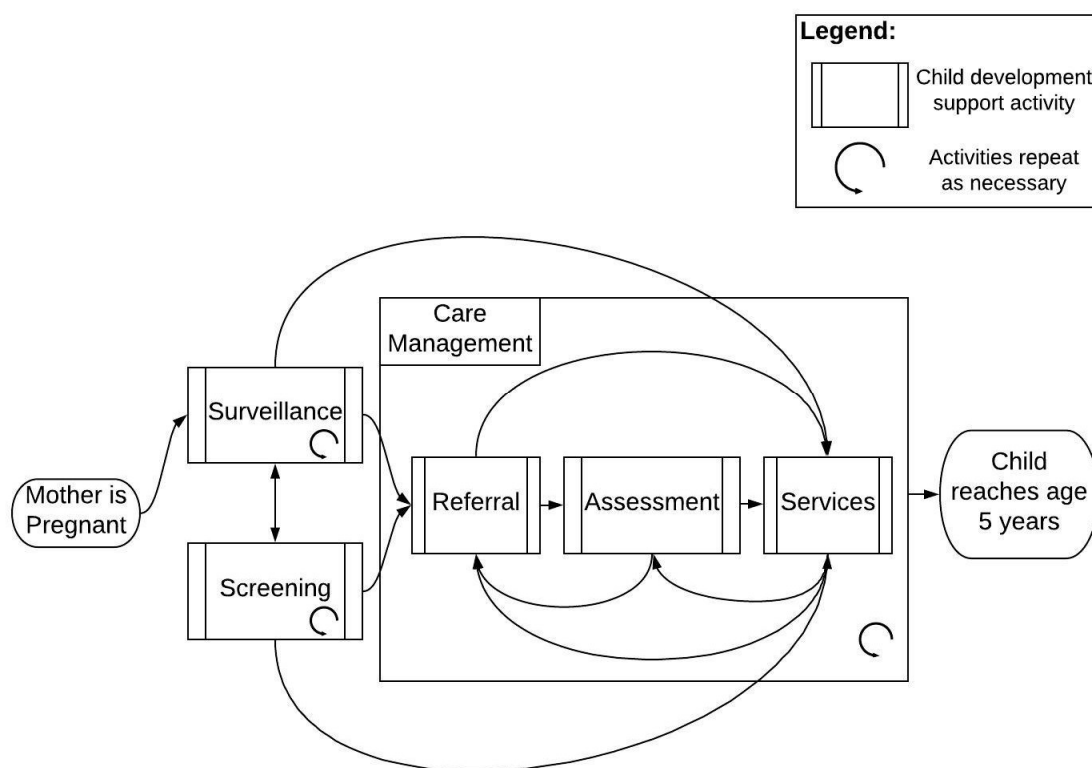


Figure 3. Overall workflow connecting best-practice child development support activities defined by the AAP.

4.3.2 Workflow Descriptions

Below are qualitative descriptions of the activities defined in the AAP best practices algorithm gathered from the interview responses.

4.3.2.1 Surveillance

Surveillance is a “flexible, longitudinal, continuous, and cumulative process” (Council on Children With Disabilities, 2006). Surveillance starts before a child is born, with considerations of the mother’s health and health services utilized while pregnant. After birth, surveillance

activities are performed by all stakeholder groups and mainly consist of observations of the child's behavior, comparisons to milestones, and considerations of the both the child's and the family's health history. Surveillance regularly involves the integration of information from multiple stakeholders, most often parents and educators.

4.3.2.2 Screening

Professionals use many different tools for developmental screening, including tools from the medical field such as the Ages and Stages Questionnaire (ASQ) (Bricker, Squires, & Mounts, 1999), tools from the education field such as the Developmental Indicators for the Assessment of Learning (DIAL), and non-standardized *ad hoc* instruments. These tools have different foci, such as considering child functional abilities, school readiness, or family risk factors such as parent-child interactions. The schedules for screening tests differ greatly, and can be administered based on the recommended AAP schedule (Council on Children With Disabilities, 2006), the beginning or end of the school year, or on an *ad hoc* basis as observations warrant.

Screening questions are most often answered by parents at the request of a service provider. Some service providers assist parents with answering questions, noting difficulties parents face with understanding the wording used in screening questionnaires. In some cases, teachers also fill out screening questionnaires in the classroom if parents are not responsive to providing answers, if they did not agree with a parent's answers, or "just to have two different pieces of information to look at." Alternately, one pediatrician noted that screening questionnaires should be completed by parents without any assistance to preserve the validity of the tool. Providers also regularly review screening questionnaire results from other providers. Screening questionnaires are age-specific, and service providers reported that organizing screenings for multiple children under their care is time consuming, which was eased through the

use of decision flowcharts or EHR reminders. One parent and a pediatrician suggested the utility of having a way for parents to complete questionnaires before service provider visits. Borderline or concerning results could prompt the start of minor services, further surveillance, further screening, or referrals to more in-depth assessments and services.

4.3.2.3 Referral

Referral is a process by which a family is connected to a new resource. Many referrals are informal and consist of a service provider handing the parents contact information for an organization and asking them to schedule an appointment, or parents finding services on their own and making self-referrals. More formal referrals consisted of providers sending reports to outside resources, usually by fax.

Regardless of who initiates a referral, it is the responsibility of the parent or caregiver to schedule appointments and provide information for intake, which may include detailed information on a child's health and developmental status. All service provider stakeholder groups noted significant problems with parents not attending referral appointments.

Responsibility for following up with parents on missed appointments can rest with either a referring provider or the outside resource. Without such follow-up, there may be a delay in the provision of needed services, prompting one community group participant to suggest that all involved stakeholders should be provided with referral and follow-up information. Families are often put on waiting lists before starting services. Children can "age out" of services while on the wait list, prompting one early intervention provider to suggest that parents get on multiple wait lists to improve chances of getting seen earlier.

Records from other providers are regularly gathered upon intake, and direct communication between providers requires a parent to sign a release of information (ROI) form.

Communication takes many forms, such as the provision of school and health records. Different stakeholders, such as the parents, the provider, or the provider's office staff may be involved in the communication of records from other service locations. After a referral is completed, many referring providers want to know the outcome of the referral, for example whether or not the child is eligible for services.

4.3.2.4 Assessment

Assessments are performed for different reasons: to determine eligibility for services, track progress over time, identify problem areas, or establish medical diagnoses. New providers regularly do assessments when the child transitions between care locations. A myriad of tools are used for assessments, including tools such as the ASQ that are also used for screening, indicating a blurred line between conceptualizations of screening and assessment. Providers of EI services for children under three years of age have teams of therapists to perform assessments, and they rely on information gathered on intake to accurately guide the focus of an assessment (e.g., whether they assess speech or motor skills). Some providers will perform multiple assessments using multiple tools to investigate different aspects of development. Programs where eligibility is determined by the degree of delay a child exhibits do not accept assessment results from other providers, but referring providers did report wanting assessment results after a referral was made. Responsibility for communicating results varied, but most often lay with parents.

4.3.2.5 Developmental Services

Support services are provided by both parents and professionals and include center- and home-based therapies, children's play groups, medications, or modifying a child's environment. Service providers reported offering training and support for parents to optimize home care,

including general parenting skills, home activities that promote development, information on navigating services, or even help with family issues. One pediatrician noted that it could be difficult to determine which interventions are specifically “development-related” because child development is a holistic thing: “it’s all keeping kids healthy, which is going to improve their child development in general.” Services and progress are documented in many different electronic systems, and communication between service providers was again inconsistent and happened through many mechanisms.

4.3.2.6 Care Management

Care management is a complex activity consisting of co-management with specialists, written care plans, and monitoring health status (Council on Children with Disabilities, 2006). Due to the focus on monitoring progress and care planning, care management is tightly intertwined with services, assessments, and referrals. Services are rendered and progress is assessed periodically either on a given schedule (e.g., every six months) or informally on an *ad hoc* basis based on “intuition.” After an assessment, decisions are made as to whether services need to change, which can lead to changes in service in the same location or referrals to other care settings. Management of transitions between care settings is an important theme due to the complexity of eligibility requirements across programs (Council on Children with Disabilities, 2005), which could consist of age, location, level of delay, income, or family characteristics (e.g., parents with substance use issues).

Transitions are common but challenging for parents to navigate. Transitions are most common at age two as a child moves from EI services to preschool-based programs, or during the summer months for services that were only offered during the school year. They can also take place when a family moves, or when a child has “graduated” from a program due to

improvement but is still considered by the parents to need support. Transitions take considerable time, requiring parents to find and contact new service providers, transfer information, and schedule assessments for new services. To help ease transitions, some services start this process up to one year before the transition happens and use standardized forms to help communicate care plans. Face-to-face meetings between parents and teams of service providers, which can include teachers, therapists, and doctors, are a regular feature of EI and preschool-based care management. In addition, some services use federally mandated documents to record information such as care plans, goals, and progress, including the 504, the IFSP for EI, or the IEP for preschool-based services.

4.3.2.7 Communication

During all steps of the development support process, “lack of communication” was identified as a major barrier to care. Direct communication between service providers was reported as inconsistent or nonexistent. When communication occurred, it was often one-way or untimely, forcing providers to make initial care plan decisions with insufficient information. Providers commonly relied on parents to communicate information or relay documents between providers. This did not always happen for a variety of reasons, such as parents feeling “too overwhelmed,” as reported by one public health nurse. Many providers commented that they did not even know all of the providers involved in an individual child’s developmental care.

Before service providers can communicate with each other, parents are required to complete ROI forms to allow direct communication. In many cases, parents reported not knowing whether any communication had occurred between providers or why referrals or assessments were made. Service providers also face difficulties with reaching parents by phone or having paper documentation being lost through fax or the mail. Multiple participants,

including parents, pediatricians, and social workers, recognized the challenges of having information stored in separate service-provider databases, and some suggested the utility of a shared system across all stakeholders.

While stakeholders reported that improved communication could aid decision-making and care coordination, increased communication could also foster conflict. Parents, EI providers, and social workers reported conflict between parents and service providers, or between multiple providers, on eligibility for services or appropriateness of specific services for a child. Two early educators questioned what the process should be in the event that multiple providers administer screening tests and receive different results. In practice, conflicts are generally handled through in-person discussions, with parents usually being the ultimate decision-maker.

4.3.3 *Work Context Factors*

Contextual factors have been defined as a broad set of environmental and social factors that affect collaboration and communication. Participants discussed many contextual factors related to their work environments that can affect the communication of child-development-related information and the use of HIT systems.

4.3.3.1 *Legislation and Policy*

Federal and state legislation, as well as policies established by national or local organizations, put significant restraints on communication and the use of electronic systems. Different policies can dictate the use of specific screening and assessment instruments, documentation tools including electronic systems, timelines for performing tasks, and the collection and reporting of specific information to maintain funding streams or participation in certain programs. Legislation

determines the eligibility requirements for important programs like EI or early education, while national and local public and private community programs set their own criteria.

Data privacy and security laws have a significant impact on collaboration, which is complicated by a mix of public and private entities. The HIPAA, governing healthcare entities, and the FERPA, governing public schools, were often cited, and both mandate that parents sign ROI forms authorizing providers to share data with each other. ROI forms and conditions for sharing data, such as the length of time that an ROI is active, can differ greatly depending on the relevant laws and policies governing different providers. Some stakeholders, such as a community-run parent help hotline, are not covered under these laws and have their own policies for protecting data. HIPAA compliance was sometimes seen as a barrier to communication, with a social worker noting that it caused people to “err on the side of not over-sharing.” One nurse home visitor reported uncertainty about the legality of receiving information from other providers, as they were unsure of whether they had an ROI from the parents. Laws affect documentation and data sharing in other ways as well, such as public health nurse field notes being publicly discoverable, or various service providers being mandatory reporters for neglect and abuse.

State laws give Child Protective Services (CPS) social workers ample leeway to gather information about a child from all stakeholders during an investigation without parent involvement, although they cannot relay information deemed to be related to an investigation to other service providers. An ROI is still required to collect information about birth parents as well, indicating that CPS may not be able to provide relevant information about a child and their family to other providers. Withholding needed developmental care can also be grounds for “medical neglect” allegations, making information around development sensitive for parents.

The legal role of caregiver also transfers from the parents to the social worker if a child is removed from the home, though most childcare activities will be undertaken by foster parents.

Insurance company policies also affect the management of developmental care. Many insurance plans require a doctor sign-off or diagnosis to reimburse for medications or treatments. Even public services that are offered to families free of charge, such as EI, still seek reimbursement from the child's insurance. Due to the importance of medical diagnoses, pediatricians or PCPs regularly act as *de facto* gatekeepers for services.

4.3.3.2 Service Provider Goals

Different services have different goals for care, which affects the information the services use, request from others, and can provide. EI and home visiting services have a strong focus on supporting families and therefore gather information about household needs and parents' personal life goals. Medical providers and school-based services are more closely focused on the child's physical health and therefore mostly manage information about a child's functioning and related services. A pediatrician reported having competing priorities due to the limited time available during well-child visits, so important topics like family stressors may not be discussed. While CPS social workers track child development and services, their first priority is a child's safety and home placement and not necessarily developmental care. Some providers focus on "information about the child," while others focus on "information about the family," which can have significant implications for data privacy and sharing, as parents may not want to share information about themselves or their household. A pediatrician and an EI provider saw "medical" information as distinct from "developmental" information and not necessarily useful for creating developmental care plans.

Based on their care management goals, stakeholders requested different levels of detail in developmental information. Some providers only want high-level information on services to stay informed of progress, as noted by a preschool teacher discussing the information needs of pediatricians: “they want a sense of how the child is doing, but they don’t want that great, big, huge document because they’re not going to have time to go through the whole thing.” Alternately, one parent reported that the preschool IEP documentation did not have the “nuts and bolts” level of instructional information to guide care at home.

4.3.3.3 Care Team Turnover

Turnover among care providers is common in the child development space. Many people reported high turnover for pediatricians due to changes in insurance, moving, or families lacking a dedicated doctor in general. Childcare providers and social workers have high employment turnover. Respondents reported that turnover leads to a loss of institutional knowledge about a family and difficulties in maintaining a consistent course of action.

4.3.3.4 Physical Environment

Child development support work takes place in different settings: home-based, center-based, classroom, remote locations like coffee shops, or even other providers’ offices. Some providers performed activities in multiple settings or in rural locations that lacked internet or cell phone access. The consideration of service location is important in surveillance due to multiple reports that children behave differently in different settings, such as not cooperating during well-child or home nursing visits due to intimidation or acting differently at home compared to in social school settings. Stakeholders reported that PCPs may not make accurate observations due to the little amount of time available during well-child visits. One participant, who was both a parent

and an EI provider, suggested that information from all environments is needed to “put all these pieces together.”

4.3.3.5 Care Team Composition

Children receive services through multiple organizations at the same time. One parent reported receiving simultaneous services from five locations. Parents are usually expected to maintain the role of care coordinator because a child’s care team may change significantly over time. One therapist noted: “It might have to change, because I know with... early intervention, that’s up to age three. Then the three to five person is going to be different.” Within service locations, providers may work with a team of professionals to support developmental care work, such as office staff, therapists, and patient advocates.

4.3.3.6 Technology

Many technologies were used to communicate information, such as fax, e-mail, electronic referrals, telephone calls, paper reports, and even text messaging. Both healthcare and education providers used a proliferation of different electronic documentation systems created by different software vendors. Service providers commonly used multiple databases for documenting information, sometimes documenting the same information in multiple systems. Screening questionnaire results were generally collected on paper and then scanned into systems like EHRs, limiting the storage of structured data for analysis. Many providers echoed the thoughts of an EI provider who does not want “yet another system we have to add a ton of data to.” Interfacing between systems was seen as useful, though rare. Parents did not report using any dedicated documentation tools outside of calendars and baby books.

4.3.3.7 Client Population

Characteristics of the family and child being supported, most notably socio-economic factors and the severity of the child's condition, has a significant impact on care management. Factors such as income, household substance use, and parents having developmental disabilities can affect eligibility for services and can mark a family as "high priority" for service providers, causing service providers to be more active in care management. A CPS social worker reported difficulties disentangling maladaptive behaviors caused by the trauma of being removed from the home with underlying developmental issues. Similarly, a parent reported that their child's depressive disorder masked the existence of other developmental disabilities, and another parent reported that their child was never given an "umbrella" diagnosis, leading to multiple assessments by many different providers. Providers discussed challenges communicating with parents with LEP and the need for language-appropriate screening questionnaires and forms.

4.3.3.8 Social Factors and Knowledge

Individual stakeholder attitudes and broader societal norms are potential barriers to communication. Parents have significant social power, and service providers regularly defer to parents about when and how interprofessional communication should happen. This can pose problems since parents may lack relevant knowledge, such as understanding milestones, being able to detect progress, or knowing the value of tracking development and fostering communication between providers. It was also suggested that some providers, including pediatricians and early educators, may not be able to distinguish normal from abnormal development. A parent reported that their pediatrician had little experience with their child's disability, and was therefore not be able to call upon prior work experience to provide adequate

care. Many respondents noted that appropriate training is needed to administer screening tests accurately. Parents lack knowledge of what service providers exist in a certain locale and the services they provide. A pediatrician also reported that stakeholders need to have the right expectations for the effects of services, since for some conditions the best that can be hoped for is no regression.

There were also reports of attitudinal barriers, such as pediatricians taking a “wait and see” approach to development or parents lacking interest in monitoring development, which could lead to a delay in seeking services. Providers also reported that some parents refused to let service providers communicate with each other, which led to suboptimal decision-making, as noted by an EI provider: “if we're concerned about autism, and they aren't... they may not allow us to talk to the person doing the assessing because they want an unbiased opinion, and they don't understand that means that the medical provider is lacking information.”

Due to CPS's ability to remove children from a home and providers such as pediatricians and teachers being mandatory reporters, parents may be motivated to hide information that they feel makes them appear to be bad caregivers. CPS situations can be divisive, making considerations around CPS involvement in the child development ecosystem and the sharing of information that can potentially cast parents in a negative light vital. There were also reports that tracking development can be a scary prospect in general and that parents may be afraid to find that their child has a delay.

4.4 DISCUSSION

The analysis of workflow and work context uncovered many implications for the design of collaborative HIT systems, which are discussed below and summarized in **Table 4**. This table

lists findings from the results, organized into themes, and their associated design implications. This analysis discovered many activities, such as managing wait lists, insurance adjudication, or following up on referrals, that take place during child development support activities and that should be considered in the design of a collaborative system. Similar to the results of the study listed in Chapter 3 (Mikles, Suh, et al., 2018), our analysis found significant task overlap for different roles, with all stakeholder groups performing activities related to surveillance and referrals. Exceptions to this overlap include: 1) requirements that pediatricians and PCPs establish diagnoses and write prescriptions for reimbursement purposes, and 2) the need for parents or foster parents to attend service appointments, provide care at home, and sign ROI forms in the absence of CPS involvement.

Table 4. Summary of design implications for creating collaborative HIT to support child development.

Theme	Description of Findings	Design Implication
Complexity of care	Children may receive many services from many different locations to treat multiple developmental delays and disabilities.	The system needs the ability to organize and filter documentation around assessments, referrals, and treatments around different functional domains to show a unified view of care for a delay or disability.
	Responsibilities for tasks such as observing a child's behavior are shared across many different stakeholders.	Stakeholders of many different job roles should have access to documentation related to activities like surveillance, screening, referrals, and care management.
Functionality for care team management	Certain child development support tasks need to be performed by specific roles.	Certain tasks need to be performed by specific roles, such as a medical doctor granting a diagnosis, or parents or appropriate caregivers signing a release of information form. These tasks should only be available to certain roles.

Theme	Description of Findings	Design Implication
Functionality for care team management	Significant turnover in stakeholder roles, such as pediatricians or social workers, and the regular nature of transitions of treatment locations over time indicate the need for robust care team management functionality.	Functionality is needed to clearly indicate everyone who is involved in a child's developmental care, and for the easy adding and deleting of care team members over time
	Determining who should have access to different types of information about a child and the child's family can be difficult.	The child's parent, or other appropriate caregivers, should be able to determine what types of information, such as information on a child's assessments or a family's household environment, will be accessible by different members of the care team.
	Knowing when release of information documentation is needed to share information, and parameters around sharing information.	The system should track the signing of release of information documentation, and the parameters around information exchange between different service providers.
	Some parents lack the time and resources to be the best advocate for their child's developmental health.	System should have the ability for service providers to indicate 'high priority' families.
Different stakeholders have different goals and practices	Wide range of child and family info is relevant to child development.	Collect a wide array of information relevant to child development activities, such as the child's health and developmental history, family home and social environment, screening and assessment results, referrals, and services.
	Stakeholders need an understanding of the information needs of other stakeholders.	Care team members should be able to indicate the types of information they are interested in receiving, such as information on a child's assessments or services, or on a family's environment and goals.

Theme	Description of Findings	Design Implication
Different stakeholders have different goals and practices	Stakeholders need to understand the fidelity of information needed by other stakeholders.	Stakeholders should be able to indicate the desired level of data detail, for example whether they are interested in a summary of progress or in details of the types of services being provided.
	Show the aims, goals, and other usage metadata about different data collection tools to aid in the effective use of results.	Different screening tests and assessment tools come from different professional fields and have different goals. When the results from screening and assessment tests are provided, metadata around the source of the tool, goals for its use, how to administer the tool effectively, who administered the tool, and the location where the tool was administered should be available.
Automation of system functions	Addressing the unreliability of communication amongst parents and service providers, and stakeholders not knowing when other providers perform tasks such as referrals.	The system should automatically notify appropriate stakeholders when new information and reports related to surveillance, screening, referrals, assessments, services, and care management have been documented.
	Parents do not complete requested referrals.	The system should keep track of whether referral appointments are completed, and periodically notify caregivers, the referral source, and the resource referred to follow up on referrals.
	Selection of the correct screening and assessment instruments for a specific child at a specific age or office visit.	The system should automatically calculate the appropriate versions of screening and assessment instruments to use based on age or gestational age, as appropriate.

Theme	Description of Findings	Design Implication
Providing requested information	Need to handle information requests between service providers during the intake process for service providers.	The system should pervasively store demographic information about the child and family, as well as historical documentation related to developmental care, such as visit summaries or care plans such as an IFSP or IEP. Access to this data should be granted to appropriate service providers when they are added to the care team. Stakeholders should also have the ability to send information queries to other stakeholders for specific information.
Providing background information	Stakeholders require more information on available services.	The system should provide information on service providers in a location, the services they provide, the intake process, their eligibility requirements, and availability and waitlist services.
	Stakeholders require more domain knowledge of development.	The system should provide background information about developmental delays and disabilities for parents and service providers who have not received formal training in child development, the different services available to treat certain conditions, and outcome expectations for services.
	Stakeholders may not understand the importance of early detection, and the importance of communication between service providers.	The system should stress the importance of monitoring a child's development, the importance of identifying issues as quickly as possible, and the importance of interprofessional communication to support collaboration.
	Parents are sometimes unsure of why actions are taken or suggested by service providers.	The system should provide information on the reasons referrals or changes in a care plan were made.

Theme	Description of Findings	Design Implication
Providing background information	Stakeholders need information on relevant laws and policies around the sharing of information.	Contextual information should be provided around data sharing laws such as HIPAA and FERPA as well as legal and policy rights held by parents and families as they seek services, such as rights outlined in the IDEA legislation.
Data entry tools	Service providers are required to use certain electronic systems by policy, and do not want to add another documentation system.	Investigate interfacing abilities to transmit structured documentation between different medical and education systems using pre-defined standards.
	Parents do not have a widely-adopted electronic documentation system.	Provide an electronic platform for documenting all forms of information to allow for parent entry of data.
System infrastructure	Work must be performed in remote or rural locations without consistent internet or mobile service.	Provide the ability to store information locally and sync with server storage when connected to the internet.
	Service provider use multiple modes of communication and documentation systems.	Allow the ability to communicate reports to others through fax.
	Service providers support families with different language proficiencies.	Provide system content in multiple languages.
	Tracking a child's development can be frightening for parents.	The system UI should use uplifting and supportive language relating to monitoring a child's development.
Needs further investigation	Child development support requires the use of standard documents such as an IFSP, IEP, and 504.	Further work is needed to determine whether electronic documentation in a newly created system will meet the legal and policy requirements for documenting forms such as an IFSP, IEP, and 504.

Theme	Description of Findings	Design Implication
Needs further investigation	Transfer of caregiver role in situations involving child protective services.	In childcare situations where CPS social workers are involved, more work is needed to determine how the system should handle communication with parents when children are removed from the home.
	Conflicts among parents and service providers on a child's care plan.	More investigation is needed to determine how to mediate conflicts between multiple stakeholders when there are disagreements on how to approach a child's care.

To support collaboration in child development, various pieces of information should be collected in an HIT system, many of which mirror the findings of the informational goals defined by Ranade-Kharkar et al. in their analysis of data needs for children with special needs (Ranade-Kharkar, Weir, et al., 2017). Stakeholders require information about a family's situation and living conditions and information about the child's care team, such as team member roles, contact information, and information needs. Members of all stakeholder groups also need background information, such as disabilities, treatments, expected treatment outcomes, and how to use and interpret screening and assessment tools. Information on navigating the healthcare system, such as available services, eligibility, how to initiate services, and applicable laws, is also important. Beyond information described by Ranade-Kharkar et al., stakeholders also need contextual information about data collection, such as the person collecting data and the location of screenings and assessments, as well as information to encourage parents to engage with a system, such as the importance of tracking development and of sharing information between providers.

Stakeholders report that sharing information across caregiving environments, reflecting multiple professional perspectives, would be useful for surveillance and care management. However, different providers have different goals that may complicate the sharing of data. Previous research has pointed out the differences between the traditional “medical” model and the more holistic “developmental” model of support that considers many social factors in the child’s life (Duby, 2007). This is also reflected in our results. Differing goals can cause providers to focus more on child-specific information or family-specific information, and want different levels of detail on services rendered, from a high-level managerial view to a detail-specific view. Since parents may want tighter control over family-specific information, a collaborative child development system should have safeguards to ensure that sensitive information is not shared against the family’s wishes.

