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Children Birth to Age Three with Feeding Difficulties: Systems Level Perspectives of Supports, Needs, and Interagency Collaboration

Sondra Marie Stegenga

A Thesis Submitted to the Graduate Faculty of

GRAND VALLEY STATE UNIVERSITY

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Abstract

Early identification and treatment of feeding difficulties greatly improves outcomes for young children with feeding difficulties (Williams et al., 2006). However, identifying and addressing feeding difficulties in young children, birth to age three, is complex; requiring not only interdisciplinary collaboration (Arvedson, 2008; Bruns & Thompson, 2010; Lefton-Greif & Arvedson, 2008; Williams et al., 2006) but also interagency collaboration due to the various partners involved in service provision for young children, birth to age three (Individuals with Disabilities Education Act, 2004). When such interagency collaboration is needed, systems level structural supports are shown to levy the greatest impact on outcomes (Tseng et al., 2011). Yet, prior to this study, no noted research had been published identifying the systems level supports needed when addressing feeding difficulties in young children. Therefore, this study examined the systems level supports, needs, and interagency collaboration when addressing the needs of young children, birth to age three, with feeding difficulties. An electronic survey was used to gather information from early intervention coordinators and early childhood administrators overseeing services for young children, birth to age three, in early intervention in Michigan. Many systems level supports and needs were identified. In addition, a significant relationship was identified between levels of interagency collaboration and access to evaluation and services for feeding difficulties. Results of the study have important implications for future research, practice, and policy.

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Chapter One: Introduction

Problem Statement

One of the most common issues brought to primary health professionals by parents of young children is feeding-related concerns (Arvedson, 2008). In fact, it is estimated that feeding difficulties affect 25-45% of children who are developing typically and nearly 80% of children with developmental disabilities (Lefton-Greif & Arvedson, 2007). These feeding concerns may include swallowing difficulties, food avoidance behaviors, limited intake, etc. (Arvedson, 2008; Lefton-Greif & Arvedson, 2007; Williams, Witherspoon, Kavasic, Peters, & McBlain, 2006). These difficulties ultimately cause inadequate nutritional intake, decreased growth, and can even become a life threatening situation if aspiration is involved (DeLegge, 2002; Newman, Keckley, Petersen, & Hamner, 2001). In addition, without adequate nutrition, health and brain growth are impacted causing lifelong effects related to learning and development (Engle & Huffman, 2010).

These concerns related to learning and development have led to recent research regarding the role of schools/education and early intervention in supporting children and learners of all ages with feeding difficulties (American Speech-Language-Hearing Association, Bruns & Thompson, 2002; Bruns & Thompson, 2014; Philipps, Reinhar, Rohde, Virgil, & Moser, 2012). Given these implications, it is imperative to quickly identify, assess, and provide treatment and support to young children with feeding difficulties. Early treatment can lead to significant improvements in feeding ability; in fact, the sooner the child is identified and treated, the greater the outcomes (Williams et al., 2006). However, early identification and treatment of young children with feeding

difficulties can be challenging due to the complex nature of best practices when addressing the needs of young children, birth to age three, with feeding difficulties.

First, an interdisciplinary team must be involved to attain optimal outcomes for children with feeding difficulties (Arvedson, 2008; Bruns & Thompson, 2010; Lefton-Greif & Arvedson, 2008; Williams et al., 2006). In addition, for young children, birth to age three, an interdisciplinary team often requires interagency coordination due to the various partners involved in service provision (Individuals with Disabilities Education Act, 2004). For example, an early intervention provider in the community may be the first to work with the family and subsequently identify a difficulty related to feeding during a home visit and observation of daily routines. However, depending on the depth of need discovered, medical assessment may be required for diagnosis, such as when examining possible aspiration (Arvedson, 2008; Bruns & Thompson, 2010; Miller, 2009; Newman et al., 2001; Philipps et al, 2012). This need for intimate interagency collaboration is complicated by the fact that each agency is governed by different rules, regulations, requirements, and funding sources.

The need for formalized interagency collaboration due to systemic complexity when working with young children, birth to age three, is not only emphasized in the literature (Adams, Tapia, & The Council for Children with Disabilities, 2013) but is also why federal programs and legislation for young children, birth to age three, were founded (Individuals with Disabilities Education Act, 2004). Specifically, Part C federal regulations were developed to coordinate and enhance services for children, birth to age three, with developmental delay or risk of delay (Individuals with Disabilities Education Act, 2004). Given this need for collaboration, it is vital that agencies and service areas

examine their collaborative efforts to ensure optimal outcomes (Ansari & Weiss, 2005; Tseng et al., 2011).

According to Tseng et al. (2011), to achieve long lasting change and receive optimal impact from interagency collaborations, structural changes must occur. Structural changes involve large system changes such as legislative mandates or funding supports (Tseng et al., 2011). Therefore, given the necessity of interagency collaboration when addressing the needs of young children with feeding difficulties, supports at a structural level are inherent to a comprehensive system for addressing the needs of young children with feeding difficulties. However, in spite of the apparent need for structural supports at a systems level when addressing the needs of young children with feeding difficulties, no research exists about the necessary systems level structural supports, including the impact of interagency collaboration.

Importance of the Problem, Background, and Rationale for the Study

Identifying levels of interagency collaboration and systems level structural supports necessary to address the needs of young children with feeding difficulties is imperative for multiple reasons. First, systems level structural supports optimize the outcomes of interagency collaborations (Tseng et al., 2011). This is crucial when addressing the needs of young children with feeding difficulties because an optimized interagency approach is necessary for quick identification and treatment (Arvedson, 2008). Quick identification and treatment is essential because a child who is aspirating is at risk of severe illness or even death (Arvedson, 2008; Newman, L.A., Keckley, C., Mario, P.C., & Hamner, A., 2001; Philipps et al., 2012).

Next, implementing pertinent structural supports is shown to produce the longest lasting changes related to interagency collaborative efforts and understanding (Tseng et al., 2011). A high level of understanding is important because when agencies, insurers, or providers are unclear about the roles or collaborative efforts between systems of services, denial of service provision or payment can occur. In fact, the issue of insurance denials due to decreased understanding of roles when working with young children with feeding difficulties was recently identified in the state of Michigan (Stegenga, 2013). In addition, other states have experienced similar difficulties and responded by clarifying provider roles through the creation of guidance to the field (Maryland, 2011) or provider notices (Illinois, 2010).

Last, consistency at the structural level optimizes and aligns practices (Ansari & Weiss, 2005). This is important because identification, evaluation, and interventions for addressing feeding difficulties have been inconsistent (Howe & Wang, 2013). In addition, there are no requirements for certification or training of providers working with young children with feeding difficulties. Occupational therapy and speech language pathology are two professions often in the forefront providing supports and services to individuals with feeding difficulties. Feeding is noted in both fields as a scope of practice (American Speech-Language-Hearing Association, 2002; American Occupational Therapy Association, 2007). However, certification for treating feeding difficulties is optional. Specifically, there are no certification or training requirements for individuals working with young children with feeding difficulties. In addition, training in feeding interventions has not always been a part of the education of speech language pathologists (American Speech-Language-Hearing Association, 2002) or occupational therapists

(American Occupational Therapy Association, 2007). In spite of the longstanding history of occupational therapists addressing feeding difficulties as part of an individual's routines and occupations, it was not until 2011 that the Accreditation Council for Occupational Therapy Education (ACOTE) began requiring college programs in occupational therapy to include specified training in feeding interventions (Philipps et al., 2012).

Overall, research pertaining to feeding difficulties in young children is longstanding. However, the research has focused primarily on therapeutic techniques (Howe & Wang, 2013), assessment (Arvedson, 2008; Lefton-Greif, 2008; Newman et al., 2001), impact on family (Suarez, Atchison, & Lagerwey, 2014), interdisciplinary collaboration between providers (Arvedson, 2008; Orentlicher, Handley-More, Ehrenberg, Frenkel, & Markowitz, 2014; Williams, S., Witherspoon, K., Kavsak, P., Patterson, C., & McBlain, J., 2006), and more recently the role of providers in school-based settings (e.g. American Speech-Language-Hearing Association, 2002; Bruns & Thompson, 2014; Philipps, Reinhar, Rohde, Virgil, & Moser, 2012). These are all notable areas of research but a gap remains. In spite of the founding principles of early intervention/Part C of the Individuals with Disabilities Education Act focusing on the importance of interagency collaboration and coordination of services (IDEA, 2004) and the large research base on the importance and impact of interagency collaboration, especially related to issues of health and development (Adams, Tapia, & The Council for Children with Disabilities, 2013; Rosenfeld, 1992; Rashid, Spengler, Wagner, Melanson, Skillen, Mays, Heurtin-Roberts, & Long, 2009), there remains a large gap in the literature

about levels of interagency collaboration and structural supports necessary when addressing the needs of young children, birth to age three, with feeding difficulties.