Aside from shared information on services and progress, widely sharing information on actions that have taken place, such as referrals, could empower providers to follow up with parents and advocate for care. This meta-information should include when actions were taken, why, and who was involved. Defining a care team for child development was seen as important across stakeholders, but this can be difficult in the child development space due to the frequent turnover of service providers and common transitions between services as the child ages. The management of the care team, and how information should be shared with each member, should be streamlined and easy. However, responsibility for maintaining care team documentation should be flexible as well. While many consider parents to be best-suited for care management, providers who work with parents facing economic or social barriers may need to shoulder some of this responsibility.

The mandated use of specific standardized instruments, documentation tools, and electronic databases poses a significant challenge to the creation of a centralized collaborative HIT system. Designers will have to determine whether screening and assessment tools such as an ASQ, privacy-protecting ROI forms, or care management documentation such as an IEP should be integrated into a centralized system, when data should be interfaced from other systems, and what data collection tools should be included in the system interface. The HIT system may require a mixture of interfaces to communicate with systems that service providers already use to minimize double-documentation, and documentation tools for parents. Since many different standardized tools are used for screening and assessment across settings, stakeholders may be confronted with unfamiliar tools. Results from the tools should be accompanied by contextualizing information, such as what the tools are measuring and how the tools are completed, in order to aid in the interpretation of results. The analysis of context also suggests other useful system features, such as automatic selection of age-appropriate screening tools, quick electronic transmission of data, mobile solutions, and language translations of data collection tools and documentation.

The results of this analysis echo many of the results from the previous chapter. Many child development support activities, most notably screening and surveillance activities, were performed by multiple stakeholder groups. Children often received services from many different locations, often simultaneously. Many service providers, including health care providers, educators, and community groups, currently document in multiple systems, while parents generally have no electronic system to aid in care management. Finding copacetic results from multiple sources of data indicates that the results are robust and valid within the field of child development support work. While this research was grounded in child development support

work, aspects of the workflow may be relevant to the collaboration of interprofessional care for other chronic diseases such as obesity and metabolic disorders as well.

The analysis in this chapter identified topics that merit further exploration. CPS can play an important and yet often contentious role in child development. In some cases, CPS can become a child's caregiver and ultimately be responsible for services, yet their involvement can cause negative feelings and social stigma, causing parents to withhold information (Nielsen, Baum, & Soares, 2013). More work is needed to understand how this dynamic could be translated into collaborative HIT features. This is an important area, however, since social worker respondents in this analysis, as well as previous research (Shannon & Tappan, 2011), recognize the association between developmental disabilities and CPS involvement. Due to the overlap in responsibilities and data collected across stakeholder groups, respondents reported disagreements in screening results, service eligibility, and service appropriateness. More research is needed to explore how collaborative HIT could help adjudicate such conflicts. Features, such as those described by Song et al. for BebeCODE (2018), could be integrated into a collaborative HIT system to aid decision-making.

Finally, in reflection on our method, the BPMN process modeling standard proved to be a useful way to visually represent a complex workflow, and the use of color-coding instead of "swimlane" notation helped to reduce the complexity of the model and improve readability. An HIT system to support the interprofessional child development space must have the flexibility to handle a nonlinear flow of tasks potentially performed by many different stakeholders.

While interviews are a standard method for collecting qualitative data, participants may be subject to recall bias. The use of methods such as observations could validate interview data (Unertl, Weinger, Johnson, & Lorenzi, 2009); however, this was not pursued for this study due to

the burden of observing many different work locations, including private home environments where child development support activities may be unscheduled. To mitigate this issue, we sought to recruit multiple people in each identified stakeholder group and oversample parents to collect data from a wide range of participants. We experienced difficulty in sequencing certain tasks across organizations, for example, when insurance was adjudicated. Final placement of tasks within the workflow was performed through team consensus, though the order may change based on the individual workflows of organizations involved. When designing prototypes or tools based on the implications from this study, it is important for designers to consider flexibility in the order of tasks to ensure that collaborative HIT does not improperly constrain actual work processes (Ash, Berg, & Coiera, 2004).

4.5 CONCLUSIONS

The identification and treatment of child developmental disabilities requires the involvement of many stakeholders in the community, and HIT has the potential to support collaboration between these varied groups. Research indicates that workflow considerations are important for the creation of collaborative HIT; however, little work has explored workflow modeling across varied groups. This research demonstrates the creation of a community-wide workflow from interviews provided by a wide range of stakeholders. The results map a complex set of interrelated activities and contextual factors that could affect the implementation and use of a collaborative HIT system. Further work is needed to incorporate these results into designs for testing, and to explore interprofessional workflows for other clinical contexts. Overall, the model and descriptions provided in this manuscript provide a detailed understanding of the work processes of people who care for children with developmental disabilities. These work processes

can be used to better design a collaborative child development support system. The next chapter presents a reanalysis of the data presented in this chapter to explore how trust is expressed amongst child development stakeholders.

Chapter 5. A THEMATIC ANALYSIS OF TRUST AND SHARING BETWEEN CHILD DEVELOPMENT SUPPORT SERVICES

5.1 INTRODUCTION

Chapter 4 outlined the workflows and activities that need to be supported by a collaborative HIT system to help identify developmental disabilities and manage a child's care. Communication was identified as a significant theme that crossed all child development support activities. Effective communication is necessary to perform activities fundamental to collaborative, patient-centered care such as delegating responsibilities, reconciling viewpoints, and making decisions (Suter et al., 2009). In the context of supporting a child's development, this relates to making and completing referrals, sharing the results of screening and assessment tests, and sharing information on treatment progress and a child's changing care plan. Many stakeholders from across the spectrum of professional and social backgrounds cited a lack of communication as a significant barrier to performing child development support work.

As noted in Chapter 3, trust is another concept identified in the literature as being fundamental to collaborative practice. Trust has received considerable attention in the areas of interprofessional collaboration (Axelsson & Axelsson, 2006; Bookey-Bassett et al., 2017; Bryson et al., 2006; Chase et al., 2014; Chi & Holsapple, 2005; Daley, 2008; D'Amour et al., 2005, 2008; Darlington et al., 2005; Körner et al., 2016; Lasker et al., 2001; Patel et al., 2012; San Martin-Rodriguez et al., 2005; Syväjärvi et al., 2005; Varda et al., 2012), organizational management (Blois, 1999; Gefen, Benbasat, & Pavlou, 2008; Mayer, Davis, & Schoorman, 1995; McAllister, 1995; McKnight, Cummings, & Chervany, 1998; Rousseau, Sitkin, Burt, &

Camerer, 1998), and the medical field (Calnan & Rowe, 2006; Gilson, 2003; M. A. Hall et al., 2001; Mark A. Hall, 2006; Mechanic, 1998a, 1998b). Collaboration literature highlights the importance of trust to both the formation and the maintenance of a collaboration (Vangen & Huxham, 2003), and trust is seen as necessary for overcoming barriers to cooperative actions (Gilson, 2003). Trust is a “glue” that holds communities together, and allows interactions without undue suspicion and policing (Mechanic, 1998b). Trust may therefore be especially important in “networked” collaborations, where collaborating partners do not share a formalized governance structure and hierarchy, as it allows entities to be in a state of vulnerability to a trusted entity without the protections of a formal contract (Lambright, Mischen, & Laramee, 2010; Vangen & Huxham, 2003). Researchers have suggested that the existence of a trusting relationship could promote the sharing of data in an accurate and timely manner (Connell & Mannion, 2006; M. A. Hall, Dugan, Zheng, & Mishra, 2001), and that a lack of trust in the medical system can cause patients to withhold sensitive medical or social information (Powell, Doty, Casten, Rovner, & Rising, 2016). This indicates that trust is an important ingredient for ensuring that the interprofessional communication inherent in child development support workflows is efficient and effective.

5.1.1 *Trust Background*

Previous literature on trust provides significant guidance to the designer who aims to consider trust in their designs. Trust has been defined as an “expectation that entities will meet their responsibilities to us” (Mechanic, 1998b), or, more descriptively, as a voluntary action of a trustier based on expectations that a trusted entity will act a certain way, and where improper actions by a trusted entity present a level of risk for the trustier (Gilson, 2003). Risk in a trust

relationship is due to an uncertainty in predicting peoples' intentions and their future actions, and is of special importance in the healthcare field due to the innate vulnerability conferred by illness and the asymmetry between patients and providers in terms of medical skills and knowledge (Calnan & Rowe, 2006; M. A. Hall et al., 2001). Trust in the medical field has been linked to various health behaviors such as seeking care, sharing information, adhering to treatments, and maintaining a long-term relationship with a clinician, and may even mediate clinical outcomes (M. A. Hall et al., 2001).

A significant portion of the academic literature concerned with trust has focused on explicating how trust is established. The core concepts of competence, benevolence, and integrity are regularly identified as the basis for the formation of trust relationships (Lambright et al., 2010; Mayer et al., 1995; J. Song & Zahedi, 2007). Lambright, Mischen, and Laramée define these as the three factors that affect "perceptions of trustworthiness": the perceived abilities of an entity, the extent to which an entity will act in one's best interests, and the extent to which an entity acts according to an acceptable set of principles (Lambright et al., 2010; Mayer et al., 1995). Framing these concepts as subjective perceptions is appropriate, as it is possible to misplace trust in entities who are ultimately not trustworthy (M. A. Hall et al., 2001). It has been theorized that these three perceptions are separable, such that a person may exhibit one but not the others, and yet they are considered in concert when ultimately determining whether to trust (Mayer et al., 1995).

The literature also posits multiple factors that will influence these perceptions, such as an innate propensity of someone to trust another, the frequency of interactions and past successful interactions, and third-party trust where an unknown entity gains trust based on their reputation amongst others (Lambright et al., 2010). Trust can also be experienced in different ways by the

trustier, either as a “cognitive” or conscious cost-benefit analysis weighing the risks and rewards of engaging with an entity, or through an “affective” form of trust that is subconscious and formed through emotional bonds (Gilson, 2003; M. A. Hall et al., 2001; McAllister, 1995). Trust is considered distinct from similar concepts such as “reliance” due to its strength and emotive element, causing breaches of trust to incur pain, resentment, anger, or even retribution (Blois, 1999; Mechanic, 1998a). Trust is usually context-specific, indicating trust in a certain entity to take a certain action in a certain situation, though past research has also invoked a “blanket” sense of trust in a person generally (Blois, 1999; McAllister, 1995).

Research suggests that trust can operate on many levels, from micro-level trust in a known individual or a stranger to macro-level trust in larger social institutions in which entities operate, and trust valuations at one level can affect valuations at other levels (Gilson, 2003). Trust in individual medical professionals or organizations is based on personal experience, whereas trust in medical institutions (i.e., doctors or hospitals in general) can be based on the actions of professional organizations, legal or regulatory protections, or portrayals in the media (M. A. Hall et al., 2001; Mechanic, 1998b). “Blind trust” in a previously unknown healthcare provider can be based on attitudes about doctors in general (M. A. Hall et al., 2001), and alternately, trust in medical institutions can be based on past interactions with individual healthcare providers.

Trust has also been described as a relationship which can change over time (Mayer et al., 1995). Hall, Digan, Zheng, and Mishra refer to a “feedback loop” where the confluence of a trustor’s expectations and the results of past interactions can strengthen or deteriorate a trust relationship over time (2001). Vangen and Huxham similarly describe a “cyclical trust-building loop” that consists of having enough initial trust to take a risk, and aiming for and reaching a

realistic successful outcome, which reinforces trust attitudes and allows for more, larger, and more ambitious collaborations (2003). Research has also suggested that the importance of different perceptions of trust may change over time. A study of trust in online health infomediaries by Zahedi and Song suggests that information quality persistently maintains trust over time, whereas the importance of other factors such as third-party-reputation-based trust disappear (2008).

Many people hold trusting beliefs about entities without the experience of prior interactions. McKnight, Cummings, and Cervany (1998) describe a model of “initial trust,” consisting of an individual’s faith in humanity, overall disposition to trust, perceptions of “normality” in a transaction, structural assurances, entity categorization and stereotyping, and a perceived level of personal control over a transaction. This indicates that a base level of trust in perceptions of institutions and individuals, as well as its continued maintenance, are grounded in a mix of not only past experience, but also cultural stereotypes. For example, the classical “medical posture of omnipotence” may naturally engender a certain level of trust in physicians, whereas changes in modes of healthcare delivery seen as disadvantageous, or the erosion of the classic “paternalistic” relationship between doctor and patient, can call this trust into question (Mechanic, 1998b, 1998a). The establishment and maintenance of trust is therefore a complex, multilevel social phenomenon based on subjective views, broader social norms, and actions (Rousseau et al., 1998).

5.1.2 *Trust and Health Information Technology*

Adding HIT systems to an interprofessional collaborative environment can complicate the assessment of trust. Song and Zahedi suggest that trust in a particular online resource operates in

an interconnected “chain” of trust consisting of the trustworthiness of the content provider, the company hosting the website, and the infrastructure of the internet in general, and that a weakness in any link of the chain can engender mistrust in the entire system (2007). Features of a website can signal the quality of the technology the website is built upon and the trustworthiness of the people maintaining the website, such as posting quality information, the use of colors and pictures, or the existence of privacy assurances (Beldad, De Jong, & Steehouder, 2010).

Research has also discovered a general concern amongst people around entering information into an electronic system (Dinev & Hart, 2006; Liu, Shih, & Hayes, 2011). A recent study by Platt, Jacobson, and Kardia (2017) found low levels of trust in a general population sample in the US with a data system that shared data between members of an integrated health system consisting of healthcare providers, departments of health, insurance systems, and researchers. A reason for such distrust may be the plethora of ways that entered data could be accessed and misused by others. Appari and Johnson (2010) define different types of threats to information privacy, ranging from unintentional and unauthorized intrusions into electronic systems by hackers and other malicious parties to the misuse of data by authorized users through accidental or inappropriate disclosures of data or unnecessary prying.

A significant focus of work on trust in health information has focused on how consumers assess the trustworthiness of information from different sources. Studies of trust in various information sources, such as TV, the internet, family and friends, and healthcare providers found differences based on race, age, income, and educational attainment (D. Smith, 2011). Multiple sources of online health information have been explored in past research, such as the use of health webpages, online support groups, and online interactions with professionals (Cline & Haynes, 2001). Concerns about the accuracy of online health information have persisted for

decades, with many websites lacking meaningful scientific review or pushing “fringe” therapies and theories (Cline & Haynes, 2001). The use of poorly sourced or malicious health information online can greatly impede medical care, since online information may conflict with information given by a healthcare provider, causing patients to question their trust in their providers (Cline & Haynes, 2001). An analysis based on the Health Information National Trends Survey (HINTS) found that people are more likely to search for health information online before approaching a health professional, even though health professionals are generally afforded a higher level of trust (Hesse et al., 2005). Other studies based on HINTS data have found that people who have less comfort with the English language, lower income, and of minority race tend to have less trust in information sources such as newspaper, the internet, and even doctors (Clayman, Manganello, Viswanath, Hesse, & Arora, 2010; A. Richardson, Allen, Xiao, & Vallone, 2012).

Many studies have also explored the factors that consumers use to judge the trustworthiness of health information posted in online sources. One study found that people reported looking at the source of the website, its aesthetic qualities, whether it had a “professional touch,” its language, and its ease of use, though few respondents remembered the websites they pulled information from in post-study interviews (Eysenbach & Köhler, 2002). A recent review (Sbaffi & Rowley, 2017) of papers on how consumers evaluate the quality of health information analyzed 73 studies, finding that studies either underscore the importance of design features, such as layout and interactive features, or content details such as author authority and information readability, in building trust.

Most of these studies focus on the assessment of information provided by sources such as WebMD where there is little personal interaction between the people posting information and people seeking information. Many of these studies also fail to explicitly consider

conceptualizations of trust, such as competence, benevolence, and integrity, from the wider trust literature. More recent studies have begun to address these deficiencies. A recent study exploring trust and its effect on patient portal usage for diabetes patients found positive associations between trust in a provider and the use of secured messaging, though associations varied across racial/ethnic and age subgroups (Lyles et al., 2013). Veinot, Campbell, Kruger, and Grodzinski consider a broader background of the trust literature in their exploration of user requirements for an intervention to prevent the spread of sexually transmitted infections, finding a general level of mistrust across their respondents, a questioning of the benevolence of institutions, and significant trust in informal reputational information (2013). Van Velsen et al. explored trust in telemedicine portals, finding that patients judged trustworthiness based on perceived control and privacy, and that providers valued technical reliability and transparency of data storage policies (2016). While this research is beginning to address the complexity of trust in the design of HIT systems, current research still fails to explore the connections between trust, HIT, and the integration of professionals outside of the healthcare field.

5.1.3 *Trust Between Collaborators Who Support Child Development*

While trust is considered important to interprofessional collaboration, current literature is too narrow and provides little guidance on how to manage an environment that includes multiple professions. Reviews of trust-related research in healthcare have noted the focus on interpersonal trust between a patient and a provider from the patient perspective (Brennan et al., 2013; Mark A. Hall, 2006; Ozawa & Sripad, 2013), with significantly less focus on trust bestowed from a provider to a patient, or between different service providers. The lack of exploration of provider trust in patients may be due to perceptions that healthcare providers do not share an equal level

of risk as the patient in a trust relationship (M. A. Hall et al., 2001; Thom et al., 2011), or that non-reciprocal relationships may not even require bidirectional trust (Blois, 1999). However, the patient-provider relationship requires trust on both sides, with providers needing to trust in a patient's ability to provide accurate information and adhere to treatment regimens (Thom et al., 2011). Trust also reduces the likelihood of complaints or lawsuits (Mechanic, 1998a). Mutual trust is needed to maintain a positive, cooperative relationship between the patient and the provider (Thom et al., 2011). Similarly, trust relationships may be necessary between healthcare providers and patients and other non-healthcare service providers who must also provide accurate information and adequately support plans of care.

When considering the ecosystem of child development services, existing literature suggests complex trust valuations between the providers that may be involved in supporting a child's development. One study found negative perceptions of school personnel by parents who perceive a lack of knowledge, skill, time, or attention in supporting children with special needs (L. S. Anderson, 2009). Another study from the field of school nursing posits that school nurses respect pediatricians' knowledge but think they don't have enough contact with kids to identify developmental issues, whereas parents have significant contact with kids but a lack of child development knowledge (Radis et al., 2016). A study of perceptions around the therapist's role in coordinating care between medical and early intervention services discovered that doctors reported feeling "used" solely as a source of prescriptions, and hospital-based clinicians saw EI services as a lower level of care than what was provided at the hospital (Ideishi et al., 2010). A study of perceptions between healthcare, social work, and schools to support children with psychosocial needs by Widmark et al. found a complex dynamic with perceptions that others lacked relevant knowledge, clashes in approach to care, and perceptions of other roles as cold,

difficult, uncommunicative, and demanding (2016). Many of these perceptions from the literature align with “perceptions of trust” in terms of competence, benevolence, and integrity, and this suggests that these perceptions could affect collaborative endeavors by changing trust valuations and thus affecting communication practices.

To this end, this chapter explores trust perceptions related to the sharing of information between heterogeneous stakeholder groups in the child development space to provide guidance on how to design collaborative systems to support trust. The following analysis extends the work presented in Chapter 4 by reanalyzing the collected interview data and focusing on how different stakeholders judge the trustworthiness of other stakeholders, and the effects of trust on the sharing and use of information related to child development.

5.2 RESEARCH METHODS

This study involves the reanalysis of qualitative interview data collected for the study described in Chapter 4 using the deductive analysis method described in Chapter 3. The recruitment details and participant demographics can be found in sections 4.2 and 4.3 in Chapter 4. During the interviews, along with questions pertaining to work activities, questions were asked pertaining to thoughts on the use of an online data system to store and share information related to a child’s development. Eight categories of information relevant to child development were defined, reflecting AAP-identified risk factors for developmental disabilities (Council on Children With Disabilities, 2006) and encompassing relevant sensitive information as defined by the National Committee on Vital and Health statistics that could change sharing behaviors (K. Caine & Hanania, 2012): (1) medical history, (2) genetic information, (3) developmental screening results, (4) behavioral observations, (5) race and ethnicity, (6) household income, (7) household

substance use, and (8) existence of household stressors such as home insecurity. We also defined a list of stakeholders involved with childhood development: parents, pediatricians, community groups (e.g., a local Help Me Grow (Bogin, 2006) affiliate), home visiting nurses, early educators, childcare providers, and government agencies. These groups reflect common stakeholders involved in supporting development with a mix of medical and non-medical backgrounds. We asked parents which information they would trust each stakeholder to access, and asked service providers which categories of information they would trust being provided by other stakeholder groups. For details, please refer to the interview protocols provided in

Appendix C.

The initial codebook for analysis included a code for “trust,” along with sub-codes on the “trust perceptions” of competence, benevolence, and integrity (Lambright et al., 2010; Mayer et al., 1995; J. Song & Zahedi, 2007). The aim of the current sub-study was to identify all excerpts related to these trust perceptions and also performed inductive coding to identify themes of how stakeholders assess trust and the effects of trust on information sharing behaviors. The author and two research colleagues analyzed the identified excerpts. The author arranged an hour-long training session on child development services and the concept of trust for all research colleagues before assigning data analysis tasks. All three researchers have formal university training in qualitative analysis methods and have conducted qualitative analyses in the areas of public health, consumer health informatics, and nursing. The identified excerpts were split among the three researchers to abstract trust perceptions and the effects of those perceptions. Each researcher then reviewed a subset of the abstracted perceptions to create themes. The three researchers consolidated the themes through discussions via video conferences and e-mail. This analysis took a constructivist orientation that values the subjective “constructed” realities

experienced by the individual respondents (Denzin & Lincoln, 2000). Therefore, the researchers were interested in analyzing the subjective thoughts and experiences of respondents without concern for whether those experiences speak to an objective reality.

5.3 RESULTS

5.3.1 *Assessing the Trustworthiness of Entities*

The analysis revealed interpersonal trust perceptions related to competence, benevolence, and integrity, as well as themes relevant to an interdisciplinary environment such as the perceived relevance of a stakeholder to child development information, and an assessment of the source of a piece of data (see **Table 5**). Participants regularly noted that perceptions of competency increased their trust in sharing information with a given stakeholder. Competence was often assessed at a granular level, associating stakeholder groups with specific skills that enabled them to be trusted to accurately use or provide certain types of information. Participants discussed competency in regard to skills related to the work domain of child development and those related to protecting data privacy. Child development skills included understanding of medical terminology, knowing developmental milestones, or a parent's ability to care for a child with complex needs. We noted conflicts between stakeholders' perceptions of domain skills and often found nuanced assessments. For example, a therapist that valued a "*medical background*" for stakeholders reporting "*medical information*" felt that pediatricians "*don't always understand developmental information.*" Stakeholders also based trust on perceptions of skills or attitudes related to protecting data privacy. One parent lost trust in a school after noticing confidential paperwork on an office desk and thinking: "*that's right here on the front desk; clean it up!*" Another parent perceived that childcare providers might gossip about children in risky situations.

Providing some general information, such as a child's age, was not seen as requiring any specific professional qualifications or training.

Table 5. Themes around assessing the trustworthiness of entities in a collaborative space.

Themes		Descriptions
Competence		<i>Belief that an entity has the ability to perform their work adequately</i>
Aspects:	Work Domain Skills	<i>Competence with specific skills relevant to a given health domain</i>
	Data Privacy Skills	<i>Stakeholder's knowledge and abilities in protecting data privacy</i>
	Work Environment Factors	<i>Aspects of work environment that can affect work practices such as workload, time constraints, physical space, or relevant regulations</i>
	General Functioning	<i>Stakeholder's general functional abilities, such as literacy</i>
Benevolence		<i>Belief that an entity will act in your best interest.</i>
Integrity		<i>Belief than an entity performs their work in a complete or whole manner, or acting according to acceptable principles</i>
Aspects:	Unbiased or Agreeable Viewpoint	<i>Entity's approach to problems agrees with approach or viewpoint of stakeholder assessing trust</i>
	Motives	<i>Whether there are ulterior motivations at play</i>
	Consistency	<i>Consistency between people in a group having similar abilities, in having a consistent care team, or being thorough with data</i>
	Transparency	<i>Openness with how data are used and shared</i>
	Responsiveness	<i>Being responsive with communications and requests, and following through</i>
Relevance		<i>Belief that information is relevant to a stakeholder's work</i>
Data Source		<i>Assessing which stakeholder is the original source of the data</i>

While trust in a stakeholder, such as a pediatrician, may be high due to their perceived knowledge and skills, participants also based trust on perceived aspects of a stakeholder's work environment that could impede work, such as workload, physical space, and applicability of certain laws. A community group representative would not trust a pediatrician's observations because, during well-child visits, *"that's just a very small amount of time, and often kids are not really themselves at a doctor's office."* A public health nurse noted that they would not trust screening results coming from a community group that provides screenings over the phone, since screening over the phone *"isn't always as reliable."* One therapist would not trust information provided by CPS since they are *"overwhelmed with a lot of work."* Participants thought that groups not beholden to the HIPAA may not understand how to keep information confidential. A few service providers had negative perceptions of parents due to experiences with parents who were seen as having generally low abilities, such as families that *"can't read or write,"* or families in *"high-risk"* situations.