Statement of Purpose

The purpose of this study is to identify systems level structural supports necessary in early intervention when addressing the needs of young children with feeding difficulties. The results of this study will be used as a foundation for guidance to the field in Michigan about addressing the needs of young children with feeding difficulties.

Research Questions

Overall, the study aims to provide valuable information about correlations between interagency collaboration, systems level structural supports, and specified needs related to addressing the needs of young children with feeding difficulties. Specifically, the study aims to answer the following questions:

1. What structural supports are in place in Michigan to address the needs of young children with feeding difficulties?
2. What structural supports for addressing the needs of young children with feeding difficulties are needed?
3. What are the levels of interagency collaboration in Michigan related to addressing the needs of young children with feeding difficulties, birth to age three?
4. What structural supports correlate to higher levels of interagency collaboration when addressing the needs of young children with feeding difficulties (e.g. proximity of medical centers providing feeding supports, administrator training and/or experience related to addressing feeding difficulties, amount of staff with specialized training related to feeding, administrator participation in collaborative efforts with community

partners, administrator training on interagency collaboration, written procedures related to feeding difficulties, teaming practices of staff)?

5. Is there a relationship between levels of interagency collaboration and reported access to medical evaluation and services for young children with feeding difficulties?

Hypotheses

Hypotheses are an important tool in the identification of potential research questions and needs. However, it is also imperative to identify that within hypotheses, there can also be bias (Maxell, 2013). In addition, in qualitative research the process of gathering information should be iterative and not static, thus, the process of creating hypotheses in qualitative research is debated (Maxwell, 2013). Therefore, the following are merely preliminary hypotheses intended to facilitate critical thinking in the research process. Thorough analysis of the data is reviewed in Chapters 4 and 5. In retrospect of these considerations, the following hypotheses emerge:

1. *Early On*® coordinators and early childhood administrators in Michigan will identify limited structural supports in Michigan related to addressing the needs of young children with feeding difficulties.
2. *Early On* coordinators and early childhood administrators in Michigan will identify many types of structural supports as needs related to addressing the needs of young children with feeding difficulties.
3. Current levels of interagency collaboration related to addressing the needs of young children, birth to age three, will be limited - if they exist.
4. Levels of interagency collaboration will correlate positively to reported access to evaluation and services for young children with feeding difficulties.

Research Design

Due to the complexity of the issue and variety of disciplines, fields, and providers involved when addressing the needs of young children with feeding difficulties, the study used a mixed-methods approach to collect data via electronic survey. The survey solicited both qualitative and quantitative information. The survey is based on interagency collaboration research in addition to research on addressing needs of young children with feeding difficulties. The study used IBM Statistical Package for Social Sciences (SPSS) and Statistical Analysis Software (SAS) for quantitative data analysis in consultation with the Statistical Consulting Center at Grand Valley State University (GVSU) to ensure accuracy of data analysis. The researcher used coding and theming for analysis of qualitative data. In addition, a qualitative data expert was consulted to ensure accuracy of qualitative data analysis.

Terminology and Definitions

Aspiration - Food or liquids that enter the trachea beyond the vocal folds (Arvedson, 2008). Aspiration is a known risk for pneumonia or even death (DeLegge, 2002).

Collaboration - Services are fully shared between agencies. Autonomy of each agency is "replaced by collective policy-making" (Tseng et al., 2011, p. 798).

Cooperation - Agreement between systems or agencies but "most influence comes from a single agency" (Tseng et al., 2011, p. 798).

Coordination - Consists of "joint work and some level of mutual adjustment between agencies." (Tseng et al., 2011 p.798).

Dysphagia - Any difficulty in swallowing (Arvedson, 2008).