Perceptions of benevolence also factored into the assessment of trust. One parent reported withholding information provided by their home care nurse from the pediatrician because *"they just seemed like they didn't care."* Another parent had negative perceptions of their child's school system after the special education director *"rolled her eyes"* at the idea of their child attending college in the future. Parents had trust in people who they perceived as being *"there to help."* Perspectives related to integrity took many different forms. Trust assessments were based on a stakeholder's approach to work, such as having a *"wait and see"* attitude with regards to monitoring development or whether a stakeholder has a *"low threshold"* for identifying issues. Others were based on the perceived motivations of other stakeholders, such as perceptions that parents *"really want what's best for their child,"* or perceptions that parents will underreport

their child's bad behaviors because "*it makes them look bad.*" Consistency was assessed for groups of stakeholders as a belief that skill levels within a group, such as parents or social workers, varied widely since group members were perceived to have greatly varying educations and backgrounds. Multiple participants also valued transparency in data sharing practices, with one parent wanting to know "*if I give you this information, who are you in turn going to share this with?*" Assessments of responsiveness and follow-through were also noted, with an early educator noting a negative perception of parents who "*never return*" the screening forms they are given, and one parent's trust of stakeholders who "*say they're going to do something and then they do it.*"

Two trust themes relevant to a collaborative, interdisciplinary environment were assessing the relevancy of certain information to a stakeholder's role and assessing the original source of a piece of data. Participants formed perceptions about whether information was relevant to the work that a specific stakeholder performs. This is demonstrated by one parent's discussion of sharing of income information with a pediatrician who helps to support their child's development: "*you have an amount of dollars, but does that translate into child development? I don't really think so.*" One parent perceived that their child's neurologist was involved in developmental care, whereas their pediatrician "*doesn't do anything other than well-child stuff and colds.*" Service providers made judgments based on whether they thought information was routinely collected during a stakeholder's normal work, trusting information that was considered to be routinely collected. One therapist would not trust developmental screenings from a social worker, even though they knew that social workers perform screenings, because they perceived that the social worker's priority is not to support development but to "*get the child out of an unsafe situation.*" Various service providers noted the importance of knowing

whether the data entry stakeholder was the original source of the data or whether the stakeholder would be reporting second-hand data from another source. Many stakeholders mirrored the perception one public health professional had of social service providers, where “*what we’re hearing from those folks is what the parent has told them.*” Trust in the data was then based on the perceived trust relationship between the original and secondary sources. For example, when assessing whether they would trust substance use information coming from a pediatrician, a community group professional thought “*people tend to lie to doctors, so maybe not so much.*”

5.3.2 Additional Themes Related to Trust

Outside of the trust assessments made of entities, we discovered other themes of how trust is assessed and how trust affects the usage of information (see **Table 6**).

Table 6. Additional themes related to trust assessment and the effects of trust on the use of shared information

Themes	Descriptions
Indicators of Trust	<i>Heuristics or symbols that people use to assess trust</i>
Aspects: Reputation	<i>Reports from others that a stakeholders or an organization has performed successfully in the past</i>
Authority	<i>Deference to professions or organizations</i>
Transferability	<i>Trust bestowed from a trusted entity to an unknown entity</i>
Education and Training	<i>Symbols of competence, such as training, degrees, and certifications</i>
Official / Standardized Tools	<i>The use of standardized or official tools, forms, and documented work policies that support good practices</i>
Relationships	<i>The amount and quality of contact between an entity and another entity</i>

Themes	Descriptions
Data System	<i>Trust assessments related to the use of an electronic data system</i>
Aspects: Data Privacy	<i>System allowing the control of access, not letting too many people access</i>
Data Security	<i>System security and ability to prevent unanticipated access</i>
System Features	<i>System functions leading to incorrect data in the system</i>
Sensitive Information	<i>Certain information is more sensitive than others, and will be withheld</i>
Collective Data Trust	<i>Valuing a “more holistic” or “multidisciplinary” look at a child based on data from multiple types of people</i>
Propensity Toward Trust	<i>A person’s natural inclination to trust others</i>
Trust Calculations	<i>Weighing the benefits and costs of sharing information</i>
Aspects: Weighing Perceptions	<i>Weighing various trust perceptions with or against each other, and the consideration of multiple trust perceptions</i>
Consequences of Sharing	<i>Negative consequences of sharing information, such as incorrect care plans, social stigma or removal of children from the home</i>
Benefits of Sharing	<i>Positive benefits of sharing information, such as access to services</i>
Untrustworthy Information	<i>How stakeholders handle information that is not completely trustworthy</i>
Aspects: Verify Information	<i>Cross-check data with known information, or follow up with stakeholders to discuss untrustworthy information</i>
Use as Contextual Information	<i>Value of all information to get “big picture” look, or to get view of other entities’ perspectives</i>

There were many symbols or “indicators” that participants used to assess competence, benevolence, or integrity. Some stakeholders based trust on a group’s reputation, which included reports of successful work from others or participation in quality rating initiatives. Some participants felt increased trust and deference toward “professionals” in general, as noted by one parent: “*I guess it’s perceived authority; I mean, the pediatrician is the pediatrician.*” Another

parent would assume that an entity has “*met all credentialing and everything*” if they held a certain job title or position. Parental authority was also recognized, with some parents putting great value in information provided by other parents, and also the notion noted by a social services worker that “*parents and families are experts on themselves.*” Some service providers that had strong trust relationships with a family used this perceived trustworthiness to instill trust in new providers. Stakeholders reported holding joint meetings with parents and new service providers during care transitions to transfer trust, as described by a family resources coordinator: “*I might just be on that piece as a familiar face to them to help decrease that anxiety, or have them trust and understand that they’re obviously still in good hands.*” When talking about a stakeholder’s competence, participants regularly used knowledge of a stakeholder’s training, education, or licensure as a reason to believe they would provide or adequately handle certain information. Participants also felt increased trust if stakeholders used “official” documentation such as HIPAA privacy forms, with one parent noting: “*[I] feel safe because they honor that.*”

Relationships figured heavily into trust assessment. Relationships were regularly defined in terms of the amount of time spent interacting, the length of relationship, and as an “affective” emotional connection, as encapsulated by this quote from an early educator about a home visiting program: “*I think I would trust the sensitive information more coming from them because I think there would be a relationship... I’m guessing that when they meet together it’s for a while. There’s just this opportunity to get to know each other.*” Many trust assessments were based on past experiences with members of other stakeholder groups. Participants had difficulty assessing the trustworthiness of stakeholders they had not interacted with in the past. Many participants were unfamiliar with community groups and struggled to make a trust assessment even when provided with a description of a community group’s work. A public health provider

noted that they will only refer parents to providers they are “*familiar with*” because “*I know that they have a program that actually could serve this child... I've learned kind of who the 'go-tos' are.*”

When discussing the usage of an online data system, participants made trust assessments based on how the proposed system would handle data access, whether the system was secure, and on the existence of functions they thought the system might have. Many participants shared the view of one parent: “*it should be private; it shouldn't be something that anyone can pull data out of.*” Many participants also noted that any centralized system needs to have security features so that it could not be “*broken into.*” One early educator based trust in system data on data entry functionality, noting higher trust in free-text data entry than click-enabled entry: “*when they type in the little descriptions, that tells me that they were looking at that and they didn't just click something on accident.*” Multiple participants noted the need for a system to have “*validity checks*” for data, and a need to know if the data in the system were “*current*” and “*up-to-date.*”

Participants noted that certain information, usually related to substance use or home stressors, was considered to be “*sensitive*” and would generally be withheld by parents. As noted by a public health professional, “*most people probably would not answer some of these sensitive questions about their stressors at home.*” Based on perceptions that this information would be under-reported, some participants would have different trust assessments for the existence or absence of pieces of sensitive information: “*Just because they don't say there's an alcohol problem doesn't mean there isn't one... but if they made a point of saying there's drug use in the home, I would feel like that's probably accurate.*” Two other factors related to assessing trust emerged from the data. Some participants indicated a general propensity toward trusting others regardless of profession or role, such as the early educator who said: “*I don't like... when people*

just shut down data just because, 'oh well, they're [a certain profession], so forget it.'”

Inversely, some participants indicated experiences with parents who had a propensity to mistrust others, such as one educator who noted that *“some people are paranoid”* about sharing information. Some service providers also noted increased trust in a collection of data that included a diversity of opinions, valuing a *“multidisciplinary”* or *“holistic”* view of the child based on reports from multiple stakeholders, or seeing a wide range of data to *“calm the outliers.”*

Participants performed trust calculations considering multiple types of trust perceptions. One community group professional described a calculation that privileged relationships over indicators of competence: *“I guess what level of time they’ve spent with the child, how long have they known the child... those would probably be the two things more than education or even role.”* One parent’s trust calculation weighed perceptions of benevolence against a service provider’s abilities: *“the primary care provider, although with best intentions, didn’t really see any of the things that I saw.”*

A lack of trust in a data system could supersede assessments attached to other stakeholders and prompt a stakeholder to not use a collaborative system, as reported by one psychologist: *“if somebody presented me with an online system and I wasn’t sure about its accuracy, then I might prefer to request the actual records.”* Participants also talked about perceived costs and benefits of sharing information. Service providers noted the dangers of reporting inaccurate information, such as this social worker talking about a recent experience with early intervention workers: *“they think this child has fetal alcohol syndrome, but really they don’t have the skills to diagnose that; now all of a sudden... a foster family is seeing this report and they’re assuming that this is true.”* An early educator likened care management with the use

of inaccurate information to “*chasing your tail*.” Parents and providers similarly noted perceived negative outcomes of parents sharing information, such as social shaming, intervention by CPS, or being taken advantage of by “*predators*” online who will “*target individuals to steal from them or take advantage of them in some way*.” On the other hand, a perceived benefit of sharing information is improved care coordination, as noted by a public health professional: “*how do you make a plan if you’re not going to include everybody else, an effective plan?*” Parents noted that sometimes reporting sensitive information such as income or substance use was necessary in order to qualify for needed services.

Participants also discussed how they would handle information they perceived to be untrustworthy. Some reported verifying the accuracy of information they do not trust by crosschecking it against information they possessed or through initiating discussions with other stakeholders. For example, a public health professional compared information they had gathered about the public service subsidies a family receives with parent self-reports that “*everything is peachy keen*,” concluding that “*it’s just not possible*” that the family does not need help. Many stakeholders would use the receipt of potentially inaccurate information to start a conversation with the family or the data provider: “*I would say, ‘You know, I see this from [social services],’ for example. I would ask them just to tell me a little bit more about it.*” Many other stakeholders, however, noted that the existence of questionable data would prompt them to collect their own data, as indicated by this early educator comment: “*if I went in and I saw that a childcare provider had done a screen... I would probably still do my own screen.*” Information from a questionable entity was sometimes seen as providing contextual information for a family’s situation. While the specifics of data might not be trusted, some service providers noted that this information could be used as a “*red flag*” or a “*general guide*” that something was wrong.

5.4 DISCUSSION

This thematic analysis validates the applicability of multiple conceptualizations of trust from the literature. Among child development stakeholders, perceptions of competence, benevolence, and integrity were prominent, and discussions of an entity's propensity to trust, the importance of interactions over time, and both the views of trust as a cost-benefit analysis as well as an affective emotion also emerged. The confluence of all of these concepts paints a complex picture of how trust is perceived and great variability in how participants weighed many trust perceptions. Trust was also affected by considerations of the information being exchanged and the use of an electronic system. This indicates that collaborative HIT designers should consider multiple trust perceptions to support collaborative work. The themes in this chapter provide a listing of considerations surrounding trust that could guide designers of future collaborative HIT systems.

The finding that stakeholders experience difficulty in assessing the trustworthiness of unfamiliar stakeholders mirrors challenges found in previous research on collaboration with determining whether an entity is trustworthy, leading to the use of trust "substitutes" like contracts (Connell & Mannion, 2006). Clearly identifying collaborating system users and their attributes could potentially mitigate uncertainty in assessing trust. The "indicators of trust" found in this study suggest that the use of symbols within an electronic system could help stakeholders form perceptions about trust criteria, such as educational degrees indicating competence or a statement of personal values indicating benevolence. The provision of such indicators could help to build rich descriptions and form a "social presence" for users of an interprofessional system to support trust (Beldad et al., 2010). Since trust is context-dependent (Connell & Mannion, 2006), the relative importance of different trust perceptions or salience of different indicators of trust

should be explored for different health conditions or care arrangements. For example, a service provider's competence may be judged by a different set of skills depending on whether they are caring for young children or older adults. Different stakeholders within a care context may also perform different trust calculations favoring different trust criteria, suggesting that designers should explore how all stakeholders assess trustworthiness to understand the information needs of all potential system users. Other researchers have also suggested that more exploration is needed on the relationship between trust and knowledge about a potential partner to be trusted (Connell & Mannion, 2006).

This study also found that the existence of relationships between stakeholders was an important factor to consider when building or assessing trust. While relationships are regularly defined by emotional connections or built on face-to-face interactions that could be difficult to capture in an HIT system user interface (Beldad et al., 2010), they could potentially be expressed by noting certain indicators such as the frequency and length of visits between entities, duration of the relationship, and how entities stay in contact. The importance of personal contact in forming trust, however, indicates that an electronic system user interface may not be able to support all forms of trust perceptions. This finding agrees with previous research noting the importance of "facework" in sustaining trust in people and institutions (Gilson, 2003), and suggests that collaborators cannot solely rely on asynchronous computer-mediated interactions to maintain trust. Aside from designing HIT tools that support the assessment of trust, system designers must also understand situations where HIT systems should not be relied upon to engender trust.

The concepts of information relevance and source of information from this study can also help to guide how data are presented in a collaborative system. It may be useful to provide a

general description of the role a stakeholder plays in a child's care, the information they collect during their work processes, and how that information is used to support care. All information could be tagged with the person who entered the data and the source of the data, such as "parent report" or "personal assessment," in order to mitigate the need for stakeholders to guess at the source of a piece of data and potentially use trust perceptions related to an incorrect data source. Many participants were also concerned about the use of a hypothetical online system and its data privacy, security, and system features. Previous work indicates that indicators such as privacy policies listed on a website may increase trust (Beldad et al., 2010). System features such as the use of appropriate data entry mechanisms and the use of "sanity checks" for incorrect data could also improve trust in using an electronic system. While some participants saw value in the use of untrustworthy information in providing generalized background information or in prompting discussions between stakeholders, inaccurate information was also seen as a danger to effective care management. Reports that stakeholders would collect their own data in the face of perceived inaccuracies, or request "*original records*" if they did not trust data in electronic systems, indicate that perceptions of data being untrustworthy may increase workloads or lead to data duplication.

This work supports existing literature demonstrating complex interpersonal perceptions in interprofessional environments to support child health. Previous studies have found perceptions that school personnel lack the abilities or time to support children with special needs (L. S. Anderson, 2009), perceptions that pediatricians have great knowledge but little contact with children (Radis et al., 2016), and perceptions that early intervention programs provide lesser care than healthcare providers (Ideishi et al., 2010). A recent study of perceptions between healthcare providers, social workers, and schools to support children with complex needs found

that one group of professionals did not necessarily understand another profession's work. There were perceptions that others lacked relevant knowledge, clashes in approaches to care, and perceptions of other professions as cold or demanding (Widmark et al., 2016). Many of these perceptions align with trust perceptions considered in this paper. This study is unique in that it focuses specifically on the concept of trust and its effects on the sharing of information, giving deeper insight into how these trust perceptions can affect communication in an interprofessional environment.

Using both deductive and inductive methods to analyze semi-structured interviews allowed for the discovery of new themes that build on the current body of literature about data sharing and trust. Previous studies on data sharing (K. Caine & Hanania, 2012; Olson, Grudin, & Horvitz, 2005) focus on consumer perspectives and treat trust as a unidimensional construct. This work supports results from a recent study to design an HIT intervention for African American youth to address transmission of sexually transmitted diseases, which also found a complex picture of trust, including considerations of competence, benevolence, integrity, technology privacy and safety, personal data privacy skills, and the cost of sharing information (Veinot et al., 2013). Additionally, results of a study of patient and provider trust in the use of telemedicine systems discovered the salience of reputation, general functional abilities, policy transparency, and usability of technical systems to all affect trust (Van Velsen et al., 2016). Our work considers trust between a wider range of participants in an interprofessional environment, including non-healthcare professionals, and how it affects the sharing of data.

The research presented in this chapter has limitations. While efforts were made to recruit a diverse array of participants, those who agreed to participate tended to be economically middle-class white women. Because previous research suggests that assessing the trust of data

sources may change based on factors such as age, race, and education level (D. Smith, 2011), more work is needed to gather the perceptions from a demographically diverse group of stakeholders. Further work is also needed to incorporate the perspectives of stakeholder groups that were not engaged in this study, such as patient advocacy groups, community health workers, and church groups. Many of the concepts defined in this chapter are also interrelated—for example, forming perceptions that an entity has low privacy skills because their workplace is not under the purview of HIPAA laws. Future work can establish and test a conceptual framework that connects these factors. Future work should also explore the effectiveness of computer-mediated communication in generating trust, test various designs meant to foster social presence, and define specific health care and service scenarios (e.g., referring a child to diagnostic testing) where HIT tools are more or less appropriate for initiating or generating trust. Due to the context-dependent nature of trust relationships, the themes in this manuscript must be explored through the lens of different health contexts. Despite these limitations, this work provides a nuanced view of trust and a set of guiding themes that could help future design work in collaborative HIT systems.

5.5 CONCLUSIONS

In the domain of childhood development, trust plays an important role in the sharing of information and in the support of interprofessional collaboration. To support collaboration around complex health issues, collaborative HIT systems must support differing trust perceptions between stakeholders. Trust is, however, a complex construct with many facets that are expressed differently between collaborators. The child development space involves service providers and caregivers from many professional fields who use complex heuristics to judge

each other's trustworthiness. Designers of HIT should take a broad view that incorporates many aspects of trust in order to support the widespread acceptability and use of collaborative systems amongst diverse stakeholders. The themes identified in this research can provide guidance for HIT designers to create collaborative systems that support the establishment and maintenance of trust, and therefore support information sharing in a complex field such as child development. The next chapter will take the concepts of competence, benevolence, and integrity, along with the idea of "indicators of trust," to create and test system prototypes that aim to support trust judgments between child development stakeholders.

Chapter 6. DESIGNING USER INTERFACE PROTOTYPES TO SUPPORT TRUST BETWEEN CHILD DEVELOPMENT STAKEHOLDERS

6.1 INTRODUCTION

Chapter 5 explored how trust is expressed in the interprofessional ecosystem of child development services. The results found that a lack of trust between different child development stakeholders could lead to the withholding of information, or the ineffective use of information that is received. Many interview respondents reported that parents would obscure socially sensitive information relevant to child development, such as socioeconomic status, from people with whom they did not have a strong, trusting relationship. When child development stakeholders received information deemed to be untrustworthy, this would cause the information receiver to perform more work to determine how the information could be used. In extreme cases, received information would be completely disregarded. Taken together, this means that trust can determine whether information is shared, or whether shared information is used. Therefore, a lack of trust between child development stakeholders could lead to the use of incomplete or inaccurate data in decision-making and, furthermore, substandard care.

Results from previous chapters suggest that work is needed to explore how to develop trust between child development stakeholders. Stakeholders exhibited difficulty in judging the trustworthiness of entities that they had not previously interacted with. Unfortunately, the workflow analysis in Chapter 4 indicated that communication between child development service providers is infrequent, and service providers most often only communicate through the exchange of reports. This indicates that the current minimal level of contact between child

development service providers may not be enough to establish trust. Accordingly, an HIT system that supports the creation of trust between child development stakeholders may improve the efficiency and effectiveness of communication. A deeper understanding of trust could help to design appropriate HIT functionalities. Building upon these results from the previous chapters, this chapter will explore the design and testing of prototype user interfaces meant to support trust in the interprofessional field of child development services.

The results from Chapter 5 were congruent with many concepts in previous literature, including the importance of perceptions of competence, benevolence, and integrity to judging trustworthiness (Lambright et al., 2010; Mayer et al., 1995; J. Song & Zahedi, 2007). These three concepts are weighed with and against each other to judge overall trust in a certain entity to perform a certain action (Mayer et al., 1995). Trust has also been explored as a relationship that changes over time (Zahedi & Song, 2008). Interventions that support the creation of “initial trust” will be important to fostering communications in the child development space, where communication between providers is infrequent. Initial trust is needed for people to engage with entities that they are unfamiliar with, and can be based on factors such as entity categorization, stereotyping, and organizational reputation (McKnight, Choudhury, & Kacmar, 2002; McKnight et al., 1998). Aside from these factors, providing information describing an entity may aid in the formation of trust judgments in general.

6.2 TRUST BASED ON SOCIAL TRANSPARENCY AND SOCIAL PRESENCE

Past research suggests that trust can be extended to strangers when one has adequate information to judge whether they are trustworthy (Connell & Mannion, 2006; Gilson, 2003). Online systems have the ability to transmit signals before user actions take place to indicate that the system itself

is trustworthy (Riegelsberger, Sasse, & McCarthy, 2005). While initial trust in the absence of direct interaction may be largely based on ingrained stereotypes of specific professions or groups, it is possible that providing personal information about a potential collaborator through an HIT interface could augment trust beyond these stereotypical views. Stuart et al. (2012) define the concept of “social transparency” as the presentation of social meta-data around information exchange. They suggest that technological system designs that provide a transparent user “profile” with information about a person’s identity can support inferences about group membership and social status, which could support the creation of trust and information sharing (Stuart et al., 2012). Such meta-data could also render information shared to be more usable, since its accuracy and usefulness can be more easily assessed (Stuart et al., 2012).

Similarly, researchers have also postulated that the creation of “social presence” may promote trust in online systems (Beldad et al., 2010). Social presence is experiencing other people as being socially present through an electronic interface, with features such as personalized greetings or pictures (Hassanein & Head, 2007). In the field of e-commerce, research has found that increased levels of perceived social presence resulted in higher levels of trust in shopping-related websites, and subsequently higher enjoyment (Hassanein & Head, 2007). There is also an increasing number of studies in the biomedical informatics field that investigate the use of social presence in health interventions, such as for diet applications (Bittner & Kulesz, 2015), self-help drug abuse (Amann et al., 2018), providing emotional support through the internet (Paul et al., 2017), applications for psychosis patients (Killikelly, He, Reeder, & Wykes, 2017), social networks for cancer survivors (Erfani, Blount, & Abedin, 2016), and informational websites (Crutzen, Cyr, Larios, Ruiter, & de Vries, 2013). Social presence has been explored in collaborative situations in a limited fashion, such as for

interprofessional education (C. T. Myers & O'Brien, 2015), or for collaborative online learning environments (Kreijns, Kirschner, Jochems, & Van Buuren, 2004).

Previous research has explored the use of various pieces of information and system functions to support social presence. E-commerce system designers have sought to instill social presence either by providing means to directly communicate with other people, or through the creation of “imaginary interactions” such as picture content, personalized greetings, audio, or video (Cyr, Hassanein, Head, & Ivanov, 2007; Erfani et al., 2016; Hassanein & Head, 2007; Killikelly et al., 2017). Aside from this “virtual re-embedding” of social cues, researchers also posit that information richness on a website can convey social presence, reduce ambiguity, and ultimately increase trust (Cyr et al., 2007; Hassanein & Head, 2007). Previous research suggests that social presence is supported by providing informational content such as testimonials and reviews (Crutzen et al., 2013; Cyr et al., 2007), a “visually friendly” virtual agent (Amann et al., 2018), emoticons and positive wording (Paul et al., 2017), or welcoming language and personal information about system users (C. T. Myers & O'Brien, 2015).

Information and system features that speak to the trust-related perceptions of competence, benevolence, and integrity may support social transparency and presence, and therefore the creation of trust in other system users. Research suggests that conveying trust through text content and features related to these separate perceptions of trust may affect trust in different ways (Gefen et al., 2008). For example, research from the field of e-commerce found that perceptions of integrity can affect a potential client's intentions to purchase, perceptions of competence impact peoples' intentions to ask questions, and perceptions of benevolence affect behaviors in online auctions (Gefen et al., 2008). Another e-commerce study found that factors

related to integrity affect intentions to buy, and factors related to social presence affected perceptions of integrity and benevolence, but not competence (Gefen & Straub, 2004).

Since different aspects of trust may support trust in performing different actions, a nuanced view of trust is needed in an interprofessional space. Trust relationships may vary significantly based on the identity of the “trustor” (i.e., the person making a trust judgment) and “trustee” (i.e., the person whose trustworthiness is being judged) involved in an interaction. Trust is generally context-specific, and is increased when a trustee exhibits behavior in accordance with a trustor’s expectations (Gefen & Straub, 2004). For example, the relative importance of considering indicators of competence versus benevolence in making a decision to trust may differ depending on whether the trustor relies on the trustee more for their high levels of skill, or for their caring nature (Gefen & Straub, 2004). In the space of child development support services, the trustworthiness of different professions, such as doctors and teachers, may be judged on significantly different criteria and are subject to differing social norms and expectations about the work they perform.

Past research on supporting trust through information technology has focused on e-commerce or general information websites, finding that visual features and perceptions of the qualities of the information listed, such as perceived bias or currency, affect trustworthiness (Fogg et al., 2003; Metzger, 2007). One of the aims of this research is to specifically identify which types of information people use to judge whether another person has trustworthy characteristics, as reported by potential end users in the child development support space. Validating the approach of previous chapters, the work in this chapter takes a UCD approach to the “ideation,” “prototyping,” and “testing” portions of the design cycle by first engaging multiple groups of child development stakeholders to discover the factors they use to judge the

different perceptions of trust, and then explore whether the provision of such information supports the creation of trust. Based on results from the preceding chapter, the goal of Aim 1 of this study is to explore how child development stakeholders judge perceptions of competence, benevolence, and integrity. Aim 2 of this study is to use the responses from the first aim to create prototype “user profile” webpages that are then evaluated by potential end users. The main findings from this research will be 1) a list of information people use to assess an entity’s competence, benevolence, and integrity in the child development space, and 2) to determine whether providing information related to these factors through an electronic user interface will affect information sharing. A secondary objective of this research is to explore the interplay between the information related to trust perceptions, trustor background, and trustee background in the judgment of trustworthiness.