Early intervention - Interagency coordination of services for young children, birth to age three. Services aim to decrease or prevent developmental delays in children with disabilities or at risk of delay or disability. Early intervention is founded on Part C of education law, also known as the Individuals with Disabilities Education Act (IDEA) (Individuals with Disabilities Act, 2004).

Early On® Only – A term unique to Michigan's two-tiered system of services for early intervention. "*Early On* only" or "Part C only" refers to children who qualify for early intervention services under *Early On*® in Michigan but do not qualify for the additional services of Michigan Mandatory Special Education (MMSE) (MAASE, 2014).

Early On® Service Areas - Designated regions throughout the state of Michigan where organizations and/or agencies collaborate to provide Part C early intervention services. The geographic area is designated by the Intermediate School District boundaries (Michigan Department of Education State Board of Education, 2013).

Feeding difficulties – Disorder of any aspect of the eating routine (Arvedson, 2008). May involve swallowing and/or eating difficulties that cause a decrease or limitation in nutrition or intake.

Interdisciplinary - Multiple disciplines working independently but toward a common purpose or goal (Rosenfeld, 1992).

Michigan Mandatory Special Education (MMSE) – Public Act 198 of 1955 was amended in 1971 to require the provision of special education services in Michigan. This was then repealed and recodified as the Public Act 451 of 1976, again requiring the provision of special education services in Michigan (Michigan Department of Education, 2005). These Public Acts provide the foundation for the delivery of special education supports and

services in Michigan for children birth through age 26 (MAASE, 2014; Michigan Department of Education, 2005). In Michigan, children may qualify for *Early On* only or *Early On* with Michigan Mandatory Special Education (MMSE).

Multidisciplinary - Multiple disciplines working independently toward a similar goal. Efforts are not coordinated (Rosenfeld, 1992).

Structural Change - Change in the structure or arrangement of an interagency collaboration (Tseng et al., 2011).

Structural Supports - Systems level supports such as funding and procedures (Tseng et al., 2011).

Transdisciplinary - Multiple disciplines working collaboratively toward a common goal. Processes include transcending disciplinary borders for collaborative problem solving (Rosenfeld, 1992).

Delimitations of the Study

The purpose of this study is to provide input to professionals and administrators in the state of Michigan regarding the structural supports, needs, and levels of interagency collaborations necessary when addressing the needs of young children, birth to age three, with feeding difficulties. Therefore, information was gathered from *Early On* coordinators and early childhood administrators in the state of Michigan. Although response rate was high, sample size is limited. In addition, the scope of the survey was focused on a particular geographic area and system of early intervention, the state of Michigan. Therefore, generalizability is limited. However, given significance of the results it does provide many promising premises for future research.

Limitations of the Study

Potential limitations include a limited sample size, subjectivity of responses within the qualitative portions of the survey design, and the inability to probe further if responses are limited due to the on-line individual format of the survey. However, the complexity of the system of early intervention (*Early On)* in Michigan is perhaps the greatest challenge of the study.

In Michigan, children qualify for early intervention (*Early On)* or both *Early On* and Michigan Mandatory Special Education (MMSE) (Michigan Association of Administrators of Special Education, 2014). Given this set of qualifiers, each local service area has a different configuration of administration overseeing services for children birth to age three depending on whether the children qualify for "*Early On* only" or if the child also qualifies for MMSE services for children birth to age three. In addition, the setup of program oversight also depends on whether the Intermediate School District (ISD), local school district (LEA), or community partner subcontracts to deliver the services for *Early On* and/or *Early On* with MMSE. Specifically, all *Early On* service areas have an *Early On* Coordinator overseeing services for children in *Early On* (whether the child is in *Early On* only or *Early On* with MMSE). However, in some areas, the *Early On* Coordinator may also oversee MMSE services for young children, birth to age three, that are also in *Early On*. Whereas in other service areas there may be multiple local district administrators, each overseeing the special education services and supports for children birth to age three in addition to preschool through graduation for their local district area. Given these complexities, to ensure input is gathered representing the population of children receiving services in Michigan/children who qualify under all

configurations (*Early On* only or *Early* On with MMSE for children birth to age three), it is necessary to receive input from all different facets of the administrators and coordinators of programs. Therefore, some service areas may have more representation in the survey results.

Organization of the Study

This concludes Chapter One which provided an overview of the thesis. Chapter Two provides a thorough review of the literature including the theoretical framework guiding the study. Chapter Three details the design of the research. Chapter Four reviews the results of the study including demographic information and findings. Chapter Five summarizes the thesis including conclusions, discussion, and recommendations with implications for research and practice.

Chapter Two: Literature Review

Introduction

The following review is a critical discussion of literature related to addressing the needs of young children, birth to age three, with feeding difficulties. The main focus is structural supports and collaborative efforts due to the complex nature of serving young children with feeding difficulties. Concepts of review include (a) theoretical framework with focus on (1) history and terminology and (2) Mind, Brain, and Education (MBE) theory. Next, (b) prevalence and impact of feeding difficulties in young children are discussed followed by (c) best practices for addressing feeding difficulties in young children. Areas of best practice when addressing the needs of young children with feeding difficulties include (1) interventions, (2) interdisciplinary teams, (3) interagency collaboration, (4) the role of early intervention, and (5) highly qualified providers are discussed. Last, (d) summary and conclusions are provided.

Theoretical Frameworks

This study is grounded in the theory of transdisciplinary collaboration. Transdisciplinary research theory is optimal for addressing multifaceted and complex issues that necessitate transcendence of disciplinary and/or agency boundaries (Ansari & Weiss, 2005; Rosenfeld, 1992; Tseng et al, 2011). Specifically, the theory of transdisciplinary collaboration is pertinent to the study of young children with feeding difficulties because addressing feeding difficulties in young children requires the interplay of multiple disciplines (e.g. occupational therapy, speech language pathology, physicians, dieticians) and multiple agencies/organizations (e.g. medical, health,

education/schools, early intervention). Therefore, a framework that can ultimately transcend traditional boundaries is necessary.

Transdisciplinary Research Theory

In 1992, Patricia Rosenfeld introduced the concept of transdisciplinary research to address multifaceted and complex issues, such as social and health problems. Prior to this time, cross disciplinary collaboration existed in research but was limited in scope and success due to the need for a more sophisticated level of collaborative problem solving (Rosenfeld, 1992). Rosenfeld discusses the three main levels of interaction in collaborative information gathering and problem solving: multidisciplinary, interdisciplinary, and transdisciplinary (Rosenfeld, 1992).

Multidisciplinary research involves individuals working in parallel to contribute information to solve a problem. However, researchers mainly approach the problem from their own disciplinary perspective. Essentially, there may be multiple disciplines completing research on a similar topic but collaboration is limited and results are often examined independently (Rosenfeld, 1992).

Another level of interaction is known as interdisciplinary. In this type of interaction, researchers may coordinate knowledge needed for a common problem but each discipline approaches an independent aspect of the problem from his/her specific disciplinary viewpoint. Results are usually reported individually but may be examined as a group (Rosenfeld, 1992).

Last, in transdisciplinary research efforts the researcher transcends his/her theoretical foundations in order to develop a true cross disciplinary vision. In a

transdisciplinary approach, the disciplinary representatives work collaboratively to "define the problem, confer about concepts, methods, and results" and ultimately develop a common solution (p. 1351). Mere collaboration on issues is not enough:

> creative collaboration requires more than social and medical scientists working on the same problem as part of the same team. To achieve the level of conceptual and practical progress needed to improve human health, collaborative research must transcend individual disciplinary perspectives and develop a new process of collaboration (p.1344).

In spite of the apparent benefits of transdisciplinary understanding, there are some cautions. First, understanding multiple disciplines and systems is complex. It requires increased time to develop relationships and knowledge beyond one's primary discipline (Rosenfeld, 1992). In addition, individuals must possess a strong foundational knowledge in their own field prior to transcending disciplinary boundaries (Bruns & Thompson, 2010). In spite of the aforementioned cautions, consensus in the literature is that transdisciplinary collaborative efforts are imperative to higher level learning and problem solving. Support of the transdisciplinary approach is shown not only through scholarly literature (Park & Son, 2010; Rappolt-Schlichtmann & Watamura, 2010; Ronstadt & Yellin, 2010; Rosenfeld, 1992), but also through cross-disciplinary initiatives such as the Federal Collaboration on Health Disparities Research (Rashid et al, 2009). In addition, legislation for young children supports collaboration across disciplines and fields, such as the Part C regulations of the Individuals with Disabilities Education Act (IDEA, 2004). This apparent need for transdisciplinary problem solving with complex

issues has also been identified within the field of education. This has resulted in a new field of inquiry; Mind, Brain, and Education or "MBE" (Fischer, 2009).