6.3 RESEARCH METHODS

This research consisted of two rounds of surveys to first discover the factors that people use to judge the trustworthiness of other users of an online system, and then to test prototype user profiles that contain such factors to determine if they support the formation of trust. To explore the potential interplay between user backgrounds and professional expectations, our respondent “trustors” consisted of two groups of child development stakeholders: a) parents, and b) pediatric healthcare providers. These respondents were asked to judge the trustworthiness of two different groups of “trustees” relevant to the child development space: a) pediatricians and family physicians in the medical field, and b) preschool teachers from the education field. Data were gathered through online questionnaires, and all data collection tools were piloted by biomedical

informatics or human-centered design graduate students at the University of Washington to evaluate the clarity of instructions, questions, and responses.

6.3.1 *Recruitment*

The initial recruitment of parents and healthcare providers was done through the Amazon Mechanical Turk (MTurk) platform. MTurk provides a population of workers who perform minor tasks online for a fee. Research has suggested that the MTurk population maintains a similar demographic distribution to the US, though the workers tend to have higher education and lower income, and that research subjects recruited through MTurk are no less attentive to a task than those recruited through other methods (Paolacci, Chandler, & Ipeirotis, 2010). The inclusion criteria for parents was recent experience raising a child under five years of age, and the criteria for healthcare providers was working in an outpatient healthcare setting and working regularly with children under five years of age. Respondents were excluded if they were under 18 years of age or resided outside of the US. MTurk qualifications for being a parent or a healthcare worker were initially used to target surveys to the two respondent groups, and a filter on location was used to target surveys to US residents. The survey description prompted workers to only respond if they had experience caring for or working with children under five years of age. Respondents were initially offered \$1 to respond.

An initial survey pilot with 20 respondents found that the MTurk qualifications and survey instructions did not adequately limit responses to the target populations based on responses to demographic questions. Many respondents had no experience with young children, did not live in the US, and the healthcare worker survey included many inpatient providers and non-clinical workers such as administrative staff, medical transport, or billing staff. Due to the

imprecision of recruitment through MTurk, a two-stage recruitment strategy suggested by Wessling, Huber, and Netzer (2017) was adopted. An initial survey asking basic demographic questions for a low fee was posted. This survey did not reveal the purpose of our overall survey to remove the motivation to lie or give “stereotypical” question responses based on subject matter (Wessling et al., 2017) and thus mitigate the possibility of respondent misrepresentation. Participant demographics from the initial survey were reviewed, and eligible respondents were assembled into a research panel for future surveys. The surveys contained an “attention” question asking what age group our research is most interested in, and a combination of a missed attention question and seemingly careless answers (i.e., short, or not answering the question directly) would cause a survey response to be rejected. Due to recruitment difficulties experienced with MTurk, supplemental healthcare providers were also recruited through electronic mailing lists maintained by pediatrician professional organizations in Washington State.

6.3.2 *Demographic Questions*

Respondents were asked basic demographic questions on all surveys, such as age, gender, race and ethnicity, state of residence, educational attainment, the number of children they have, and whether any of their children have had a developmental delay or disability. Healthcare workers were also asked for a job title, age ranges of the people they regularly serve, a description of how they interact with children and families, and whether they regularly care for people with developmental disabilities. All respondents were also asked questions that previous research suggests may be associated with the assessment of trustworthiness, such as whether they consider people to be generally trustworthy, whether they have had experience with personal

information being stolen or inappropriately shared online, and how often they use the internet (Bansal & Gefen, 2010; Gefen & Straub, 2004; Hui, Teo, & Lee, 2007).

6.3.3 *First Survey Questions and Analysis*

Both groups of “trustors” responding to the survey (parents and pediatric healthcare providers) were asked which of the following trust perceptions was most important to consider in determining whether to trust both “trustee” groups (“pediatricians and family doctors” and “preschool teachers”) to effectively support a child’s development:

- 1) Whether they have the knowledge, skills, and abilities to help a child (competence)
- 2) Whether they care about a child and the child’s family (benevolence)
- 3) Whether they are consistent, reliable, and unbiased (integrity)

Respondents were then asked to imagine a webpage with information about a doctor or teacher they had not previously met, and provide a ranked list of up to three pieces of information they would like to see on that webpage to help them judge whether the given professional was competent, benevolent, or had integrity, as defined previously. These responses were open-ended. Respondents were then asked to imagine a recent experience with a doctor or teacher they had worked with to support a child’s development and describe why they do or do not trust the noted individual. See **Appendix E** for a template of the first survey.

Responses related to assessing the relative importance of the three trust perceptions (i.e., competence, benevolence, and integrity) were analyzed to explore any associations with demographic factors using nominal multinomial logistic regression models. Models considered the background of the respondent “trustor” (parent or healthcare), the background of the “trustee” being assessed (healthcare or education), gender, age, race, whether the respondent has

kids, whether they have personal or professional experience caring for children with developmental delays and disabilities, whether they consider people to be generally trustworthy, whether they had attained a college degree, and internet use. General estimating equations (GEE) were created in SAS to account for correlations between respondent answers for healthcare and education providers. Models were built in a stepwise fashion, initially including all variables and subsequently removing statistically insignificant variables. A final model was chosen based on fit statistics: having the smallest difference between QIC (quasilikelihood under the independence model criterion) and QICu, and the smallest QIC value.

The primary author reviewed all open-ended responses related to the information respondents use to judge competence, benevolence, and integrity. Responses were collected into themes identifying types of information sought, and more specific subthemes—categories of information within each theme. The primary author randomized half of the responses for each trust perception to be reanalyzed by a colleague to check for validity in themes. There was a high level of agreement between the themes generated by the two researchers, and a final set of theme and subtheme categories was agreed upon through discussion.

Each entry in the ranked lists of information people used to assess trustworthiness was assigned one of the aforementioned themes and a more specific subtheme category when possible. Each entry was given a value from 3 (i.e., the first-ranked entry) to 1 (i.e., the last-ranked entry), and the sum value of each subtheme category and theme was calculated for each combination of trustor, trustee, and trust perception to determine the most salient factors. Answers to questions pertaining to recent experiences with doctors and teachers were used to enhance the description of themes and categories.

6.3.4 *Prototype Design*

For each trust perception, the summed rank scores for each information category were used to determine which information categories were most relevant to each trust perception. The top information categories for each trust perception were used to create low-fidelity informational webpage prototypes in Microsoft PowerPoint. The author created a set of 16 prototype informational webpages displaying information about a hypothetical child developmental stakeholder. These designs fulfilled a full 2^4 factorial design for testing based on the background of the depicted trustee (healthcare or education), and whether or not the webpage listed information related to competence, benevolence, or integrity. When portraying competence, benevolence, or integrity in a prototype, the page either listed all of the identified information categories for the perception, or none of them. This was done to compare the effects of information pertaining to a hypothesized “high” level of a trust perception, versus the absence of such information.

6.3.5 *Second Survey Questions and Analysis*

For the second survey, participants were sequentially presented with all 16 prototypes in a random order and prompted to answer questions about whether they promoted the creation of trust. Parents were asked to imagine that they were reviewing a website listing of providers to help support their child’s development, and healthcare providers were asked to imagine that they were reviewing a website listing of providers who may be supporting current or future patients. All respondents were given instructions to read each prototype for 15 seconds, imagining that they represent providers that they had not previously met, and were asked to rate their agreement with the following two statements related to trust:

1. I could trust them to **provide me with accurate and useful information** about child development.
2. I could trust them to **appropriately and effectively use information I share with them** about child development.

Agreement was measured with a four-response Likert scale: strongly agree, agree, disagree, strongly disagree. See **Appendix F** for a template of the second survey. A set of cumulative logits regression models were fit using GEE in SAS to determine which factors were associated with a higher agreement with statements related to trust. Models were built in a stepwise fashion, as described for the first survey, with the same predictor variables.

6.4 RESULTS

Table 7 provides a summary of the respondents for both surveys. MTurk was used to recruit 77% of healthcare provider participants for the first survey, and 80% for the second survey.

Table 7. Aggregate demographics for study participants, split by recruitment group and survey answered.

Demographic	Survey 1		Survey 2	
	Parents	Healthcare Providers	Parents	Healthcare Providers
Sample Size	45	35	30	25
Age (average)	40.2	38.5	35.5	38.9
Gender (female, number and %)	36 (80%)	25 (70%)	27 (90%)	17 (68%)
Has children (number and %)	45 (100%)	27 (78%)	30 (100%)	18 (72%)
Number of children (average, for participants with children)	2.6	1.7	2.1	1.7

	Survey 1		Survey 2	
Demographic	Parents	Healthcare Providers	Parents	Healthcare Providers
Has a child with developmental disability (number and % for participants with children)	18 (40%)	11 (41%)	12 (40%)	5 (28%)
Hispanic (number and %)	6 (12%)	2 (6%)	3 (10%)	2 (8%)
Non-white race (number and %)	7 (16%)	5 (14%)	5 (17%)	3 (12%)
Received college degree (number and %)	28 (62%)	32 (91%)	24 (80%)	23 (92%)
Believe people are generally trustworthy (yes, number and %)	30 (67%)	29 (83%)	19 (63%)	22 (88%)
Internet usage:				
Almost constantly (number, %)	30 (67%)	17 (49%)	21 (70%)	12 (48%)
Several times / day, or less (number and %)	15 (33%)	18 (51%)	9 (30%)	13 (52%)
Has had information stolen (yes, number and %)	13 (29%)	13 (37%)	9 (30%)	11 (44%)
Service Provider Information				
Profession:				
Nurse (number and %)		14 (40%)		12 (48%)
Doctor (number and %)		9 (27%)		5 (20%)
Other (number and %) (audiologist, therapists, rehabilitation counselor, psychologist, medical assistant)		12 (34%)		8 (32%)
Experience serving children with developmental disabilities (%)		34 (97%)		24 (96%)

6.4.1 First Survey Results

6.4.1.1 Modeling Importance of Trust Factors

Table 8 shows the distribution of the most important trust factor responses split by trustor and trustee types. Overall, competence was overwhelmingly considered to be the most important factor, being chosen in approximately 72% of questionnaire responses. **Table 9** displays the results of the best-fit nominal multinomial logistic regression model. Statistical modeling yielded a final model with five factors: trustee profession, respondent trustor group, whether the respondent has a college degree, whether the respondent had children, and age. Age, trustee profession, and having children were statistically significant at a level of 0.05. The odds of choosing benevolence over competence were approximately 4.7 times larger when assessing educators versus healthcare providers. The odds of choosing benevolence over competence were approximately 10.8 times larger for respondents without children than respondents with children. A one-year increase in respondent age was associated with a 1.06 times larger odds of choosing benevolence over competence.

Table 8. Trust factors considered most important, split by respondent background and trustee background.

		Trust Factor			Totals
Respondent Type	Trustee Type	Competence	Benevolence	Integrity	
Healthcare		50	8	12	70
	Healthcare	27	2	6	35
	Teacher	23	6	6	35
Parent		65	13	12	90
	Healthcare	35	3	7	45
	Teacher	30	10	5	45

Totals	115	21	24	160
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Table 9. Multinomial logic regression model results.

Statistically significant findings at a significance level of 0.05 are bolded.

Parameter	Parameter Comparison	Trust Perception Comparison (Reference = Competence)	Estimate	SE	P
Trustee Profession	Teacher vs. Healthcare	Benevolence	1.55	0.55	<0.01
	Teacher vs. Healthcare	Integrity	0.01	0.46	0.99
Trustor Type	Healthcare vs. Parent	Benevolence	-1.13	0.65	0.08
	Healthcare vs. Parent	Integrity	0.24	0.52	0.65
Education	No College Degree vs. Has Degree	Benevolence	-0.44	0.73	0.54
	No College Degree vs. Has Degree	Integrity	1.03	0.56	0.07
Age	Adding one subsequent year	Benevolence	0.06	0.03	<0.05
	Adding one subsequent year	Integrity	0.03	0.02	0.29
Has Children	Has No Children vs. Has Children	Benevolence	2.38	0.91	<0.01
	Has No Children vs. Has Children	Integrity	1.12	0.71	0.12

6.4.1.2 Information to Judge Trustworthiness

When eliciting ranked information participants to judge trustworthiness, participants reported 417 responses for competence, 353 responses for benevolence, and 338 for integrity. These responses were split into 23 categories of information encompassed by 7 overall themes: demonstrating skills, personal characteristics, relationships, third-party trust, training, work experience, and workplace practices. **Table 10** lists the themes, associated categories of information, and descriptors used by respondents. While many categories indicate information that may be provided through a user interface, the category of “relationships” is related to repeated personal interactions, and may therefore be difficult to portray through a computerized interface. Since responses related to relationships were not reported in the ranked lists of information, but in the open-ended responses recalling recent interactions with doctors and teachers, this theme is not considered in further analysis. While descriptors for many of the 23 informational categories were the same regardless of trustee role, some descriptions were more salient for doctors and others were more salient for teachers. These differences are also noted in **Table 10**.

Table 10. Information categories and encompassing themes.

Categories are accompanied by specific descriptors used by respondents, split by descriptors used for doctors, those used for teachers, and those used for both.

Theme	Categories	Description	Descriptors for Both Groups	Descriptors Only for Doctors	Descriptors Only for Teachers
Demonstrate Skills Information or actions that indicate competence in the domain area of interest.	Activities Beyond Regular Work	Profession-related activities outside of normal daily work	Extra-curricular activities, quality assurance projects, research, and publications	N/A	Additional skills outside of teaching
	Communication Competence	Skills related to effective communication with children and families	Communicative, listens, responsive to communications	Allows parents to ask questions, asks own questions, giving advice, using understandable language	Communicates goals, pays attention, provides feedback on the child's performance
	Outcomes	Whether the results of their work are positive or negative.	Existence of legally filed complaints	Correct diagnoses, "number of patients helped," success with different treatments, statistics on past successes	"Students learn," student test scores, student grades, sees improvement in development after school, no history of child abuse or neglect

Theme	Categories	Description	Descriptors for Both Groups	Descriptors Only for Doctors	Descriptors Only for Teachers
	Specialized Knowledge and Skills	Actions, tools, or teachings that demonstrate mastery of a professional's domain	Knowing about high-quality services in the area, understanding needs of delayed children, understanding milestones and developmental progression, having realistic expectations for children with developmental delays	Offers backing information on statements given, provides details, knowledge agrees with trustor's own research, knows things that trustor did not know and provides education, has a comprehensive plan for care, information on treatments used, the use of developmental screening tools, how to identify medical emergencies	Information on teaching techniques, examples of communication, homework assignments, classroom policies and syllabi, lists of classroom activities, how they help children feel comfortable in the classroom, list of home activities for parents, classroom management skills
Personal Characteristics Information pertaining to the professional's personal life.	Personal Information	Personal information about a provider and their life	Biography about life, information about family, whether they have children, demographics like age, race, religion, and where they were born	N/A	N/A

Theme	Categories	Description	Descriptors for Both Groups	Descriptors Only for Doctors	Descriptors Only for Teachers
	Personality	Perceived personal qualities, disposition, and demeanor	Friendliness and kindness, caring about children and families, empathy, confidence, patience, liked by children, hobbies, and having a “personal” statement	Attentive, good “bedside manner,” being “old school,” open-minded, respectful, language such as “child’s health” or “happy and healthy”	Humble, calm and gentle, resourceful, language about being “involved” and “there to help”
	Pictures	Pictures of the professional and their work environment	A smiling picture of the professional, the professional with their family, interacting with clients, pictures of a clean, kid-friendly clinic or office	N/A	N/A

Theme	Categories	Description	Descriptors for Both Groups	Descriptors Only for Doctors	Descriptors Only for Teachers
	Values	What a service provider holds to be important or worthwhile; Whether the values of a professional match the values of the trustor	Going “above and beyond” the call of duty, considering cultural context and language, unbiased, nonjudgmental, respecting the parents’ wishes and opinions and involving them in care, being flexible, dependability, consistency, reliability, being thorough, volunteering, providing a mission statement, discussing their work philosophy or approach to care, motivations for working with young children	Not connected to pharmaceutical companies, breast-feeding friendly, thoughts on vaccines, being honest about conditions and treatment, splitting personal beliefs from the care provided, belief in “evidence-based treatment,” belief in collaborative work, willingness to learn about a child’s condition	Safety-oriented, “protects child morally,” “ethical approach to education”

Theme	Categories	Description	Descriptors for Both Groups	Descriptors Only for Doctors	Descriptors Only for Teachers
Relationships Building a personal connection through repeated interactions over time		Regular interpersonal interactions over a long period of time	Knowing someone for a long time, either personally or through work	N/A	N/A
Third-Party Trust Trust formed due to a person's relationships with other people or entities	Associated Organizations	Consideration of the organizations that a professional is or has been affiliated with.	Schools they attended, organizations where they have worked, professional organization memberships	Affiliated hospitals, where they have admitting privileges, board membership, where they attended residency	N/A
	Awards	Being presented with an award or commendation	N/A	N/A	N/A

Theme	Categories	Description	Descriptors for Both Groups	Descriptors Only for Doctors	Descriptors Only for Teachers
	Certifications	Certification from a third-party organization that a provider maintains a level of expertise	N/A	Medical licensure, board certification	Accreditation by a group such as NAEYC or with certain skills such as CPR, passing a background check
	Reviews	A review or statement about a provider, written by another person who has experience with the provider	Reviews, testimonials, ratings, rankings, and comments from parents, peers, and others in the community	N/A	Comments from students
Training Information pertaining to formal educational training in the	Continuing Education	Whether a professional partakes in current educational activities to stay current	N/A	N/A	N/A

Theme	Categories	Description	Descriptors for Both Groups	Descriptors Only for Doctors	Descriptors Only for Teachers
domain area of interest	Degrees	Qualifications awarded from an educational institution denoting expertise in a certain area of study	N/A	N/A	N/A
	Specialties	Specialized training within a domain	Additional training in child development	Training in behavioral health, training in specific programs like Incredible Years	Specialization on working with children with disabilities, child development, cultural sensitivity, first aid
	Education Details	Information describing the depth of training	Years in school, performance in school	N/A	N/A
Work Experience Information pertaining to real-world domain	Work History	Information about the course of a professional's career.	Years in their current position, years working in the relevant field, past work positions and locations, resume	N/A	N/A

Theme	Categories	Description	Descriptors for Both Groups	Descriptors Only for Doctors	Descriptors Only for Teachers
experience gained through practicing.	Work Populations	Consideration of the different populations that a professional has served	Working with a diverse population in terms of culture, nature of disability, age	N/A	N/A
Workplace Practices Information related to the policies and procedures practiced in the professional's place of work	Accessibility	Consideration of how easy it is to contact a professional and access their services	High level of availability and ease of contact, accurate information about days and hours of operations, accurate contact information, lists wait times for appointments and services, language accessibility and interpretation services, having an on-call service for urgent matters, geographic location served	Ability to message online, ability to talk to staff when doctor is unavailable, easy to set up appointments, long appointments, schedules standing appointments, which insurance is accepted	"Open-door" policy, cost for services

Theme	Categories	Description	Descriptors for Both Groups	Descriptors Only for Doctors	Descriptors Only for Teachers
	Client Staffing	Information about the staff who support the professional at work	Number of clients seen per provider, having a team to support families, staff is competent and friendly	Having a social worker as a part of the care team	N/A
	Work Systems	Information or communication systems in use at professional's office	Websites with information, or to contact professional	System to access health records	Use of classroom management system
	Work Policies	Information about the policies surrounding professional's work	N/A	N/A	Grading and homework policies
	Services Provided	The collection of services provided at the professional's service location	N/A	Services that "meet basic needs," counseling	N/A

Matrices displaying cumulative rank scores for competence, benevolence, and integrity for the identified information categories are in **Appendix G**. These matrices show sums of scores by theme, split by trustor and trustee groups. The matrices show significant variability in the information that people use to judge the three trust perceptions; however, cumulative scores can be used to identify the most important factors. Scores across trustor groups show significant similarities in the information that is used to judge all three of the perceptions of trust, and few differences based on the trustee job role. For competence, healthcare providers and parents both noted the importance of seeing *certifications* and a *work history*, while parents were more interested in seeing *degrees* and healthcare providers were more interested in seeing *specialties*. *Specialties* were deemed more relevant when assessing healthcare providers than when assessing educators. For benevolence, both parents and healthcare providers noted the importance of seeing *reviews* and information related to a person's *personality* and *values*, while parents showed a much greater interest in seeing *personal information* than healthcare providers. For integrity, parents and providers again noted the importance of *reviews* and information about *values*, but also thought that information related to a provider's *accessibility* was important.

6.4.2 *Prototype Designs*

Categories of information that received high rank scores in the first survey were used to create prototypes with varying information to be evaluated by a second round of surveys. Every prototype listed the profession and name of a hypothetical doctor or teacher, a work address and phone number, and an icon representing a picture of the hypothetical person. Different categories of information were then added to prototypes depending on what perceptions of trust the prototype was meant to portray. **Table 11** lists the information categories that were used to

indicate competence, benevolence, and integrity, and how the information categories were operationalized for the prototypes. **Figure 4** displays a sample prototype for a doctor with high levels of competence, benevolence, and integrity.

Table 11. Information categories that were leveraged, and how they were operationalized for the prototypes.

Competence	
Information categories:	How they were operationalized:
Work history	Years working
Certification	Board certified / NAEYC certified
Degrees	MD / MEd or MA
Associated Organization	School attended
Specialties	Pediatrics / early or special education
Benevolence	
Information categories:	How they were operationalized:
Reviews	Section with positive reviews
Values	Language related to involving the family in care
Personal Information	Section with personal statement, noting they're local to community
Personality	Language about treating people like family, being friendly, caring
Integrity	
Information categories:	How they were operationalized:
Reviews	Section with positive reviews
Values	Language about being reliable and culturally sensitive
Accessibility	Extended contact information, buttons to contact provider, review noting language services

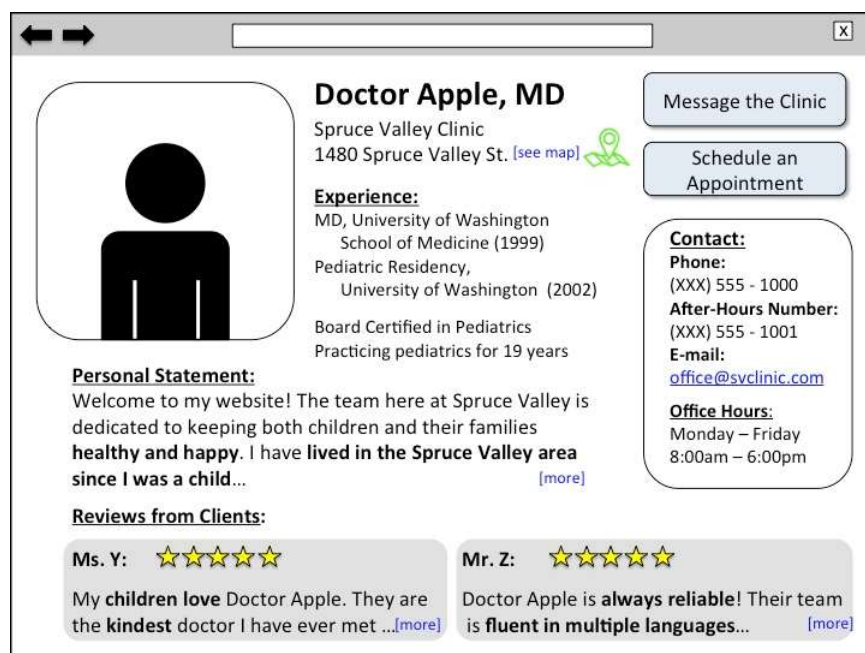


Figure 4. Prototype depicting a doctor with information portraying competence, benevolence, and integrity.

Competence was indicated by the “Experience” section. Benevolence was indicated by the “Personal Statement” section and entries in the “Reviews” section related to being caring and kind. Integrity was indicated by entries in the ‘Reviews’ section related to being reliable and culturally sensitive and an extended “Contact” section with buttons to send messages and schedule appointments.

6.4.3 *Second Survey Results*

Table 12 lists the results of the final cumulative logits model exploring more or less agreement with statements about whether the prototypes indicate trustworthiness. The model did not discern any significant effects based on trustor type, trustee type, or whether the statement was related to trusting information from the trustee or sharing information with the trustee. The display of information related to competence, benevolence, and integrity all had statistically significant

effects. Viewing information related to competence lead to a 3.3x increase in the odds of having higher agreement with statements related to trust. Increased odds when viewing information related to benevolence was 3.13, and increased odds when viewing information related to integrity was 2.14. The model, however, found significant interaction effects between trust perceptions. When competence and integrity were simultaneously listed, or when benevolence and integrity were simultaneously listed, there was a significant interaction effect that decreased the overall odds of higher agreement with trust statements. Demographic factors also had an effect on the assessment of the prototypes. Increased age, being male, having children, being of Hispanic ethnicity, and having a college degree all led to a lower odds of having higher agreement with statements related to trust.

Table 12. Results of the cumulative logits model listing log-odds of having a higher level of agreement with statements related to trust. The table contains parameter estimates, standard errors, and p-values. All factors are significant at a level of 0.05.

Parameter	Parameter Comparison	Estimate	SE	P
Competence	Listed vs. Not Listed	1.2	0.12	<0.0001
Benevolence	Listed vs. Not Listed	1.14	0.09	<0.0001
Integrity	Listed vs. Not Listed	0.76	0.08	<0.0001
Competence and Integrity interaction	Both Listed vs. Both Not Listed	-0.11	0.06	<0.05
Benevolence and Integrity interaction	Both Listed vs. Both Not Listed	-0.57	0.07	<0.0001
Age	Adding one subsequent year	-0.02	0.01	<0.05
Gender	Male vs. Female	-0.35	0.09	<0.001
Has Children	Has Children vs. Has No Children	-0.46	0.14	<0.01
Ethnicity	Hispanic vs. Not Hispanic	-0.41	0.17	<0.05

Parameter	Parameter Comparison	Estimate	SE	P
Education	Has College Degree vs. No Degree	-0.32	0.13	<0.05

6.5 DISCUSSION

This chapter undertook a deeper exploration of findings from the previous chapter that trust perceptions related to competence, benevolence, and integrity are important to supporting communication in the child development space. These concepts were considered in more detail through the crowd-sourced “ideation” of “indicators of trust” to generate trust in child development stakeholders through an online user interface, and the subsequent evaluations of prototypes. The results of this research underscore the complex and personalized nature of trust and the difficulty in separating conceptualizations of competence, benevolence, and integrity. Previous work that considered trust as a single-dimensional construct, instead of considering its component parts, does not support a deep understanding of how the multi-dimensional nature of trust operates (Gefen & Straub, 2004). The results of this study provide a robust, if interrelated, array of information types that people use to judge trustworthiness in the child development space, encompassing information pertaining to a person’s education and knowledge, personal characteristics and values, and work practices.