Mind, Brain, and Education

Stemming from the foundations of transdisciplinary collaboration is a relatively new field in research, Mind, Brain, and Education (MBE). MBE "aims to bring together biology, cognitive science, development, and education to create a strong research foundation for education" (Fischer, 2009, p.3). Although much of the research in MBE focuses on K-12 educational efforts, its theory encompasses the necessary principals of early intervention. Specifically, early intervention is founded in education law/Part C of the Individuals with Disabilities Act (IDEA, 2004). In addition, as discussed prior, addressing issues in early intervention often requires intimate interdisciplinary and interagency collaborations, which are basic tenets of Mind, Brain, and Education theory. In fact, transdisciplinary service delivery, also known as primary service provider, are recommended as the primary mode of service delivery in early intervention (Early Intervention Workgroup on Principles and Practices in Natural Environments, OSEP TA Community of Practice: Part C Settings, 2008).

Last, early intervention is the epitome of collaborative efforts surrounding health, education, and development. Therefore, the study of Mind, Brain, and Education is an optimal framework for examining the issue of young children, birth to age three, with feeding difficulties. It not only focuses on transdisciplinary problem solving, which is necessary for the complex issues and needs surrounding feeding difficulties in young children, but its foundations include a focus on education, development, and health.

Summary of Frameworks

Given the need for interdisciplinary and interagency transcendence when examining how to optimally support young children, birth to age three, with feeding difficulties, this research study aims to gather and synthesize information from a multitude of disciplines through literature review and survey as part of the transdisciplinary approach.

Synthesis of Research Literature

When completing scholarly research, identifying historical and current scholarly literature as part of the process is imperative. Without a thorough literature review, gaps in the research cannot be adequately identified (Freankel, Wallen, & Hyun, 2012). In addition, researchers must exhaust the literature and identify primary sources within the literature to ensure accuracy when examining the problem and developing research methods (Freankel, Wallen, & Hyun, 2012). Therefore, the following represents a comprehensive review of the literature. Databases used to search the literature include ERIC, CINAHL, MEDLINE, and ProQuest with access provided through the Grand Valley State University Library.

Prevalence and Impact of Feeding Difficulties

A significant amount of children are impacted by feeding difficulties. In fact, it is one of the most common concerns brought to physicians by parents of young children (Arvedson, 2008). It is estimated that feeding difficulties affect 25-45% of children who are developing typically and nearly 80% of children with developmental disabilities (Lefton-Greif & Arvedson, 2007). In addition, researchers estimate that the prevalence of swallowing difficulties is increasing due to greater survival rates of infants born

prematurely (Lefton-Greif & Arvedson, 2007). To complicate matters, feeding difficulties do not only impact physiological factors, such as growth and development. Limited nutrition, often an outcome of feeding difficulties, can ultimately impact a child's educational performance (Engle & Huffman, 2010) and even social relationships (Suarez, Atchison, & Lagerwey, 2014). Last, significant feeding difficulties put a child at risk of death (DeLegge, 2002). However, the sooner a child's feeding difficulty is identified, the greater the outcome. In fact, Williams et al. (2006) found when feeding difficulties were identified before age one, the child had a "high overall success rate" (p. 190). Specifically, success rates were 92.5% in their study group (Williams et al., 2006, p.190). Therefore, early identification and intervention for children with feeding difficulties is imperative. However, this notion of early identification is complicated due to the multifarious nature of supports and services for a young child.

Best Practices for Addressing Feeding Difficulties in Young Children

The process of eating and mealtimes for young children is multifaceted and dyadic. Specifically, eating cannot be examined as purely a physiological process (Howe & Wang, 2013). The process of eating involves physiological, cognitive, environmental, behavioral, sensory, social, and developmental skills (Howe & Wang, 2013). In addition, research identifies that parents correlate feelings of caregiver satisfaction and confidence with the outcomes of their child's eating (Thorne, Radford, & McCormick, 1997). Given these complex dynamics of feeding in young children, multiple approaches to address feeding difficulties in young children have emerged in the literature.