6.5.1 *Information Indicating Trust*

Survey results provided a rich set of information supporting trust that could be presented on a webpage as well as factors that would be difficult to portray on a user interface. The importance of *third-party* trust related to reviews and organizational affiliations agrees with

previous studies of trust in the biomedical informatics field (Veinot et al., 2013). Important information categories related to competence present many concrete indicators, such as the receipt of an academic degree, that could be easily displayed on a webpage. Alternately, benevolence and integrity speak to ephemeral concepts that are more difficult to observe, such as a person's personality and personal characteristics. Some factors, such as being communicative, might be difficult to determine without repeated, face-to-face interactions. *Relationships* between two people might be inferred from information such as the amount of time people interact with each other, as suggested in the previous chapter (Mikles, Haldar, Yin, Kientz, & Turner, 2018), but the existence of a relationship itself may be difficult to portray through an HIT interface. In previous studies, patients reported that the first face-to-face contact with a provider is when they decided to trust or not (Van Velsen et al., 2016). This supports the notion from the previous chapter that information provided through an electronic user interface may not be sufficient to maintain a strong trust relationship. While this list of themes and informational categories can guide future HIT system designs, the informational categories presented here should be validated with a larger population. Some categories, such as *education details*, were noted infrequently by respondents and ultimately may be of little value to support trust.

Recording rankings associated with the identified information categories indicated which categories were potentially high impact in supporting trust. However, there was significant overlap in which categories of information were relevant to which perception of trust. For example, concepts such as *personality* or *work history* had sizeable scores across all of the three trust perceptions. This indicates that trust judgment may depend on an individual's perspective. For example, one person may believe that attending a prestigious medical school speaks to a professional's abilities, while another may think that it shows a willingness to go "above and

beyond the call of duty.” *Values* is a broad category that figures heavily into assessing both benevolence and integrity. This research found that certain values, such as being “family-centered” were reported more often as being associated with benevolence, and others like being “nonbiased” were more related to integrity; however, a deeper exploration of values is needed to understand how they affect perceptions of trust. An alternate explanation of the significant overlap is that study participants may have had trouble consciously thinking about how exactly they judge a person’s benevolence or integrity. These results therefore may indicate more of a “tendency” for certain information to be associated with certain trust perceptions based on social norms than a pure reflection of a certain trust perception.

6.5.2 *Statistical Analysis Results*

The first survey discovered statistically significant yet practically modest differences in how people judge the trustworthiness of people with different backgrounds, finding that teachers were more likely to be judged based on benevolence. However, this finding was not necessarily substantiated by the second survey, which found no significant differences in how people judge trustworthiness based on the background of the trustor or the background of the trustee. This apparent contradiction may be due to the framing of the questions answered by the different statistical analyses. The first analysis considered a relative ranking of trust perceptions, while the second analysis addressed the value of the different trust perceptions separately. While benevolence may receive slightly outsized attention compared to other perceptions when considering the trustworthiness of teachers, providing information related to any of the perceptions of trust may be enough to support a trust relationship. The second analysis indeed found that information pertaining to all three perceptions had large, statistically significant

effects in supporting perceptions of trustworthiness. The lack of differences between the results based on whether the statement pertained to receiving information from the trustee or providing information to the trustee suggests that trust may support communication in both directions. An alternate explanation is that a lack of differences may be due to response bias, or the disconnect between a respondent's reported wishes in a study versus how they would act in a real-world situation.

Throughout both statistical models, personal characteristics of the trustor, such as age, gender, education, or having children, affected the assessment of trust. This indicates the importance of taking a user-centered approach to understanding how trust is assessed for different populations, and also ensuring adequate representation across studies assessing trust. Different health domains will involve people with different characteristics. For example, trustworthiness may be assessed differently for young patients than for older adults. One unexpected finding was that participants without children had much higher odds of valuing benevolence over competence versus participants who have children. This could possibly be due to the stereotyping of providers who work with young children. People without practical child-raising experience may think that professionals who serve children must be caring individuals, whereas participants who have such experience would prefer their children's caregivers and service providers to be skilled. Such a claim, however, would require further exploration to substantiate.

The significant effects seen in the second model for information relating to competence, benevolence, and integrity support the notion that the identified categories of information support the generation of trust. However, the results also suggest a possible effect related to the quantity of information presented and not solely the content of the information. Prototypes that

listed information pertaining to one or none of the trust perceptions necessarily displayed less information overall than prototypes portraying two or three trust perceptions, and therefore may have seemed less transparent than prototypes with more information. The act of sharing more information itself may engender trust. This notion may also be supported by the statistically significant and negative interaction effects seen between integrity and competence, and between integrity and benevolence. The larger negative interaction between benevolence and integrity may be due to both perceptions relying on *reviews*. It is possible that respondents were more concerned with seeing a “reviews” section than with the contents of the reviews themselves. Therefore, when both were listed in tandem, the modest benefit conferred by listing information related to integrity would therefore be mainly due to the listing of more extensive “contact” information. Future research should design studies that can separately test the quantity and the content of the information on an informational webpage to determine the relative effects of each factor. Also, when information relating to competence, benevolence, and integrity were present on a prototype, all of the information was meant to project a unanimously positive image of the represented professional. More research is needed to explore how varying levels of positivity or negativity in information related to the three trust perceptions can affect trust relationships.

6.5.3 *The Dark Side of Trust*

During the first survey, some respondents indicated that trust was related to potentially maladaptive or even harmful characteristics or behaviors. Two respondents indicated that a “willingness to treat unvaccinated children” would support positive trust through benevolence or integrity, though accepting unvaccinated children in a clinical setting may be considered poor medical practice by some pediatric healthcare providers. Some respondents reported that they

would have increased trust in providers who took fewer vacation days and spent more time in the office, which may be disadvantageous to a provider's well-being. Reports that some respondents would want to see links to a provider's social media page or detailed information about a provider's family and personal life may encroach on a provider's privacy. Trust in these cases is based on unreasonable expectations for the amount of information a provider is willing to share about themselves. Providing information that supports trust in a healthcare provider or educator needs to be balanced with the needs of the professional being represented.

While the information listed in this chapter may support the creation of higher levels of trust, it could also support willful distortions of how people present themselves online. Information in the indicated categories could be used to inappropriately project a trustworthy image when one is not warranted. This potential for misrepresentation has been recognized in past literature. Connell and Mannion (2006) discuss the "dark side of trust," which is the use of false information to engender trust, and Blois discusses the use of perceived trust to manipulate others (1999). There are significant ethical considerations for using information related to trustworthiness responsibly. Research on trust, therefore, should be focused not on the support of positive trust per se, but on providing users with the information they need to differentiate between trustworthy and untrustworthy sources (Riegelsberger et al., 2005). Providing inaccurate information to improperly project a trustworthy image is a risky proposition. Previous research has indicated that breaching a trust relationship can cause severe pain and negative reactions (Blois, 1999; Mechanic, 1998a). Therefore, if a deception is discovered, this can sever a trust relationship and engender an unwillingness to engage with the deceptive party.

6.5.4 *Limitations*

While steps were taken to decrease potentially biased responses from MTurk respondents, there is still the potential for MTurk respondents to misrepresent themselves demographically or provide stereotypical answers (Wessling et al., 2017). Steps were taken to assess the validity of results through attention-checking questions; however, data was not collected with a validated instrument. The results also suggest that social desirability may have biased respondent answers. For example, for the second survey, 73% of answers to the questions related to trust were either “agree” or “strongly agree,” which may indicate an aversion to criticizing the prototypes by the respondents. More functional prototypes need to be tested in real-world situations or scenarios to ensure that the effects seen in this study are truly reflective of how user profiles would function. As seen in the demographics table (**Table 7**), most healthcare providers recruited from MTurk were nurses, assistant providers, or allied health professionals. Such providers may use different criteria to judge trustworthiness than a pediatrician or other physician, so further analysis to explore perceptions by job role with a large enough sample may be warranted. Future studies could use methods like reverse coding of questions to detect stereotypical answers, or partial block designs to cut down on respondent fatigue.

6.6 CONCLUSIONS

The research in this chapter considered results from the initial needs assessment presented in Chapters 4 and 5, and used UCD methods to ideate and test potential solutions to support trust in the interprofessional child development support space. This research provides practical guidance for system designers in the form of information that speaks to a person’s trustworthiness, and

validation for the idea that information provided through an online user interface can support the creation of trust. This demonstrates that a needs assessment guided by concepts from the literature can lead to actionable results that can be used to inform collaborative HIT system designs.

Chapter 7. CONCLUSION

7.1 INTRODUCTION

A child's development can be supported by a diverse collection of caregivers and community service providers who span a number of professional fields. All children deserve the attention and support required to gain the needed skills to live a long, successful life. Unfortunately, the web of child development services is complex and fragmented, and a great number of overlapping and complementary services have been established from various laws, funding sources, and professional mandates (Council on Children with Disabilities, 2005; Council on Children with Disabilities, 2006; Malone et al., 2000; Shonkoff & Phillips, 2000). The path that a child and their family may traverse to seek adequate care for potential developmental delays, and the people they enlist in this endeavor, can differ greatly depending upon the child's age, the nature of a delay, and the family's social and economic characteristics (Council on Children with Disabilities, 2005). There need to be improvements community-wide to support collaboration between families, healthcare providers, education providers, public health entities, social workers, and community groups to ensure that all children receive adequate support, regardless of who is engaged in their care. There must be "no wrong door" into the ecosystem of support services.

The care of chronic conditions regularly extends far outside the walls of a clinic or hospital, and requires a solution that integrates many resources from professionals who have not traditionally collaborated to address health issues (R. J. King et al., 2016). The various people involved in identifying or addressing a childhood developmental disability struggle to maintain the regular, bidirectional communication that is needed to formulate, attenuate, and follow a care

plan. Information technology has been touted as a powerful tool to support communication across organizational or even national boundaries. Unfortunately, current HIT tends to exist primarily for the use of healthcare providers and related administrative staff. Even within the healthcare field, interorganizational communication tools such as health information exchanges are underutilized (Hersh et al., 2015). The use of HIT to facilitate communication between healthcare entities and other professional fields has received even less attention. The field of biomedical informatics has made only rudimentary steps into the interprofessional space that exists between healthcare entities and the rest of the community. The purpose of this research was to utilize UCD methods to explore and describe the complex, interprofessional space of child development services to guide the design of future collaborative HIT systems.

7.2 CONTRIBUTIONS

This research contributes to the current biomedical informatics literature by answering the three research questions posed at the beginning of this dissertation. To answer the question of how existing literature can be leveraged to design collaborative HIT systems (RQ1), Aim 1 demonstrated that using concepts from the literature during a deductive qualitative analysis of empirical end-user data leads to the creation of concrete design implications. This is a methodological contribution to the biomedical informatics literature, and the analysis method can be applied to collaborative domains across healthcare, such as the care of homebound older adults, or providing chronic disease care in the community for adults with metabolic disease.

The research in Aims 2 and 3 provided answers to the second research question (RQ2) of what unique considerations exist for the design of a collaborative HIT system to support the ecosystem of child development stakeholders. Using the method described in Aim 1, these aims

discovered many implications for the design of collaborative systems by focusing on considerations of workflow and trust, such as the need for care team management functions, and how trust can affect the sharing of information. These empirical contributions provide guidance for the design of future systems to support collaboration amongst child development stakeholders using HIT.

The research in Aim 4 addresses the third research question (RQ3), related to how design implications can lead to system designs. This research drew upon design implications from the previous aims to create design artifacts in the form of user prototype webpages intended to support the creation of trust. These prototypes were successfully tested with end users, and results indicate that the prototypes fulfilled their intended purpose to support trust. This empirical contribution indicates that a system user interface can be leveraged to support trust, which is an approach that can be used across care settings. Throughout this research, the successful iteration of a UCD cycle, from research to discover user needs through the testing of prototypes, validates the effectiveness of a design approach leveraging concepts from the literature.

7.3 IMPORTANT EMPIRICAL FINDINGS

Overall, results indicate significant overlap in the work done by different stakeholders, especially during activities related to surveillance, the use of screening tests, and referrals between services. This suggests that certain functions should be available to all involved stakeholders. However, there are also important differences between roles as well. Parents hold responsibilities for completing referrals and filling out intake paperwork, such as signing ROI forms. PCPs are responsible for filling out prescriptions required by insurance for reimbursement purposes. Specialized medical and community service providers are responsible for assessing a child's

eligibility for services and performing diagnostic tests. Differences in responsibilities need to be recognized by system designers to ensure that the appropriate stakeholders handle appropriate documentation and communication responsibilities.

Multiple research studies in this dissertation highlighted the current poor state of communication across all child development support activities. Service providers relied on information from other service providers to help identify developmental delays, perform assessments, and create effective care plans. Communications in these endeavors, unfortunately, were inconsistent. Stakeholders relied on different modes of communication, and communications tended to consist of a one-time sharing of reports. Having a shared data storage and communication system would greatly benefit communication across the spectrum of child development support services, supporting the timely and efficient exchange of information. Such a system would be especially important in the field of child development, where care transitions are common and support activities are fluid and interrelated.

Results indicate that functions are needed to define and manage a child's care team. Many service providers were unaware of who is even involved in a child's care, indicating a lack of familiarity across team members. Providing information about team members would support effective communication, as different professionals had differing goals, information needs, and expertise. Furthermore, providing information about team members that speak to their competence, benevolence, and integrity could support the creation of trust between disparate professionals, thus supporting effective communication. Increasing the number of interactions between providers could lead to an environment of trust where an increased amount of information is shared, and where shared information is effectively used.

Contextual factors such as laws and policies hold significant implications for the use of new technologies to share child development information across different professions. Policies dictated by state and local governments, as well as national lead organizations for community service programs, can mandate the use of specific tools and technologies. Many service providers current have electronic systems that they use to document child development information, and some even juggle double-documentation into multiple systems. To support these service providers, interfaces between existing systems are required. However, stakeholders such as parents and many childcare providers may not currently use any electronic documentation systems, meaning that they will require data entry functions to a centralized system.

Healthcare providers and public schools are governed by the federal HIPAA and FERPA laws, respectively, that determine how they can share their records. These are two important stakeholders in the child development space, so any shared data system will need to consider the mandates of both laws. Laws governing the services provided by EI services and public school systems mandate the use of IFSPs and IEPs, indicating that a shared data system must have functions that comply with those documentation tools. A child's developmental care also figures heavily into the work done by CPS, indicating a need to consider the implications of social worker involvement. The contexts within which work is performed across professional bounds provides unique challenges to designers of interprofessional systems.

7.4 LIMITATIONS

Despite striving to recruit a diverse sample of the population for this research, study participants may not be representative of the general population. Participants interviewed for the analyses in

Chapters 3 and 4 tended to be financially secure, and participants in all studies tended to be white. This potentially omits the perspectives of a more ethnically and racially diverse sample. It is also possible that the mix of participants who agreed to partake in an interview or survey might have been affected by self-selection bias based on the reported topic of research. For example, most of the parent participants in the interviews analyzed in Chapters 3 and 4 were familiar with the concept of child development and interested in exploring the topic, so the perspectives of parents with limited experience with development were under-explored. In Chapter 6, only one participant reported using the internet less than “several times a day.” Overall, the research may have omitted people with little knowledge about child development and technical literacy. Participants may therefore have a much more positive view of using HIT to communicate with child development service providers than the general population.

All studies used qualitative methods to assess user needs, with three relying on interview data. While this yielded rich data for analysis, the use of multiple methods to triangulate results could both improve validity and potentially lead to further insights (Patton, 1999). The use of observational methods would decrease the potential for recall bias that can occur when an interview subject is remembering past events. Unfortunately, the unscheduled and private nature of service provided in the home and the difficulties inherent in gaining permission to observe work within multiple organizations made observations impractical for this research. Methods such as member checking are also regularly used to validate syntheses of qualitative findings. However, member checking may introduce its own threats to the validity of research results (Birt, Scott, Cavers, Campbell, & Walter, 2016; Sandelowski, 1993). An attenuated member-checking method, such as synthesized member checking suggested by Birt et al. (2016), may provide guidance to synthesizing member-checking feedback without causing unintended harm

to participants. However, it may add significant burden for both researchers and participants when interviews are long and subsequently analyzed using multiple lenses based on concepts from the literature.

While the researchers involved in this work aimed to describe the variability within the field of child developmental services, the magnitude of differences between participating organizations was difficult to portray in a visual format. When mapping workflows with many different paths, some of which conflict, decisions must be made by the research team as to whether and how to portray this variability. The results presented in Chapter 4 presented a high-level view of sequenced activities with an eye to presenting a flow that would have relevancy to all potential stakeholders. However, this omits specific tasks and details, such as explicit data storage and exchange requirements, that would need to be considered in a system design. More work is needed to define what pieces of information need to be considered within each activity, and what is needed to fulfill the business needs and goals of each separate organization. The research team was also unable to engage all potential stakeholder groups who perform developmental support work, such as community health workers, church groups, extended relatives, or services supporting foster and adoptive parents. Such groups should also be considered in a collaborative system design as distinct stakeholders. Also, the services that are available to support development, and how they are managed, will vary between legal jurisdictions. For example, the parent help hotline call center that was engaged in this research does not operate in all 50 states within the US (Help Me Grow National Center, 2018). The services considered in this research are also specific to the United States. This limits the generalizability of the results outside of Washington State and the US, though the methods utilized to understand a collaborative environment will be relevant regardless of care location.

In the final study described in Chapter 6, the researchers faced difficulties in recruiting an appropriate sample of healthcare providers through MTurk. While the population of MTurk workers may be demographically similar to the US population overall (Paolacci et al., 2010), this does not guarantee a demographically similar sample within a specific study. MTurk was also an inefficient means for collecting data from a population of people working in a specific profession. A significant proportion of people with the “qualification” for healthcare worker did not provide clinical care, and a majority of healthcare providers found through recruitment were nurses or various medical assistants or technicians. The relatively low percentage of medical doctors who participated in this research might have limited the perspectives of professionals who underwent full physician training. Future work should use a more targeted approach to recruiting specific types of medical providers.

7.5 FUTURE WORK

The study presented in Chapter 3 describes a method for leveraging the literature on collaboration to understand a collaborative interprofessional environment. The current research, however, only considered two important concepts in detail: workflow and trust. Future work is needed to understand how other important factors such as role definitions and power dynamics affect collaborative work. The review of the literature presented in **Appendix A** provides a starting point for synthesizing a more complete model of collaboration for use in future research. However, this collection of literature overall presents many overlapping and tightly related concepts that will need to be reconciled to create and adequately describe such a model.

More work is needed to determine how to incorporate HIT research results related to interprofessional collaboration across health domains and patient populations. Generalizability is

difficult when considering interprofessional collaboration due to the variability in collaborative arrangements and practices. To create generally effective collaborative HIT, designers must not treat collaboration itself as a monolithic structure or a single organizational form, but as a highly fluid and variable construct that can be radically different depending on the facets of the people and organizations involved (Lemieux-Charles & McGuire, 2006; Nylén, 2007). Recent reviews of interventions that use HIT to support collaborative work note significant heterogeneity in the features of the interventions considered and the practice settings they inhabit (Körner et al., 2016; S. M. Smith et al., 2017), indicating that one HIT system may not be able to support all collaborative arrangements. Instead, a body of different features that are deployed in different situations is needed. To support this conceptualization, more work is needed to adequately describe the structure of collaborations themselves to determine their similarities and differences. Identifying similarities may help to understand what types of HIT system features can be transferred to different collaborative care settings. For example, a care setting such as child development has stakeholder groups with high turnover and, as such, may require more flexible care team management functions than collaborations with relatively stable work teams.

Current literature provides several potential classification systems for collaborative work. Collaborations can have many different arrangements and defining characteristics such as the physical distribution, number of different professions involved, functional differentiation between professions and roles, the formalization and authority of collaborative mechanisms, and the frequency of communication (Axelsson & Axelsson, 2006; C. P. Lee & Paine, 2015; Nylén, 2007; Retchin, 2008). Retchin (2008) created a model for collective healthcare that defines collaboration based on three constructs: temporality, urgency, and structured authority. Hack (1997) defined different paradigms of care of CSHCN based around the role of their PCP: either

as main manager, as a gatekeeper to other care, or as a co-manager under the direction of a specialist. Axelsson and Axelsson (2006) noted different motivations for integration, such as top-down management hierarchies or contractual relations that lead to tightly integrated structures, and loosely integrated structures working in a “network mode” based on voluntary cooperation. Collaborative work could also be defined in terms of how separate professionals interact to solve problems. Research has defined different types of interactions used to create solutions, such as “pooled,” where everyone contributes separate pieces of work, “sequential,” where everyone has to work in order, and “reciprocal interdependence,” where information is exchanged back and forth (Chi & Holsapple, 2005; Nylén, 2007).

The Model of Coordinated Action (MoCA) defines seven dimensions that could be used to characterize coordinated action: synchronicity, physical distribution, scale, number of communities of practice, nascence, planned permanence, and turnover (C. P. Lee & Paine, 2015). Defining a collaborative endeavor in these terms may help to identify where certain HIT functions are needed. **Table 13** lists the dimensions of the MoCA (C. P. Lee & Paine, 2015), the range of values, and descriptions of how these values are expressed in the child development space. This demonstrates the potential utility of a classification system, but also the complexity of using such a system in the child development space where families follow many different paths to seek care. When many organizations are potentially involved in a collaborative endeavor, factors such as the synchronicity of communication could take on multiple values. Taken as a whole, the collaborative care of a child can require a mix of services that can encompass different values for each dimension. An approach to design using such a classification system might require the identification and characterization of the most complex cases, with consideration given to making a system configurable or amenable to less complex

cases. As more design research ties characteristics of collaborations to the HIT features that work in each case, researchers and designers can build a body of work that can be summarized by these factors to determine what is most effective.

Table 13. The dimensions of the MoCA and how they are expressed in the domain of child development work.

Dimension	Value Range	Rationale
Synchronicity	Synchronous to Asynchronous	Communications related to referrals tend to be asynchronous, whereas communications related to surveillance, screening, assessment, services, and care management can have both synchronous and asynchronous features. Synchronous communications may involve more than two people simultaneously.
Physical Distribution	Same or Different Locations	Services are generally provided in separate locations. However, certain services such as Head Start, Early Head Start, and Early Intervention may be provided by the same organization.
Scale	One to Many	In the smallest case, the parent will be involved in development. On the high end, respondents reported involving up to five other service providers simultaneously.
Number of Communities of Practice	One to Many	In the smallest case, only a parent will be involved. In a complicated case, healthcare providers, schools, social workers, therapists, public health practitioners, and community groups may be involved.
Nascence	New to Established	In a few cases, providers have defined their own referral pipelines to services that are used over time. Service providers are also regularly presented with new and unknown services as well.

Dimension	Value Range	Rationale
Planned Permanence	Short-term to Long-term	A parent's involvement with development services is generally time-limited based on the child's age. Many service providers also will only collaborate with another service provider on a limited basis to support a specific child. However, some organizations will have more permanent arrangements and referral pipelines with familiar providers.
Turnover	Low to high	Stakeholders such as parents experience low turnover. All service providers will experience high turnover due to changes in service location, the child's age, the child's functional abilities, the family's insurance coverage and stability of the home, and regular employee turnover.

A significant barrier to supporting interprofessional care between professional fields is the lack of exploration of data standards that cross professional boundaries. The findings of Chapter 4 indicate that many service providers would not adopt a new piece of software for entering data since many would not be able to abandon old systems for policy, legal, or funding reasons. While the biomedical informatics field has established many data exchange standards from organizations such as HL7 and Integrating the Healthcare Enterprise (IHE), the interfacing capabilities of systems such as education systems has not been explored in a biomedical informatics context. In the child development space, standards have been created to support the exchange of child developmental screening information (HL7 International, 2017), but work is needed to explore the potential adoption of these standards by other fields, the attenuation of biomedical informatics standards to accommodate standards in other fields, or possibly the generation of new standards. Work across professional fields to support not just the syntactic nature of interoperability around data structures, but the semantic interoperability around

meaning (Ouksel & Sheth, 1999), may prove difficult when collaborators have significantly different educations and professional traditions. Future work needs to engage researchers and practitioners from fields such as education and social work to explore this issue further.

Lastly, more work is needed to create and test prototypes based on the results of this body of research to gain a deeper understanding how collaboration concepts such as “trust” operate in real-world settings. Recent research explores system functions similar to those indicated in this dissertation, for example the CareNexus system to support care team management (Ranade-Kharkar, Norlin, & Del Fiol, 2017) or the BeBeCode system, which resolves disagreement in the observations of child development milestones (S. Song et al., 2018). Future work should explore how functions such as these can be integrated with clinical documentation systems to create a unified system to support child development. Due to the complexity of interprofessional collaboration, including within child development services, explorations in the field of implementation science are needed to determine the best methods for engaging heterogeneous stakeholders in an HIT implementation. In addition, the ongoing maintenance of a collaborative HIT system through time should also be explored.

7.6 CONCLUDING REMARKS

To support the care of children with chronic developmental delays, the field of biomedical informatics needs to explore beyond the biomedical box. This requires a more substantial consideration of relevant work undertaken by professionals who are not trained in the field of medicine. In the ecosystem of child development support services, providers from the medical field may only play a marginal role in a child’s developmental care. Interprofessional connections between healthcare providers and others in the community are vital to supporting

child development. Unfortunately, such work is underexplored in the biomedical informatics field due to its complexity. Interprofessional collaboration requires considerations of the different resources, training, practice paradigms, and policies that will affect what is possible and needed to support collaborative care.

This research has demonstrated that academic literature on collaboration provides designers of HIT systems with important guidance to tackle this complexity and formulate concrete solutions. Many of the intricacies inherent in collaborative interprofessional work have been defined by models and concepts across multiple academic traditions. Considerations of factors that affect collaborative practice such as workflow and trust can help define a collaborative space and therefore the functions of an HIT system to support collaboration. This research successfully demonstrates and validates a useful approach to leveraging this literature in the design of collaborative HIT systems. The results of this research also contribute to a deeper understanding of how collaboration unfolds between child development supports stakeholders, and what implications this collaborative work has for HIT system design. Future researchers and system designers should utilize the methods and results from this research to create new systems to support collaborative practice throughout the healthcare system. The task is daunting, but the field of biomedical informatics has the tools to ensure that children and other patients with complex needs are given the care and attention they need to thrive.

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APPENDIX A: FACTORS THAT AFFECT COLLABORATIVE PRACTICE FROM THE LITERATURE

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(Mikles, Suh, et al., 2018).

Manuscript	Discipline	Purpose	Constructs
Axelsson and Axelsson (2006)	Public Health	Defining a framework for inter-organizational integration and collaboration in public health and related welfare services	• <u>Different Forms of Integration (with differing levels of horizontal and vertical integration):</u> Co-ordination, co-operation, contracting, collaboration • <u>Factors Affecting the Extent of Inter-Organizational Collaboration:</u> Functional/structural differentiation, fragmentation of responsibility, different sectors involved, need for integration, willingness to collaborate • <u>Management of Collaboration:</u> Facilitate contacts and communication between team members, managing conflict, trust management, facilitation of work/contacts

Manuscript	Discipline	Purpose	Constructs
Bookey-Bassett et al (2017)	Nursing	Concept analysis of interprofessional collaboration among providers delivering chronic disease management to community-living older adults	• <u>Antecedents</u>: Role awareness, interprofessional education, trusting relationships, belief that interprofessional collaboration improves care, organizational support • <u>Attributes</u>: Evolving process, shared goals, shared decision-making and care planning, interdependence, effective and frequent communication, evaluation of processes, engaging patients and caregivers as team members, diverse and flexible team membership • <u>Consequences</u>: Redefining team composition and function, knowledge and confidence about patients, comprehensive care planning and service coordination, professional satisfaction, reorganization of workflows
Bronstein (2003)	Social Work	Create a model of interdisciplinary practice	• <u>Components of interdisciplinary collaboration</u>: interdependence, newly created professional activities, flexibility, collective ownership of goals, reflection on process • <u>Influences on Interdisciplinary Collaboration</u>: Professional role, structural characteristics, personal characteristics, history of collaboration

Manuscript	Discipline	Purpose	Constructs
Brown, Dennis, and Venkatesh (2010)	Management, Information Technology	Explain the adoption and use of collaboration technology	• <u>Technology Characteristics</u>: social presence, immediacy, concurrency; • <u>Individual and Group Characteristics</u>: Collaboration technology experience, computer self-efficacy, familiarity with others; • <u>Task Characteristics</u>: idea generation, decision-making, others; • <u>Situational Characteristics - Coworkers</u>: Peer influence, superior influence; • <u>Situational Characteristics - Environment</u>: Resource-facilitating conditions, technology-facilitating characteristics
Bryson, Crosby, and Stone (2006)	Public Administration	Defining factors affecting the formation and functioning of cross-sector collaborations	• <u>Initial Conditions of Formation</u>: General environment (turbulence, competitive and institutional elements), sector failure, direct antecedents (conveners, general agreement on problem, existing relationships or networks); • <u>Process</u>: Forging agreements, building leadership, building legitimacy, building trust, managing conflict, planning; • <u>Structure and Governance</u>: Formal and information (membership, structural configuration, governance structure); • <u>Contingencies and Constraints</u>: Type of collaboration, power imbalances, competing institutional logics; • <u>Outcomes and Accountabilities</u>: Outcomes (first-, second-, and third-order effects, resilience and reassessment), accountabilities (inputs, processes, and outputs, results management system, relationships with political and professional constituencies)

Manuscript	Discipline	Purpose	Constructs
Chi and Holsapple (2005)	Information Systems	Develop a process model of interorganizational systems (IOS) collaboration, and a framework for understanding and classifying IOS technologies	• <u>Motives to Use</u>: Necessity, asymmetry, reciprocity, efficiency, agility, innovation, stability, legitimacy; • <u>Relational Bonding</u>: Trust, commitment; • <u>Behavioral processes</u>: Knowledge sharing, shared decision making, conflict governance • <u>Collaborative Advantage</u>: Productivity, agility, innovation, reputation; Types of Interdependency: pooled, sequential, reciprocal
Chase et al (2014)	Biomedical Informatics	Examine how the EHR and related systems support or inhibit provider collaboration	• <u>Collaboration Roles for EHR</u>: Repository, messenger, orchestrator, monitor • <u>Collaboration Behaviors</u>: trust and respect (willingness to rely on work of others), communication (information flow, contextual background, understanding), coordination (managing and timing order of activities), adaptive collaboration (changing actual work content, tailoring solutions)
D'Amour et al (2005)	Interprofessional Care	Identify conceptual frameworks that can improve understanding of interprofessional collaboration in health organizations	• <u>Concepts of Collaboration</u>: sharing, partnerships, power, interdependence, process • <u>Key elements of Collaboration</u>: construction of collective action to address complexity of client needs, construction of team life that integrates perspectives of each professional and in which team members respect and trust each other
D'Amour et al (2008)	Health Services	To validate a structural model of collaboration and propose a typology of collaboration	• <u>Governance</u>: Centrality, leadership, support for innovation, connectivity • <u>Shared Goals and Vision</u>: goals, client-centered orientation vs. other allegiances • <u>Formalization</u>: Formalization tools, information exchange; Internalization: Mutual acquaintanceship, trust

Manuscript	Discipline	Purpose	Constructs
Daley (2008)	Public Administration	Examining factors promoting or inhibiting working relationships between environmental agencies and health departments in WI	• Problem agreement • Collaborative experience • Trust • Top leadership • Performance evaluation • Professional experience
Darlington, Feeney, and Rixon (2005)	Social Work	Examining factors that facilitate and hinder interagency collaboration between social services and mental health	• <u>Attitudes toward collaborators:</u> Mutual mistrust, positive regard, adequacy of training • <u>Potential Barriers:</u> Gaps in interagency processes, inadequate resources, professional knowledge domains and boundaries, unrealistic expectations, confidentiality
Darlington and Feeney (2008)	Social Work	Best practices for improving interagency collaboration when supporting children of parents with mental illness	• <u>Communication - Organizational Level Strategies:</u> Practice guidelines and formal protocols, clarity of roles between services, clarity of confidentiality requirements, joint-agency meetings, key interagency liaison • <u>Communication - Case Level Strategies:</u> Joint case plan and management, joint case conferences, sharing information • <u>Interprofessional relationships</u> • <u>Professional Knowledge and Skills - Staff Training:</u> Joint agency training, supervision and support for staff • <u>Professional Knowledge and Skills - types of knowledge required:</u> Procedural knowledge, substantive knowledge • <u>Resources</u>

Manuscript	Discipline	Purpose	Constructs
Dorr, Jones, and Wilcox (2007)	Biomedical Informatics	Develop a framework to determine which clinical information system functions are useful in collaborative care	• Various functions for providing information access, supporting best practices, and facilitating communication based on the HL7 EHR-S functional model
Eikey, Reddy, and Kuziemy (2015)	Biomedical Informatics	Defining a model of concepts related to collaboration with respect to HIT	• <u>Technology</u>: Patient/provider, functionality • <u>Context</u>: Settings, user groups, modality • <u>Outcomes</u>: maintaining awareness, establishing common ground • <u>Processes</u>: workflow, communication, information exchange
Fewster-Thuente and Velsor-Friedrich (2008)	Nursing	Examine factors that may influence interdisciplinary collaboration	• <u>Barriers</u>: Patriarchal relationships, time, gender, culture, lack of role clarification
Gaboury et al (2009)	Medicine, Interprofessional Care	Exploring how interdisciplinary collaboration is experienced by medical doctors and complementary and alternative medicine practitioners	• <u>Individual Factors</u>: Awareness of one's own clinical paradigm, education/training • <u>External Factors</u>: lack of reimbursement for collaboration, regulations inhibiting integrative healthcare practice • <u>Processes</u>: communication (mode and frequency), terminology barriers, patients' referral, power relationships

Manuscript	Discipline	Purpose	Constructs
Gocan, Laplante, and Woodend (2014)	Healthcare, Interprofessional Practice	Defining factors that influence the quality of team collaboration in Family Health Teams in Ontario	• <u>Healthcare System Determinants:</u> Adequate funding, adequate remuneration, adequate human resources, degree of professional preparation for collaborative practice • <u>Local Context Determinants:</u> EHR integration, facilitating partnerships • <u>Team determinants:</u> Clarity of vision, group culture, flattened hierarchy, effective leadership, clearly defined and understood roles and scope of practice, patient-centered approach to care, patient education regarding their role, systems and processes to ensure that the right patient is seen by the right professional, communication strategies, shared time and space
Horsky, Morgan, and Ramelson (2014)	Biomedical Informatics	Examining how technology was used to coordinate chronic care management	• <u>Activities to support care coordination:</u> Aggregation, abstraction, interpretation, visit planning, situational awareness, care planning, medications and problems reconciliation
Karunakaran, Reddy, Spence (2013)	Management, Information Technology	Creating a model of collaborative information behavior in organizations, or the collaborative aspects of seeking, retrieving, and using information	• <u>Phase 1:</u> problem formulation (shared representation, shared understanding) • <u>Phase 2:</u> collaborative information seeking (retrieving, sharing, searching) • <u>Phase 3:</u> information use (synthesis, assessing unmet needs)

Manuscript	Discipline	Purpose	Constructs
Körner et al (2016)	Medicine, Interprofessional Care	Identify key features of teamwork and interventions to enhance interprofessional teamwork in chronic care	• <u>Teamwork Inputs</u>: team model (multi-, inter-, or transdisciplinary), team member characteristics (skills, knowledge, personality, attitudes, commitment), team characteristics (team composition, heterogeneity), structure of communication, leadership, organizational structures (policies, guidelines, workplace), team culture • <u>Teamwork Process</u>: Common goal/task, communication, cooperation, coordination, shared decision-making, knowledge integration, responsibility, conflict management, cohesion, mutual trust, role understanding and clarity, working climate
Kuziemy and Peyton (2016)	Biomedical Informatics	Creating a framework for process interoperability for HIT	• <u>Patient care processes</u>: Support continuity of care, remotely monitor patients in the community, support patient-centered pain and symptom management • <u>Clinical care processes</u>: Support patient encounters/assessments, integration with clinical workflow, support team based care delivery • <u>Administrative process interoperability</u>: Tracking educational activities including resident training, capture real-time critical events for audit, provide data to support analytics and decision-making

Manuscript	Discipline	Purpose	Constructs
Lee et al (2012)	Administration, Mental Health	Defining the process involved in inter-agency collaboration to provider services to families with severely emotionally or behaviorally disturbed children	• <u>Making Initial Contact</u>: Self, professionals • <u>Relational and Communication Aspects</u>: Follow-through, responsive, professional, explicit about role and expectation • <u>Treatment-Related</u>: Effective, involved and knowledgeable, being an advocate for clients, realistic treatment, focus on real and not superficial change • <u>Collaboration</u>: Working together, relationship building, making referrals
Lasker, Weiss, and Miller (2001)	Health Services	Defines synergy as a desirable outcome of collaboration, and creates a framework to assess partnership synergy and identifying its determinants	• <u>Determinants of Partnership Synergy</u>: Resources (money, space, equipment, goods, skills and expertise, information, connections, endorsements, convening power), partner characteristics (heterogeneity, level of involvement), relationships among partners (trust, respect, conflict, power differentials), partnership characteristics (leadership, administration and management, governance, efficiency), external environment (community characteristics, public and organizational policies)

Manuscript	Discipline	Purpose	Constructs
Légaré et al (2011)	Primary Care, Interprofessional Practice	Create an interprofessional model of shared decision making	• <u>Individual Level SDM Process:</u> Decision point situation, exchange of information, clarification of values/preferences, feasibility of the options, preferred choice, actual choice, implementation, health outcomes • <u>Interprofessional Team Members:</u> Professions (physician, nurse, pharmacist, specialist, librarians, clerks), team roles (first contact person, decision coach, family members, healthcare professionals) • <u>Environmental factors:</u> Policies, values, rules, culture, resources, social context, federal or regional governments or health authorities, professional organizations, healthcare organizations

Manuscript	Discipline	Purpose	Constructs
Lemieux-Charles and McGuire (2006)	Medicine	Define factors related to the effectiveness of healthcare teams	• <u>Task Design</u>: Type (management, project, care delivery), features (interdependence, autonomy, specialized knowledge/expertise, clarity of rules and procedures, work cycle, use of quality frameworks/guidelines), team composition (size, age, gender, tenure, discipline, diversity) • <u>Team Processes</u>: Communication, collaboration, conflict, leadership, decision-making, participation • <u>Team Psycho-Social Traits</u>: Cohesion, norms, efficacy, problem-solving effectiveness • <u>Team Effectiveness</u>: Objective outcomes (patient, team, organization), subjective outcomes (perceived team effectiveness by team members) • <u>Organizational Context</u>: Goals/standards, structures/characteristics, rewards/supervision, resources (human, technological), training environment, information system • <u>Social and Policy Context</u>
McDonald et al (2011)	Primary Care, Interprofessional Practice	Exploring the influence of organizational factors on collaboration between private and public sector community health services involved in diabetes care	• <u>Collaborators</u>: Public, private, non-government sector • <u>Supports</u>: referral processes, financial incentives, information and education, planning mechanisms; • <u>Benefits</u>: achieving health and/or organization related goals • <u>Costs</u>: differences in organizational size, structure, complexity, and cultures

Manuscript	Discipline	Purpose	Constructs
Modin et al (2009)	Primary Care	Increase knowledge concerning family physicians' experiences in managing care for older adult patients with district nurses	• <u>Gaining Sufficient Insight</u>: Relying on information from nurse and others • <u>Making Adequate Decisions</u>: Close observation and follow-up by the nurse and others, being constantly ready to change the goals of treatment • <u>Maintaining Appropriate Treatment</u>: Relying on nurse and others to provide treatment
Modin et al (2010)	Primary Care	Create a model to illuminate the process by which family physicians collaborate with district nurses	• <u>Factors influencing decision of physician to be the conductor of medical treatment or take a consulting role</u>: working conditions, attitude toward collaboration, the type of disease
Morgan, Pullon, McKinley (2015)	Primary Care	Identify essential elements of effective interprofessional collaboration in primary care settings	• <u>'Top Down' Organizational Factors</u>: Practice policy and structure, organizationally endorsed formal processes, collaborative management and leadership, opportunities for informal communication (space and time, shared communication methods) • <u>'Bottom Up' Intrinsic Factors</u>: Informal communication, shared knowledge creation, shared clinical decision making

Manuscript	Discipline	Purpose	Constructs
Mulvale, Embrett, Razavi (2016)	Primary Care	Identifying factors that influence collaboration in interprofessional primary care teams from studies that demonstrate associations between factors and collaborative processes	• <u>Macro Policy</u>: Governance • <u>Meso Policy</u>: Information systems, organizational culture • <u>Micro Team Structure</u>: Champions/facilitators, team size; • <u>Micro Social Processes</u>: Levels of conflict, open communications, supportive colleagues • <u>Micro Formal Processes</u>: Team vision/goals, quality/audit process, recognition, group problem-solving, team meetings, decision-making processes • <u>Micro Team Attitudes</u>: feeling part of a team, support for innovation • <u>Individual Factors</u>: belief in interprofessional care, flexibility
Nylén (2007)	Public Administration	Investigating the consequences of different collaborative arrangements of human services in Sweden	• <u>Collaboration Arrangement Dimensions</u>: project, formalization, intensity
Ødegård (2006)	Mental Health, Integrated Care	Proposing a theoretical model to measure mental health and school professionals; perceptions of interprofessional collaboration	• <u>Organizational Factors</u>: Domain, culture, goals, environment • <u>Group Factors</u>: Communication, social support, leadership, coping • <u>Individual Factors</u>: Motivation, role expectancy, personality style, professional power

Manuscript	Discipline	Purpose	Constructs
Patel, Pettitt, and Wilson (2012)	Ergonomics	Create unified understanding of the component factors of collaboration, defined by the literature and case studies in the aerospace, automotive, and construction industries	• <u>Context</u>: Culture, environment, business climate, organizational • <u>Support</u>: Tools, networks, resources, training, team building, knowledge management, error management • <u>Tasks</u>: Type, structure, demands; Interaction: Learning, coordination, communication, decision making • <u>Teams</u>: Roles, relationships, shared awareness/knowledge, common ground, group processes, composition • <u>Individuals</u>: Skills, psychological factors, well being • <u>Overarching Factors</u>: Trust, conflict, experience, goals, incentives, constraints, management, performance, time
Petri (2010)	Nursing	Explore the meaning of interdisciplinary collaboration within the context of healthcare	• <u>Attributes of Collaboration</u>: Problem-focused process, sharing, working together • <u>Antecedents</u>: Interprofessional education, role awareness, interpersonal relationship skills, deliberate action, support • <u>Consequences</u>: patient, organizational, healthcare professional
Retchin (2008)	Medicine, Interprofessional Care	Present a conceptual framework to describe different models of interprofessional and co-managed care	• <u>Framework for Interprofessional Care</u>: Temporality (time frame, episode of care), urgency (intensity of care, degree of necessity for rapid decision-making), structured authority (delineation of leadership, final authority in decision-making)

Manuscript	Discipline	Purpose	Constructs
Roussos and Fawcett (2000)	Public Health	Define conditions and factors that may determine whether collaborative partnerships are effective for community health	• <u>Factors Affecting Rates of Community and Systems Change</u>: Having a clear vision and mission, action planning, developing and supporting leadership, documentation and ongoing feedback, technical assistance and support, financial resources, making outcomes matter • <u>Broader Contributors to the Effectiveness of Partnerships for Community Health</u>: Social and economic factors, social capital, context of partnership, community control in agenda setting
San Rodriguez-Martin et al (2005)	Healthcare, Interprofessional Practice	Compilation of determinants of successful collaborations	• <u>Systemic Determinants</u>: Social systems, cultural system, professional system, educational system • <u>Organizational Determinants</u>: Organizational structure, organization's philosophy, administrative support, resources, coordinating mechanisms • <u>Interactional Determinants</u>: Willingness to collaborate, trust, communication, mutual respect

Manuscript	Discipline	Purpose	Constructs
Schmied et al (2010)	Nursing, Integrated Services	Reviewing models of integrated services to explore their impact on services for pregnant women, children, and families	• <u>Approaches to Ensure Continuity of Care</u>: Shared care between different health professionals, use of liaisons between different professionals, multidisciplinary teams, care coordination, co-location of related services; • <u>Key Elements of Successful Collaboration</u>: shared vision and values, agreement on common goals and aims, inspirational and energetic research, enthusiasm and commitment of collaborators, sound governance, recognizing and valuing diverse professional contributions, addressing issues of power, willingness to share risks and rewards, mechanisms to deal with conflict, recognition of all contributions, public recognition of worth, evaluations to assess effectiveness, frequent and effective communication, time and resources to build relationships, mechanisms to facilitate sharing of information and administrative data, understanding characteristics of participants' practice (philosophy, culture, ideas, beliefs)

Manuscript	Discipline	Purpose	Constructs
Sloper (2004)	Public Administration	Collecting facilitators and barriers to coordinated multi-agency work in children's services	• <u>Models of Multi-Agency Working:</u> Strategic level working, consultation and training, placement schemes, center-based service delivery, coordinated service delivery, multidisciplinary and multi-agency teams, case or care management • <u>Facilitators to Multi-Agency Working:</u> Clear and realistic aims that are accepted by all agencies, clearly defined roles and responsibilities, commitment of both management and frontline staff, strong leadership and a multi-agency management group, linking projects with other planning and decision making processes, ensuring good systems of communication at all levels • <u>Requirement for the Management of Services:</u> Shared and adequate resources, recruitment of staff with the right experience and knowledge, joint training and team building, appropriate supports and supervision staff, monitoring and evaluation of services • <u>Barriers to Multi-Agency Working:</u> Constant reorganization, frequent staff turnover, lack of qualified staff, financial uncertainty, different professional ideologies and agency cultures
Supper et al (2015)	Public Health	Identifying facilitators and barriers to interprofessional collaboration as perceived by actors other than nurses	• <u>Facilitators:</u> Common interest in collaboration, perceived opportunities to improve quality of care and develop new roles • <u>Barriers:</u> Definition and awareness of each others' roles and competencies, shared information, confidentiality and responsibility, team building and interprofessional training, long-term funding and joint monitoring

Manuscript	Discipline	Purpose	Constructs
Suter et al (2009)	Healthcare, Interprofessional Care	Understanding the competencies for collaborative practice as considered most relevant by health professionals	• Role understanding and appreciation of other roles • Communication
Syväjärvi et al (2005)	Management, Information Technology	Understanding the impact of information and communication technology on individual capacity, collective interprofessional practice, and management	• <u>Structural Dimension</u>: Distribution of tasks, cooperation, resources and their use, management of work • <u>Cognitive Dimension</u>: Professional identity, technology and its meaning, making changes • <u>Dimension of Human Capacity</u>: professional skills, technology skills, customer service, resources in work management • <u>Dimensions of Interaction</u>: social codes, trust, reciprocity
Thomson, Perry, and Miller (2007)	Public Administration	Conceptualizing and creating a measure for collaboration	• Governance • Administration • Organizational Autonomy • Mutuality • Norms
Varda, Shoup, and Miller (2012)	Public Health, Public Administration	Explore how the literature in public affairs research can inform public health practice on collaboration and partnerships	• <u>Primary Themes From Public Administration Literature</u>: Network Structure, Management Strategies, Outcomes of Collaboration • <u>Other Themes</u>: Trust, social determinants, accountability, setting a research agenda, capacity, motivation, incentives, public/private partnerships, knowledge management/continuity of information, collective decision-making/problem-solving, constructing measurement, alternative to influence policy

Manuscript	Discipline	Purpose	Constructs
Walter and Petr (2000)	Social Work	Presenting a framework of family-centered interagency collaborations	• Shared values • Resources • Evaluations • Structures • Authority • Responsibilities • Goals/tasks • Rewards • Stakeholder involvement
Xyrichis and Lowton (2007)	Primary Care	Explore the factors that inhibit or facilitate interprofessional teamworking in primary and community care settings	• <u>Team Structure</u>: Premises, size and composition, organizational support • <u>Processes</u>: Team meetings, clear goals and objectives, audit
Xyrichis and Ream (2007)	Healthcare	Analyze the concept of teamwork	• <u>Antecedents</u>: Two or more health professionals, open communication and information sharing, understanding professional roles, common health goals • <u>Attributes</u>: concerted effort, interdependent collaboration, shared decision making

APPENDIX B: MAJOR RESEARCH FINDINGS AND DESIGN IMPLICATIONS CONSIDERING THE COLLABORATION SPACE MODEL

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(Mikles, Suh, et al., 2018).