Interventions. The main categories of interventions include: behavioral, parent-directed and educational interventions, and physiological interventions (Howe & Wang,

2013). Multiple approaches have yielded success in feeding skills in young children. However, the highest success rates are noted when a parent-directed and educational approach is used either in combination with traditional therapy or when it is used independently (Black, Dubowitz, Hutcheson, Berenson-Howard, & Star, 1995). In addition, due to the complex needs of a young child, the need for an interdisciplinary team is also emphasized (Arvedson, 2008; Bruns & Thompson, 2009; Lefton-Greif, 2008; Lefton-Greif & Arvedson, 2008).

Interdisciplinary teams. Literature about feeding in young children from various areas of research including medical, educational, and early intervention, all discuss the importance of a multidisciplinary or interdisciplinary team when addressing the needs of a young child with feeding difficulties (Arvedson, 2008; Bruns & Thompson, 2009; Howe & Wang, 2013; Lefton-Greif, 2008; Lefton-Greif & Arvedson, 2008). Most common team members include parents, a speech language pathologist, an occupational therapist, and a pediatrician. However, depending on the needs of the child and setting served, a dietician, a behavioral psychologist, a teacher, a physical therapist, a respiratory therapist, and/or other specialists may also be involved (Bruns & Thompson, 2009; Howe & Wang, 2013).

Interagency collaboration. In recent educational and early intervention literature related to feeding, the necessity for collaboration between agencies (medical and educational) is discussed (Bruns & Thompson, 2010; Lefton-Greif & Arvedson, 2008; Miller, 2009). This is very important given that Part C/early intervention is founded on the premises of service coordination and interagency collaboration (Mackey-Andrews & Taylor, 2007). In addition, interprofessional education is becoming

foundational to those entering therapy fields (Orentlicher, Handley-Moore, Ehrenberg, Frenkel, & Markowitz, 2014). However, in spite of these strands of coordination and collaboration, discussion about interagency collaboration in the literature related to feeding difficulties in young children is limited. Even in a recent systematic review exploring feeding interventions with young children by Howe & Wang (2013), the topic of interagency collaboration was not identified as a major theme in the literature. This is a concern since interagency collaboration is shown to have one of the largest impacts on long term outcomes (Tseng et al, 2009).

Part C of IDEA references service coordination and interagency collaboration as main areas of focus in early intervention (IDEA, 2004; Mackey-Andrews & Taylor, 2007). This importance of collaboration between systems involved in early intervention is also emphasized in recent medical literature (Adams et al, 2013). Specifically, Adams et al. (2013) state, "seeking to enhance collaboration between the sister systems and to minimize systematic barriers is clearly in the best interest of infants, toddlers, their families, and the larger community" (p. e1082). Fluid interagency collaboration is imperative when working with young children with feeding difficulties and their families. As previously discussed, the sooner a child is identified and receives the necessary supports and services for feeding difficulties, the better the outcome (Williams et al, 2006). However, the process of quick identification and treatment can be greatly impacted if interagency collaboration is weak or nonexistent.

Early intervention providers work closely with families to identify functional needs and supports to assist their child in his/her daily routines (Workgroup on Principles and Practices in Natural Environments, 2008). Therefore, the early intervention team

may be the first to identify a possible difficulty with feeding. However, their observations may not be sufficient to identify specific medical needs or risks. Research indicates that "clinical observation of swallowing is not adequately sensitive to aspiration" (Newman et al, 2001, p. 4). Thus, health care provider involvement is necessary for more advanced medical assessments such as radiographic or fiber-optic study (Newman et al, 2001). These collaborative efforts require trust and communication between the early intervention teams, physicians, and medical therapy providers to ensure referrals for medical evaluations are necessary and appropriate. Understanding between medical providers and early intervention teams regarding roles and scope of services to optimally identify service provision once evaluation is complete is also necessary.