Construct	Findings	Design Implications
Process	Overlap in processes (screening, surveillance, etc.) across stakeholder groups	Provide access to screening, surveillance, referral, and care management functions to all users
Surveillance	Surveillance data required by stakeholders	Provide information on milestones reached, observations, baby and parent medical history, and subjective feelings
Screening	Needing to transfer screening results from paper forms into EHR; Scanning paper forms	Interface screening results between systems, and capture and transmit structured data elements and numeric results
Screening	Parents sometimes use out of date screening forms	Electronic form data entry that automatically picks right form based on child's age (adjusted for prematurity if necessary)
Screening	Sometimes screens are completed in school without parent involvement	Allow screens to be completed by service providers, and capture the name of the stakeholder entering screening data
Screening	Screening data required by stakeholders	Provide information on the name of screening instrument, numeric screening scores, discrete results
Referral	Inconsistent referral, communication, and appointment creation process	Create database with centralized storage of referral information, accessible by parents, referring provider, and provider referred to

Construct	Findings	Design Implications
Referral	Referring providers not receiving consistent feedback on whether parent completed referral; Reliance on parents to make referrals	Generate alerts and reminders to parents, referring providers, and the provider referred to if referral isn't completed
Referral	All developmental assessments occur outside of doctor's office	Automatically send results of initial assessments to referring provider
Referral	Need to send referrals to multiple school districts; Finding providers that have space in their programs (no wait list)	Ability to send referrals to multiple service sites
Referral	Referral data required by stakeholders	Create configurable referral reports with information relevant to stakeholders: screening test results, medical notes, descriptions of concerns, who the child is being referred to, insurance authorization, date, height, weight, vision, hearing, health summary, care summary, problem lists, medication lists, standardized mandatory forms such as IFSP, and demographics including name and address, date of birth, age, sex, insurance, race and ethnicity, language, and contact preference.
Assessment	Some assessments require input from multiple providers in different locations (i.e. PCPs and teachers assessing ADHD)	Provide shared notes that allow editing/input by multiple providers; Built-in structured documentation for specific delays or disabilities (i.e. ADHD checklist)
Assessment	Children receive multiple assessments during the course of their care for different delays or disabilities	Allow for multiple assessments, organizing assessments by developmental delay or disability

Construct	Findings	Design Implications
Care Management	Parents face difficulties in managing developmental care over time and across multiple providers	Facilitate the sharing of documentation between providers, and between providers and parents; Allow multiple organizational schemes (i.e. chronologically, by provider, by delay or disability)
Care Management	Standardized documents like IFSP and IEP are useful for care management	Allow integration with systems that store IFSPs and IEPs
Care Management	Care coordination requires multiple providers in different locations (i.e. monitoring medication regimen)	Provide shared notes that allow editing/input by multiple providers; Built-in structured documentation for specific care management situations (i.e. medication dose tracker)
Care Management	Care Management data required by stakeholders	Provide information on service provider, time, treatment/activity/results, observations/notes, and data relevant to IEP/IFSP
Developmental Services	Developmental services are provided by parents at home	Parents need the ability to contribute to documentation on developmental care; Need easy and intuitive documentation for busy parents
Developmental Services	Providers educate parents on activities to do at home	Allow providers to document instructions on activities parents can do at home, organized into their own unique category of documentation
Context	There is a wide range of potential users, including administrative staff who do not perform clinical or educational functions	Allow a broad and extensible list of service providers for a child; Need a way to determine who should have access to the system across roles and organizations
Context	Services can be center-based or home-based	Need to have a mobile solution for home-based services; Need ability to document quickly and easily when working with multiple children
Context	Sites affected by HIPAA and FERPA laws	Parental consent features that conform to requirements of HIPAA and FERPA laws

Construct	Findings	Design Implications
Context	Both synchronous and asynchronous communications are used	System features to route reports between recipients and maintain a data archive; Features for ad hoc communication such as messaging
Context	School-based services are tied to school year	Need to provide information on when services are active
Technology	Service providers have existing systems for some functionality; Parents do not have a dedicated electronic system	The system should provide robust functionality for parents and providers who need it, but also allow for interfacing with other systems such as EHRs
Awareness	Service providers rely on information from others; Reliance on parents to communicate	Allow service providers to read notes from other providers as they are published, or a 'subscription' system to automatically receive notes from certain providers
Common Ground	Unfamiliarity with available organizations and services	Providing a registry of nearby organizations and the services they provide
Common Ground	Stakeholders use different assessment and screening tools with different goals and interpretations	Ensure that assessment and screening results include the profession of the evaluator, goal of the assessment, and information on how to interpret results
Common Ground	Parents and service providers report needing more knowledge about child development	Providing links to educational materials aimed at both parents and service providers
Common Ground	Stakeholders reported that various topics require special attention and education	Provide information related to developmental milestones, screening tests and how they are used, calculating gestational and adjusted age, information on special topics like bilingual households, twins, and congenital disorders

APPENDIX C: INTERVIEW GUIDES FOR CHAPTERS FOUR AND FIVE

Interview Scripts

[The interviews scripts below are semi-structured – not all questions were asked of all participants.]

Parent Question Guide – 12.01.2015

Thank you for participating in this study! We are gathering information from parents about their experiences with the identification and treatment of child developmental delays. This information will help us design a website or application to support child development across Washington State.

Administer Demographics [See the Questionnaire Form following the Interview Scripts].

Questions About Children

7a. Could you please tell me how many children you have, and then their ages, and their genders? [Fill in table below]

_____	_____	_____	_____
Y / N			
_____	_____	_____	_____
Y / N			
_____	_____	_____	_____
Y / N			

7c. [IF diagnosed after age 5] Did you have any concerns about your child's development before they turned 5 years old? [Indicate above]

Monitoring Development

8. When your child/children was /were 5 years old or younger, did you monitor your child's development? Y / N

[IF yes]

How did you monitor your child's development?

What activities do you perform, and how often?

Were you following any specific schedule laid out in a book, pamphlet, website, etc.?

Are you using any systems, such as a spreadsheet or a website, to keep track of your child's development?

Have you used any specific surveys or questionnaires to monitor development?

Are there any people who have helped you monitor development? How?

How did you learn about child development and how to monitor?

What information sources or resources have you used during this process?

What useful information did you get from these sources?

Did you communicate your child's development information to anyone?

Who? Why? How?

Was it difficult for you to communicate this information?

What are/were your biggest challenges in monitoring your child's development?

What helped you the most with monitoring your child's development?

What do you know now about monitoring your child's development that you wish you would have known when your child was born?

[IF no]

Are you aware of anyone else, such as a doctor or childcare provider, monitoring your child's development? Y / N

[IF yes] Who was monitoring your child's development? [ask questions above]

[IF no]

Has your doctor talked to you about child development in general, or your child's development? Have you gotten information about child development from any other source?

Are you aware of developmental milestones for children?

Do you have any concerns about monitoring your child's developmental milestones?

Would you be interested in learning more about monitoring your child's development?

[If one or more of their children was diagnosed with developmental delay in part 7a., continue below with questions 10-17:]

9. Describe how you went about getting your child diagnosed for developmental delays:

Who first suspected that your child may have had a delay?

What caused them/you to suspect that there may be a delay?

When did they/you first suspect that your child had a delay?

Have you fill out any questionnaires related to your child's development?

When you suspected that your child might have had a delay, what did you do next?

What resources or people did you work with through this process?

How did you collaborate and communicate with these resources?

What did you need to know as you navigated this process?

Who made the actual medical diagnosis?

How did you find this provider?

Was a referral necessary to see this provider or get reimbursed for seeing this provider?

What information did you or your doctor have to give to this provider in order to get their services?

How did you feel about this?

Have you had a need to communicate this diagnosis to people outside of your immediate family?

Schools? Health specialists? Social services? Population surveys?

Who did this reporting? How?

Why?

Did you have difficulties communicating this information?

What are the biggest challenges you have faced or do you face in getting your child diagnosed?

What helped you the most during the diagnosis process?

10. Once your child/children was/were diagnosed with a delay, how did you go about addressing this delay?

What is the first step you took to address the delay after the diagnosis?

What interventions, programs, or treatments were/are being used to treat your child's delay?

Who is providing services to help address your child's delay?

How did you find these services?

What information did these providers require before your child could receive services?

How do you collaborate and communicate with service providers?

Why did you choose these services?

How do you keep track of the services being provided to your child?

Making sure they happen regularly/on time/in a satisfactory manner?

Keeping track of results?

Have you communicated information about your child's treatment to people outside of your immediate family?

Schools? Health specialists? Social services? Population surveys?

Who did this reporting? How?

Why?

Did you have difficulties communicating this information?

What was the biggest challenges you have faced in getting adequate treatment or services for your child?

What helped you the most during this process?

11. [If their child underwent treatment for delays] How do/did you know whether these treatments had or are having the intended effect?

How do you get this information?

What have you done, or what would you do if the interventions or services being used weren't/aren't working?

Who would or did you tell? Why? How?

12. What do you know now that you wish you had known before your child was diagnosed with a developmental delay?

13. Have you used any electronic systems, such as spreadsheets, informational websites, applications, or specialized software to help you during the tracking of your child's development or their treatment?

Final thoughts?

[All parents answer the following]

14. How often do you use a computer, a tablet, or a smart phone with web browser or applications?

☐ Once a week or less

☐ Multiple times a week

☐ Once per day

☐ Multiple times per day

15. Which computing device do you prefer to use?

☐ Computer

☐ Tablet

☐ Smart phone

15b. What do you usually do online? _____

15c. How often do you text on your phone? _____

16. We are investigating the creation of an online website that will be used to share child development information amongst people who identify and treat developmental delays in the community. We want to share information on a ‘need to know’ basis to give people the information they need to do their jobs effectively. Keeping this in mind:

a) What would you want such a system to do to help you through the process of monitoring development and addressing any developmental issues?

b) What wouldn’t you want the system to do? What concerns would you have with using such an online system?

17. As a part of this website, we want people involved with child development to be able to share information with each other to support your child’s health and the health of all children in the community. These people could potentially include you, your child’s primary care provider, early educators, and state and local government agencies. We want to ensure that this information would be shared on an ‘as needed’ basis. Keeping this in mind, I would like to ask you questions about how you think information should be shared:

a) There are a number of different pieces of information that could be useful in finding and treating child developmental disorders and also in community service planning. This information ranges from the child's medical history to their home environment. To ensure that our system holds useful information, we want to get the most accurate information possible. What information do you think that you could reliably and accurately provide? Please check the box if you think you could accurately and reliably provide the noted information. **[See Table 17a on the Questionnaire Form]**

b) I would now like to ask you about sharing '**personally identifiable information**'. By that I mean health information such as a diagnosis that is attached to personally identifying information such as a name, address, or phone number. This is useful information that is necessary to support your child's developmental health. Who do you think should have access to your child's or your family's personally identifiable health information to support your child's development?

Why should they have access?

c) How do you determine whether someone in the community can be trusted with your child's or your family's **personally identifiable information**? Developmental information?

What makes someone untrustworthy?

I have a few examples of people who support child development. Which information (from the list) would you be comfortable sharing with these people?

- Child's primary care provider
- A community group that provides information on developmental screening and that can refer to services
- A home care nurse
- Staff at an early education center, such as Head Start
- Child care provider such as daycare
- Government agency that provides services to families, such as the Department of Health or the Department of Social Services

E2) What information would you like to know about someone entering data into the system in order to be able to determine whether you 'trust' their data?

E3) [If some data is 'trust, but verify'] Is partially trusted information useful? Confusing? How would you use that information?

E4) Who should be the steward of the data in this system? Who should control who has access, and what information they can see?

d) Do you think that any entities outside of you and your family should have the ability to share your child's **personally identifiable** information with other people who work in child development without your expressed permission? If so, who should be able to, and under what circumstances? Do you have concerns with information being sent to someone you have not met before?

For example, consider the following scenarios:

Your child's primary care provider would like to send your child's information to a speech pathologist to get their opinion on a treatment plan. Is this OK?

Your child's daycare has concerns about your child's behavior and would like to send their observations to your child's PCP. Is this OK?

Your child's physical therapist believes that specialized home care is important for your child's development and would like to send your child's health information to the Department of Health's home nursing program. Is this OK?

e) We want to ensure that your child's information is only shared with people you are comfortable sharing it with. This is generally accomplished by having an agreement you sign where you agree to let people have access to your child's data. Would you be comfortable with an agreement that covers multiple organizations? Everyone within an organization? Only people you have met?

f) I would now like to ask you about sharing ‘**de-identified information**’. This is information that is not attached to any personally identifying information such as name, address, or phone number. This information could be useful to help plan developmental services for a specific location or a specific population. Thinking of the types of information we have previously talked about, would you be comfortable with providing this information to an agency like the Department of Health if no identifying information were attached?

g) Thinking about this potential system to help support child developmental screening and treatments, who do you think should store and maintain the data in the system? Who should own the computers where this information will reside? Why?

Are there specific groups who you would not want to host this data?

4 Potential options:

- Electronic health record at primary care provider’s office

- Central repository maintained by Department of Health
 - This would be like the Immunization Registry.
 - What experience have you had with that registry?

- Department of Early Learning?

-WithinReach?

Service Provider Question Guide – 12.08.2015

Thank you for participating in this study! We are gathering information from healthcare/child care/public health professionals about their experiences with the identification and treatment of child developmental delays. This information will help us design a website or application to support child development across Washington State.

Administer Demographics [See the Questionnaire Form following the Interview Scripts].

Organization Info

1. What is your job title?

2. What is the highest level of education you have attained, and what kinds of certifications or licenses do you have related to your job?

[If a medical provider] What is your specialty?

3. Do you have any special training in the monitoring and/or treatment of child development? If so, please describe:

What is the age range of the children you have worked with?

4. What organization do you work for?

What is the nature of the work your organization does? Main mission?

How large is your organization? Feel free to give a number of people working here, and/or a subjective assessment of size for an organization of your type:

General Work Information

5. Do you provide services directly to children and families, or do you interact directly with children and families? **[Not relevant for PCPs]** **Y / N**

6. **[IF YES for 5] [Not relevant for PCPs]** How do children and families find you or your organization? How are they referred to you for service?

Probing questions:

Do you provide additional medical or other services to families outside of child development?

Does a medical professional generally have to provide a referral for your services?

What kind of advertising do you do to communicate your services?

Do you work closely with any other healthcare, public health, or community groups to communicate your services to the public?

Who qualifies to receive your services?

6. What services does you provide in terms of supporting child development? Starting when you are contacted by a parent or see a child, please walk me through the tasks you perform to provide your developmental-focused services:

How do you determine whether a child has a developmental delay, and what kind of delay they have?

How do you help children, families, or both address a developmental delay?

[If they screen] What kind of screening tools do you use?

7. What information do you need to do your work successfully?

Probing questions:

How do you determine a child's or a family's needs?

Do you consult with any resources or professionals to help you do you work?

How do you consult with these resources?

8. Who do you work with during the process you described to provide services, programs, or interventions to children or families?

Other professionals or organizations?

How do you communicate and collaborate with these resources?

9. What information do you send to other healthcare providers, to the parents, or to other organizations during the process you just described?

Is there information that you think should be passed on to others that isn't?

[If appropriate] For screening results, how do you make referrals? Do you have existing relationships with groups you refer children to? What kind of relationship? Do you refer parents to general resources to help them find support?

- Are there processes in place to follow up and make sure that parents make or take their kids to referral appointments?

10. How do you know when you have successfully helped a child, family, or the community at large?

What metrics do you use to judge the success of your process?

Do you have to report specific metrics any public or private entities?

How do you communicate the success of your process to families or other stakeholders?

What do you do when a service is not working as expected?

11. Who do you communicate the outcomes of your services to? How do you communicate these outcomes?

12. What are the greatest barriers you face to successfully performing your job?

13. What would help you as you perform your job?

14. Have you used any electronic systems, such as spreadsheets, websites, or specialized software, to help you perform your work?

Electronic Systems

15. We are investigating the creation of an online website and application to help collect and communicate child developmental information between families, healthcare providers, public health, and others who support child developmental screening and treatment. Keeping this in mind:

a) What would you want such a system to do to help you effectively provide services to children, families, or the community at large?

b) What wouldn't you want the system to do? What concerns would you have with using such an online system?

16. As a part of this website, we are envisioning a system where you and other people involved with child development can access information about a child's development and communicate with each other to support their work. These stakeholders could potentially include **[as appropriate]** you, parents, your child's primary care provider, early educators, and state and local government agencies. Keeping this in mind, I would like to ask you questions about how you think information should be shared between these stakeholders:

a) There are a number of different pieces of information that could be useful in addressing child developmental disorders and also in community planning to address issues throughout the community. This information ranges from the child's medical history to their home

environment. To ensure that our system holds useful information, we want to get the most accurate information possible. Which child or family information do you routinely collect and use during the course of your work? Please indicate which information you collect. **[See Table 17a on the Questionnaire Form]**

[Questions about ‘personally identifiable information’ more relevant to people who provide direct services to children and families (Q5)]

- A2) Some of this information can be seen as being more or less ‘sensitive’. **Which of the information on the list would you consider to be more sensitive, or less sensitive?**

b) I would now like to ask you about sharing ‘**personally identifiable information**’. By that I mean health information such as diagnoses or treatments that is attached to personally identifying information such as a name, address, or phone number. To adequately do your job, are there situations where you would want to:

- A) Contact someone directly without going through the parents?
- B) Contact someone without parents’ express permission?

For example, doing a referral?

e) Thinking of the types of information we talked about earlier related to monitoring or treating a child's development, would you trust this information if it were reported to you from: **[As**

Appropriate]

- A Parent

- Child's PCP

- A community group like WithinReach that refers people to services?

- A home care nurse

- Staff at an early education center such as Head Start

- Child care provider, such as a daycare

- A government agency that provides family services, such as the Department of Social Services

E2) What information would you like to know about someone entering data into the system in order to be able to determine whether you 'trust' their data?

E3) [If some data is 'trust, but verify] Is partially trusted information useful? Confusing? How would you use that information?

E4) Who should be the steward of the data in this system? Who should control who has access, and what information they can see?

f) Would you have concerns with providing government agencies like the Department of Health with **de-identified** or **anonymized** information related to child developmental status, referral to services, and receipt of services?

g) Thinking about this potential system to help support child developmental screening and treatments, who do you think should store and maintain the data in the system? Who should own the computers where this information will reside? Why?

Are there specific groups who you would not want to host this data?

4 Potential options:

- Electronic health record at primary care provider's office

- Central repository maintained by Department of Health
 - This would be like the Immunization Registry.
 - What experience have you had with that registry?

- Department of Early Learning?

-WithinReach?

Questionnaire Form

[Form filled out by all respondents]

Demographics

1. Age: _____

Prefer not to respond

2. Sex: _____

Prefer not to respond

3. Yearly household income:

Less than \$15,000

\$15,000 - \$34,999

\$35,000 - \$49,999

\$50,000 - \$74,999

\$75,000 - \$99,999

More than \$100,000

Prefer not to respond

4. City or Town of residence: _____

Prefer not to respond

5. Are you of Hispanic, Latino, or Spanish origin [please check one box]:

Prefer not to respond

No, not of Hispanic, Latino, or Spanish origin

Yes, Mexican, Mexican American, Chicano

Yes, Puerto Rican

Yes, Cuban

Yes, another Hispanic, Latino, or Spanish origin. Please write origin: _____

6. What is your race [please check one or more boxes]:

Prefer not to respond

White

Black or African American

American Indian or Alaska Native. Please print name of tribe: _____

Asian Indian Japanese Native Hawaiian

Chinese Korean Guamanian or Chamorro

Filipino Vietnamese Samoan

Other Asian. Please print race: _____

Other Pacific Islander. Please print race: _____

Other race. Please print race: _____

7. What is your occupation? _____

Prefer not to respond

Table 17a [Parents]: What information could you accurately and reliably provide?

Child's medical history

This includes medical information such as current and previous medical diagnoses, the family's medical history, medications and other treatments, medical referrals, and the results of medical tests such as physical exams and lab tests.

Child's genetic information

This includes information about any genetic conditions or abnormalities that may affect child development.

Child's developmental screening results

This includes information about developmental screening tests that have been filled out, when they were filled out, and results.

Observations about child's behavior

This includes daily observations about a child's functioning and behavior.

Child's race and ethnicity

Yearly family household income

Household substance use

This includes information about smoking, alcohol usage, and drug usage among family members in the household.

Household environmental stress

This includes perceptions of the safety of the neighborhood the child lives in, food security within the household, and relationship stress between parents and other members of the family.

Table 17a [Service Providers]: What information do you collect and use?

Child's medical history

Current and previous medical diagnoses, medications and treatments, referrals, and the results of medical tests

- Do you collect this information during the course of regular practice? 0Yes 0No

- Do you use this information to support child development, or would you use it if it were available to you? 0Yes 0No

Child's genetic information

Genetic conditions or abnormalities that may affect development.

- Do you collect this information during the course of regular practice? ☐Yes ☐No
- Do you use this information to support child development, or would you use it if it were available to you? ☐Yes ☐No

Child's developmental screening results

Information about developmental screening tests that have been filled out and results

- Do you collect this information during the course of regular practice? ☐Yes ☐No
- Do you use this information to support child development, or would you use it if it were available to you? ☐Yes ☐No

Observations about child's behavior

Daily observations about a child's functioning and behavior.

- Do you collect this information during the course of regular practice? ☐Yes ☐No
- Do you use this information to support child development, or would you use it if it were available to you? ☐Yes ☐No

Child's race and ethnicity

- Do you collect this information during the course of regular practice? ☐Yes ☐No
- Do you use this information to support child development, or would you use it if it were available to you? ☐Yes ☐No

Yearly family household income

- Do you collect this information during the course of regular practice? ☐Yes ☐No
- Do you use this information to support child development, or would you use it if it were available to you? ☐Yes ☐No

Household substance use

Smoking, alcohol usage, and drug usage within the household

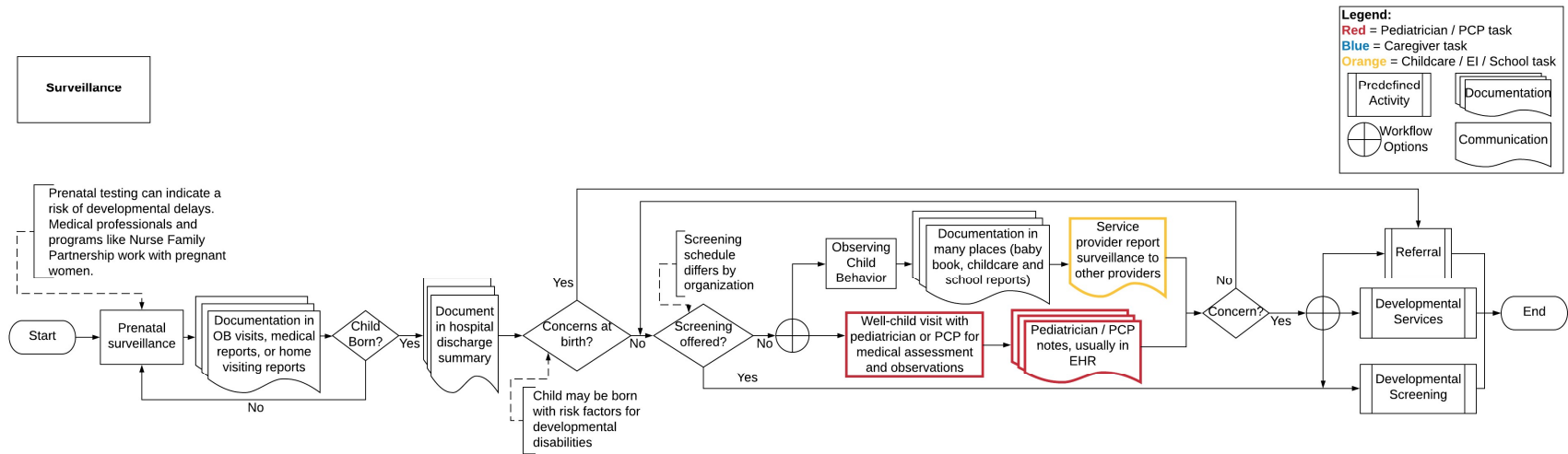
- Do you collect this information during the course of regular practice? ☐Yes ☐No
- Do you use this information to support child development, or would you use it if it were available to you? ☐Yes ☐No

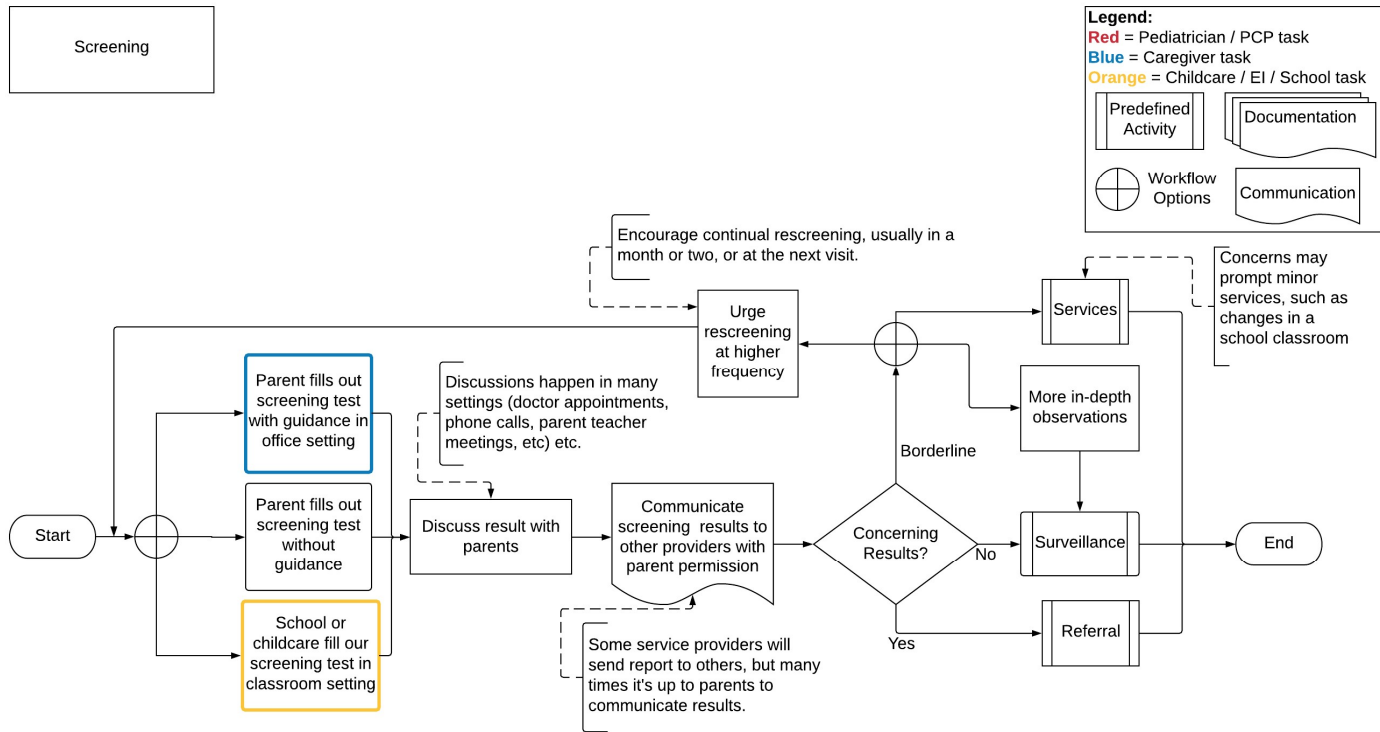
Household environmental stress

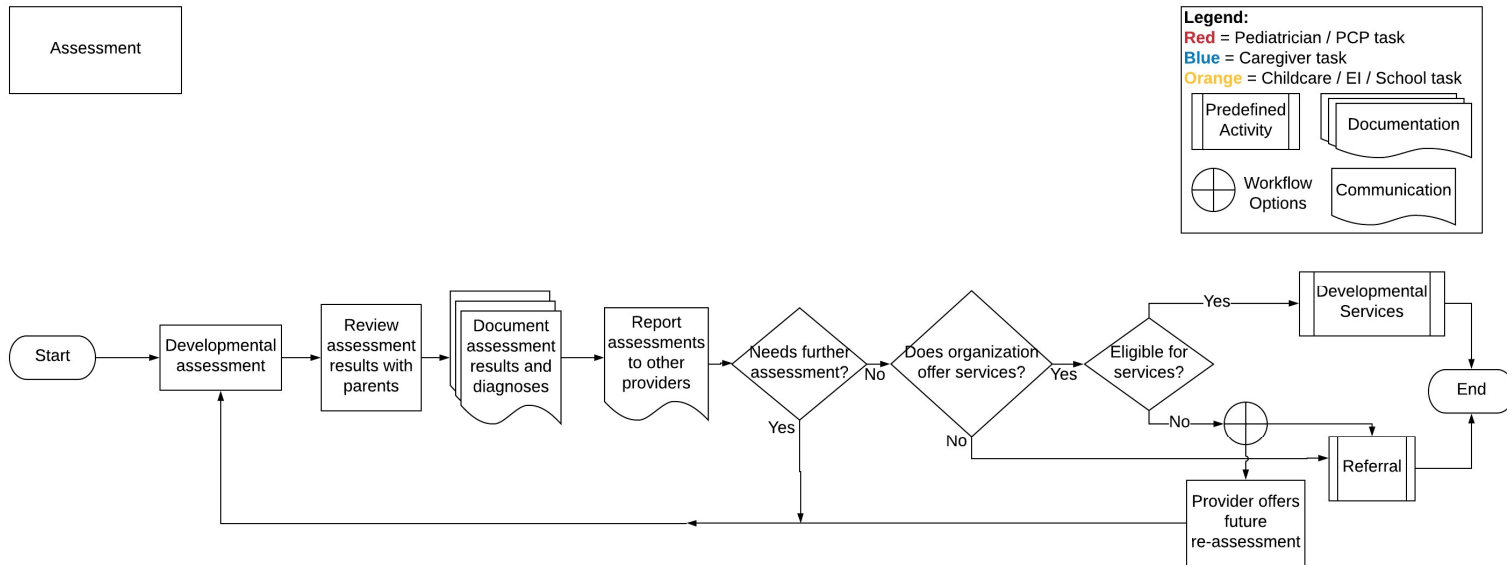
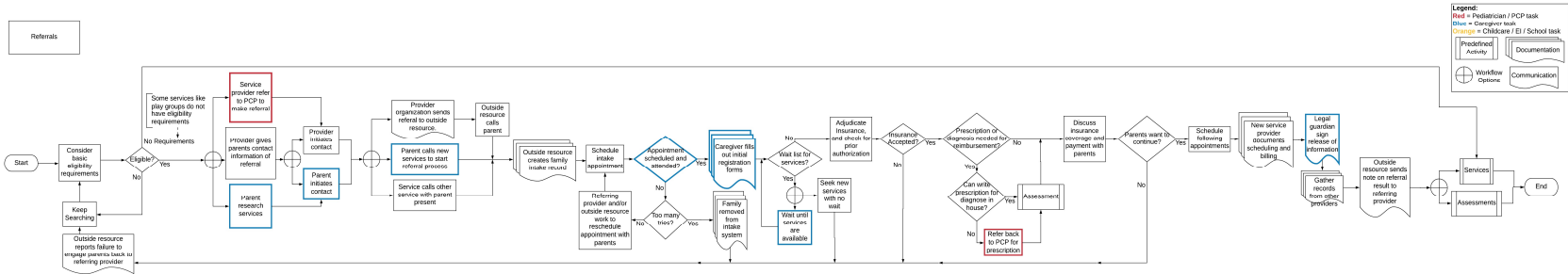
Perceptions of the safety of the neighborhood, food security within the household, and relationship stress between parents and other members of the family.

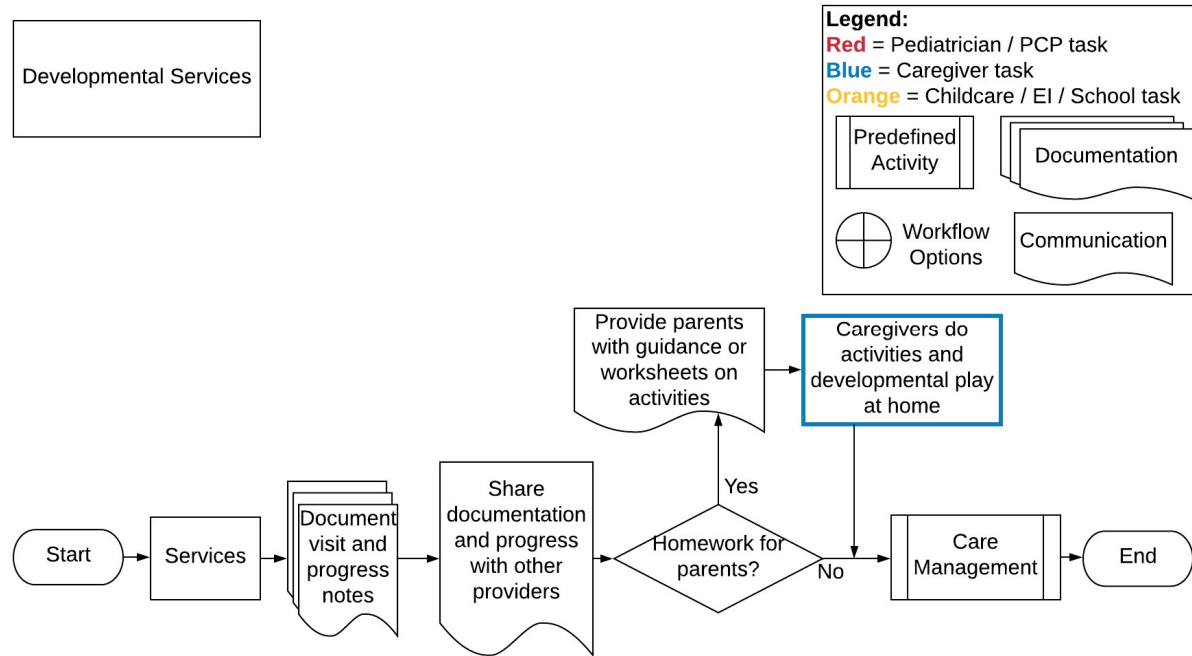
- Do you collect this information during the course of regular practice? ☐Yes ☐No
- Do you use this information to support child development, or would you use it if it were available to you? ☐Yes ☐No

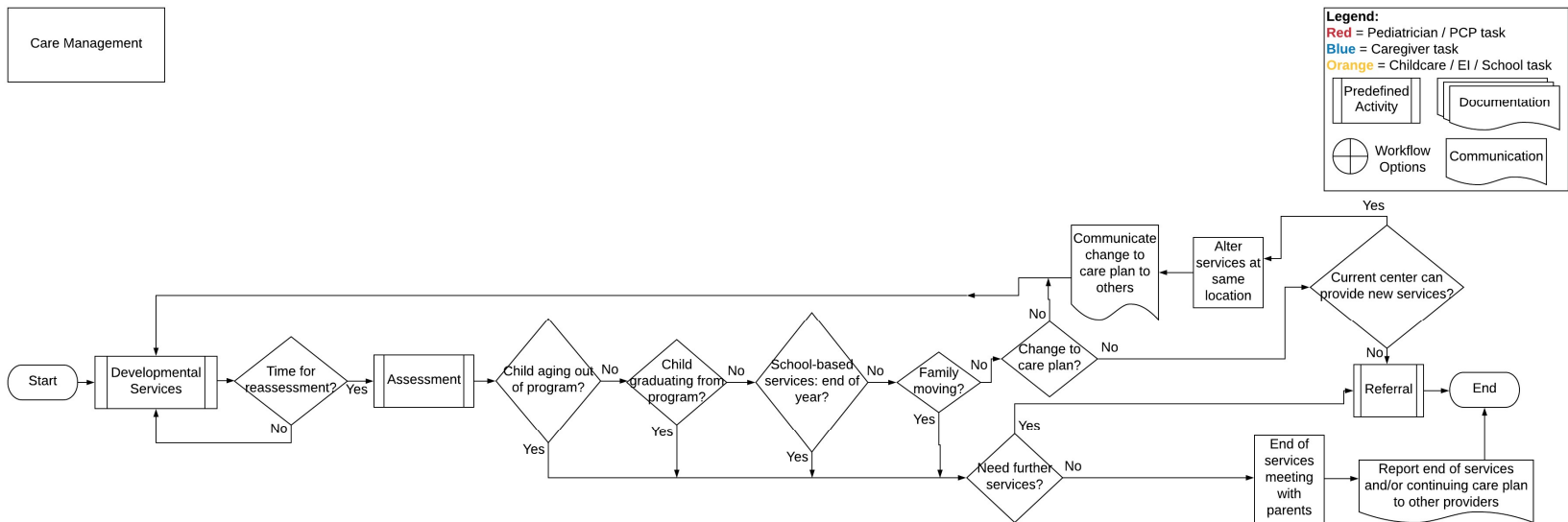
APPENDIX D: DETAILED CHILD DEVELOPMENT SUPPORT WORKFLOW MAPS











APPENDIX E: SURVEY COLLECTING INFORMATION CHILD DEVELOPMENT STAKEHOLDERS USE TO ASSESS TRUSTWORTHINESS

This survey is aimed at parents who were recruited through MTurk, and includes the ‘Demographics’ section that was utilized in both surveys. The questions below related to ‘pediatricians or family doctors’ were repeated for ‘preschool teachers’. The survey aimed at healthcare providers contained similar questions.

Study Introduction

Assessing Trust Between People Involved in Supporting a Child’s Development From Birth Through Age Five

Researchers’ Statement

This study is intended for parents who have recent experience caring for children under the age of five years.

We are asking you to participate in a University of Washington research study. The purpose of this study is to help design an online system that will store and communicate information related to a child’s development. This system would focus on the development of children from birth through five years of age. To better design the system, we are conducting research to understand how different people such as parents, healthcare providers, and teachers assess the trustworthiness of others who may be

involved in the care of a child.

This study consists of questions relating to how you judge the trustworthiness of different professions. Additionally, we will also collect information about your age, race, employment, and internet usage. We estimate this survey will take approximately 10 minutes to complete. You are being offered a \$1 payment through Mechanical Turk after completing this questionnaire. All provided information will be kept private and we will not report any names of participants or other identifiers in any oral or written report of the study results. If you have any questions or concerns, please contact Sean Mikles (smikles@uw.edu). Note that we cannot ensure the confidentiality of any information sent by email.

To begin the survey, please click the “Next” button. By clicking next, you agree:

to participate in this study,

that you understand the statement above,

that you understand that you can exit the survey at any time,

that you have experience caring for or serving children age 5 years or younger

that you should refrain from providing identifiable data, such as your name or address, in open-ended questions, and

that you are at least 18 years of age.

Please note that careless entries will be rejected.

Study Introduction

The following questions are related to supporting a child's development, meaning either the tracking of a child's development, or treating a developmental delay or disability. In order to support child development, it may be beneficial for many different caregivers and service providers, such as *doctors* and *teachers*, to share information about a child's development with each other.

Please answer the following questions related to trust in *doctors* and *teachers*.

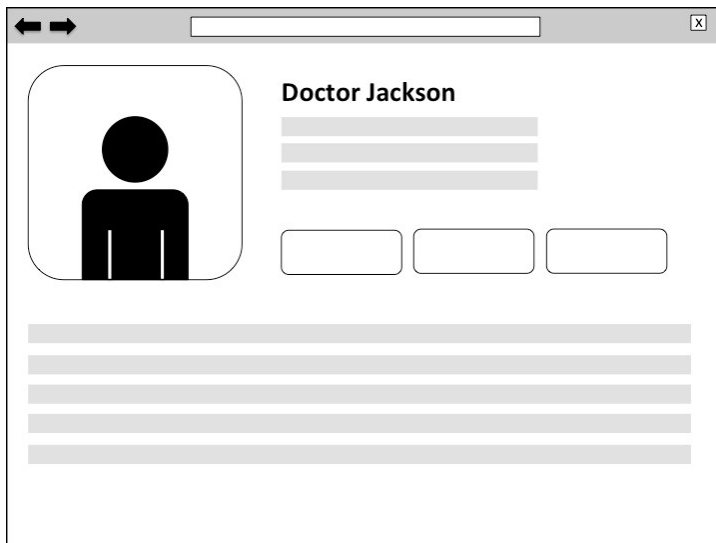
Doctors

1) When determining whether to trust a pediatrician or family doctor to effectively support a child's development, which of the following do you consider to be the most important? (Please choose one)

- ☐ Whether they have the knowledge, skills, and abilities to help a child
- ☐ Whether they care about a child and the child's family
- ☐ Whether they are consistent, reliable, and unbiased

Doctors

Imagine that you are looking at a webpage with information about a *pediatrician or family doctor* you have not previously met.



2) *What kind of information would you like to see displayed on this pediatrician or family doctor's webpage to help you determine whether they have the knowledge, skills, and abilities to help support a child's development?*

Please list at least one and up to three things you would like to see, in order of importance (i.e. the first thing is the most important).

Most important::

Second most important::

Third most important::

3) What kind of information would you like to see displayed on this pediatrician or family doctor's webpage to help you determine whether they will care about the well-being of a child and the child's family?

Please list at least one and up to three things you would like to see, in order of importance (i.e. the first thing is the most important).

Most important::

Second most important::

Third most important::

4) What kind of information would you like to see displayed on this pediatrician or family doctor's webpage to help you determine whether they will provide services in a consistent, reliable, and unbiased way?

Please list at least one and up to three things you would like to see, in order of importance (i.e. the first thing is the most important).

Most important::

Second most important::

Third most important::

5) Have your children regularly been seen by a pediatrician or family doctor?*

☐ Yes

☐ No

6) Think about the most recent pediatrician or family doctor your children have seen. Do you trust them to support your child's development?*

☐ Yes

☐ No

7) Why, or why not?*

Demographics

15) What is your age?*

16) What is your gender?*

☐ Male

☐ Female

☐ Other - Write In:

17) How many children do you have?*

18) Have any of your children been identified as having a delay in their development, or a developmental disability?*

☐ Yes

☐ No

19) Are you of Hispanic, Latino, or Spanish origin?*

☐ Yes

☐ No

20) What is your race? (Mark all that apply)*

☐ American Indian or Alaskan Native

- ☐ Asian
- ☐ Black or African American
- ☐ Native Hawaiian or Other Pacific Islander
- ☐ White
- ☐ Other - Write In::

 *

21) What is the highest level of education you have attained?*

- ☐ Less than a high school diploma
- ☐ High school diploma or equivalent
- ☐ Some college, but no degree
- ☐ Associate's degree
- ☐ Master's degree
- ☐ Professional degree
- ☐ Doctorate

22) What is your current job title?*

23) *What state do you live in?**

24) *Do you feel that people are generally trustworthy?**

☐ Yes

☐ No

25) *How often do you use the internet?**

☐ Almost Constantly

☐ Several Times a Day

☐ About Once a Day

☐ Several Times a Week

☐ Once a Week

☐ Less Than Once a Week

26) What do you use the internet for? (Mark all that apply) *

- ☐ E-mail
- ☐ Work
- ☐ School
- ☐ Banking and Paying Bills
- ☐ Shopping
- ☐ Social Media
- ☐ Videos, Games, and Entertainment
- ☐ News
- ☐ Web Searching, Independent Research

27) How often has your personal information been stolen or inappropriately shared online in the past, that you are aware of? *

- ☐ Never
- ☐ A few times
- ☐ Many times

28) What type of information has been stolen or inappropriately shared? (Please check all that apply)*

- ☐ Medical information
- ☐ Financial information
- ☐ Other personal information

29) Have you performed a task similar to this on MTurk in the past?*

- ☐ Yes
- ☐ No

30) This study is most concerned with children of the following ages:*

- ☐ Birth through age 5 years
- ☐ Ages 6 through 7 years
- ☐ Ages 8 through 13 years
- ☐ None of the above

31) Please enter your MTurk ID:*



APPENDIX F: SURVEY EVALUATING PROTOTYPES TO GENERATE TRUST

The template questions below represented by “Teacher Triangle” were repeated 16 times for the 16 different prototypes.

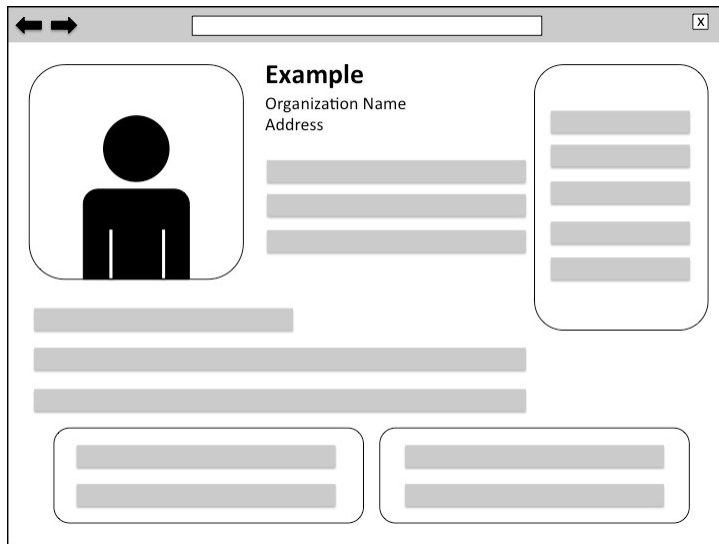
Instructions:

Consider the following scenario:

You are looking for doctors and teachers in the community to help you support your child's development. Imagine that you are looking at a website that contains a listing of professionals in your community who work to support child development. This website has webpages providing information on local doctors and teachers.

You will be presented with 16 pictures which represent informational webpages for a doctor or a teacher, similar to the example shown below. Imagine that you have never met any of the people depicted in these webpages.

Example user profile webpage.



Please take at least 15 seconds to review and read each picture. Then, based on the information provided, state how much you agree with the following statements about the doctor or teacher represented:

1. I could trust them to provide me with accurate and useful information about my child's development.
2. I could trust them to appropriately and effectively use information I share with them about my child's development.

Teacher Triangle:

- 1. Please read the webpage below about Teacher Triangle and answer the following questions.**

Teacher Triangle, M.Ed.
 River Birch School
 1820 River Birch Ln. [\[see map\]](#)

Experience:
 M.Ed, Special Education
 Vanderbilt University,
 Peabody College (1996)
 Teaching young children for 22 years
 River Birch is NAEYC Accredited

Contact:
Phone:
 (XXX) 555 – 1000
E-mail:
office@rbschool.com
Office Hours:
 Monday – Friday
 8:00am – 6:00pm
 Drop in any time!

Reviews from Clients:

Ms. E: ★★★★★
 Teacher Triangle is dedicated, and they respect my child's culture... [\[more\]](#)

Mr. F: ★★★★★
 Teacher Triangle maintains a **safe** classroom. They have always been reliable... [\[more\]](#)

2. 12) Rate your level of agreement with the following statements about Teacher Triangle:*

	Strongly Agree	Agree	Disagree	Strongly Disagree
--	-----------------------	--------------	-----------------	--------------------------

I could trust them to provide me with accurate and useful information about my child's development	☐	☐	☐	☐
I could trust them to appropriately and effectively use information I share with them about my child's development	☐	☐	☐	☐

APPENDIX G: CUMULATIVE RANK SCORES FOR INFORMATION CATEGORIES

Below are tables showing the summed rank scores for the information categories that participants used to judge competence, benevolence, and integrity. These information categories are organized by overall themes, and cumulative scores are split by ‘trustor’ and ‘trustee’ groups. The top three summed scores for each column are color coded for emphasis (green = top, orange = second, red = third). Gray rows indicate the reporting of a general theme, but not a specific category.

Competence

Themes and Categories	Sums of Competence Ranks by Trustor and Trustee Groups						
	Healthcare Providers		Health care Total	Parents		Parents Total	Grand Total
	Medical	Education		Medical	Education		
Demonstrating Skills	16	2	18	18	15	33	51
Activities Beyond Work	4		4	4	2	6	10
Communication				1		1	1
Results	4	1	5	1	5	6	11
Specialized Knowledge	3		3	6	5	11	14
Non-specific	5	1	6	6	3	9	15
Personal Characteristics	15	13	28	32	25	57	85
Personal Information	2	1	3	9	3	12	15
Personality	6	8	14	15	13	28	42
Pictures				1	1	2	2

Themes and Categories	Sums of Competence Ranks by Trustor and Trustee Groups						
	Healthcare Providers		Health care Total	Parents		Parents Total	Grand Total
	Medical	Education		Medical	Education		
Values	7	4	11	4	7	11	19
Non-specific				3	1	4	4
Third Party Trust	62	40	102	56	49	105	207
Associated Organizations	11	6	17	16	11	27	44
Awards	2	1	3	1	2	3	6
Certifications	33	23	56	24	26	50	106
Reviews	16	10	26	15	10	25	51
Training	61	78	139	80	91	171	310
Continuing Education	2		2	4	1	5	7
Degrees	3	6	9	22	32	54	63
Education Details		7	7				7
Specialties	23	5	28	18		18	46
Non-specific	33	60	93	36	58	94	187
Work Experience	44	46	90	57	60	117	207
Work History	20	18	38	39	34	73	111
Work Populations	3		3	2	3	5	8
Non-specific	21	28	49	16	23	39	88
Workplace Practices	3	3	6	9	5	14	20
Accessibility		1	1	8	4	12	13
Client Staffing	3	2	5	1	1	2	7
Services Available							

Themes and Categories	Sums of Competence Ranks by Trustor and Trustee Groups						
	Healthcare Providers		Health care Total	Parents		Parents Total	Grand Total
	Medical	Education		Medical	Education		
Work Systems							
Grand Total	201	182	383	252	245	497	880

Benevolence

Themes and Subthemes	Sums of Benevolence Ranks by Trustor and Trustee Groups						
	Healthcare Providers		Healthcare Total	Parents		Parents Total	Grand Total
	Medical	Education		Medical	Education		
Demonstrate Skills	8	22	30	12	20	32	62
Activities Beyond Work					6	6	6
Communication	1	12	13	3		3	16
Results	1	2	3	2	2	4	7
Specialized Knowledge	3	10	13	7	14	21	34
Non-specific	3		3	2		2	5
Personal Characteristics	67	80	147	96	111	207	354
Personal Information	9	6	15	28	37	65	80
Personality	22	30	52	28	27	55	107
Pictures	1	11	12	9	20	29	41
Values	33	33	66	31	27	58	124
Non-specific	2		2				2

Themes and Subthemes	Sums of Benevolence Ranks by Trustor and Trustee Groups						
	Healthcare Providers		Healthcare Total	Parents		Parents Total	Grand Total
	Medical	Education		Medical	Education		
Third Party Trust	44	44	88	62	43	105	193
Associated Organizations				6	4	10	10
Awards	4	6	10		1	1	11
Certifications	4	6	10	2	3	5	15
Reviews	36	32	68	54	35	89	157
Training	5	7	12	8	14	22	34
Continuing Education				2		2	2
Degrees				3	2	5	5
Education Details					2	2	2
Specialties	3		3	3	4	7	10
Non-specific	2	7	9		6	6	15
Work Experience	19	11	30	30	9	39	69
Work History	10	3	13	16	4	20	33
Work Populations				3		3	3
Non-specific	9	8	17	11	5	16	33
Workplace Practices	30	7	37	20	10	30	67
Accessibility	15	3	18	18	4	22	40
Client Staffing	10	4	14		4	4	18
Services Available	2		2	2		2	4
Work Systems	3		3		2	2	5
Grand Total	173	173	346	230	209	439	785

Integrity

Themes and Subthemes	Sums of Integrity Ranks by Trustor and Trustee Groups					
	Healthcare Providers		Healthcare Total	Parents		Grand Total
	Medical	Education		Medical	Education	
Demonstrating Skill	16	14	30	25	28	83
Activities Beyond Work	1		1	4		5
Communication	2	8	10		4	14
Results	4		4	17	4	25
Specialized Knowledge	8	3	11	4	20	35
Non-specific	1	3	4			4
Personal Characteristics	47	43	90	57	72	219
Personal Information		5	5	1	5	11
Personality	4	9	13	15	12	40
Pictures		1	1	2	11	14
Values	43	28	71	37	44	152
Non-specific				2		2
Third Party Trust	61	55	116	60	54	230
Associated Organizations	3		3	5	2	10
Awards	3	2	5	5	5	15
Certifications	6	8	14	2	2	18
Reviews	49	45	94	48	45	187
Training	7	9	16	9	15	40
Continuing Education	2	5	7			7
Degrees				3	2	5
Education Details						

Themes and Subthemes	Sums of Integrity Ranks by Trustor and Trustee Groups						
	Healthcare Providers		Healthcare Total	Parents		Parents Total	Grand Total
	Medical	Education		Medical	Education		
Specialties	2	1	3	3		3	6
Non-specific	3	3	6	6	10	16	22
Work Experience	20	20	40	32	25	57	97
Work History	8	12	20	25	11	36	56
Work Populations	5	3	8	1	6	7	15
Non-specific	7	5	12	6	8	14	26
Workplace Practices	21	23	44	31	12	43	87
Accessibility	20	17	37	27	9	36	73
Client staffing	1	3	4				4
Services Available				1		1	1
Work Policies	3		3	3	3	6	9
Grand Total	172	164	336	214	206	420	756

VITA

Sean Mikles was born in Grand Rapids, Michigan. He earned his Bachelor of Science in Engineering from the University of Michigan before moving to Wisconsin to work for electronic health record vendor Epic. After five years of working in industry, he returned to academia to earn a Master of Public Health degree in epidemiology at the Mailman School of Public Health at Columbia University. In December of 2018, he expects to earn his Doctor of Philosophy in Biomedical and Health Informatics from the School of Medicine at the University of Washington.