Illinois and Maryland have addressed the issue of understanding roles through either guidance to the field (Maryland, 2011) or notice to providers (Illinois, 2010). Roles must be understood and trust present to ensure quick and fluid identification, referral, assessment, and treatment. After all, quick responses related to feeding difficulties are imperative to avoid and eliminate potentially devastating health effects, including developmental delays and death (Arvedson, 2008; Newman, L.A., Keckley, C., Mario, P.C., & Hamner, A., 2001; Philipps et al., 2012).

Role of education and early intervention in addressing feeding difficulties. The link between nutrition and educational performance has been recognized for many years. In fact, there are many programs that aim to improve nutritional access for children, including federally funded programs such as the Hunger Free Kids Act of 2010. However, in spite of this link, literature examining the role of school providers in working with children who have feeding difficulties has only recently emerged.

Recent research mainly focuses on the relation of feeding to accessing one's education (Lefton-Greif & Arvedson, 2008). Literature on the role of schools in addressing the needs of children with feeding difficulties discusses ethical issues (Huffman & Owre, 2008), legal issues (Power-deFur & Alley, 2008), procedures (Bruns & Thompson, 2014; Homer, 2008), and multidisciplinary or interdisciplinary teams (Arvedson, 2000; Bruns & Thompson, 2014; Homer, 2008; Lefton-Grief & Arvedson, 2008; McNeilly & Sheppard, 2008). In addition, multiple articles allude to interagency collaboration and partnership (Arvedson, 2000; Homer, 2008; Lefton-Grief & Arvedson, 2008; McNeilly & Sheppard, 2008). Specifically, McNeilly and Sheppard (2008) state that school professionals "need to collaborate with professionals outside the school" when addressing feeding difficulties (p.273). This is due to the complex nature of feeding disorders and necessary medical assessments. In addition, some research discusses necessary structural supports for promoting interagency collaboration between the schools and medical partners (e.g. procedures, team processes and roles, and forms) (Homer, 2008). However, in spite of this building base of research on addressing feeding difficulties in the context of schools, none of these processes are outlined in the literature related to early intervention.

Research about the role of early intervention in addressing the needs of young children with feeding difficulties is limited. Most research related to young children with feeding difficulties is broadly focused on children birth to five. Few articles examine the complex but very necessary role of early intervention in addressing the needs of young children with feeding difficulties. Bruns and Thompson (2010) highly focus on best practices for feeding interventions with children in early intervention. Specifically, they

summarize recent research and the relation to early intervention best practices including specified treatment techniques, parent/caregiver roles, natural environments, and teaming. Although they do not discuss structural supports or interagency collaboration beyond key discussion points (e.g. adequate funding to allow for teaming time), they do emphasize the importance of a transdisciplinary team and the importance that all providers must demonstrate knowledge of feeding difficulties as part of the transdisciplinary team (Bruns & Thompson, 2010).

Highly qualified providers. Highly qualified providers are extremely important in the process of identification and treatment of young children with feeding difficulties. Feeding is a complex and potentially dangerous process when children have significant feeding difficulties. In addition, feeding difficulties are not simple to identify given potential symptom overlap when a child has multiple needs or disabilities (Arvedson, 2008). Therefore, it is recommended that providers have specialized training when working with young children with feeding difficulties (American Speech-Language-Hearing Association, 2002; the American Occupational Therapy Association, 2007). In spite of these recommendations, there is not a requirement for professionals working with individuals with feeding difficulties to obtain specialized certification. In addition, the available certifications contain differing areas of focus and are discipline specific to either occupational therapy or speech language pathology (AOTA, 2007; ASHA, 2002).

Last, if *Early On* service areas follow best practice recommendations in early intervention and use a primary service provider approach, the primary professional working with a child and family on a regular basis may not be occupational therapist or speech language pathologist (Workgroup on Principles and Practices in Natural

Environments, 2008). There are many disciplines listed as appropriate early intervention services in order to best meet the needs of the child and family (IDEA, 2004). This array of backgrounds is a key piece of Part C law that benefits families. However, it also means the primary service provider working with the family may not have background or training in identification and treatment of feeding, let alone specialized certifications or training in the area. Therefore, identification and treatment could ultimately be delayed or missed due to lack of understanding and training if local procedures are not in place related to the identification and treatment of feeding difficulties.

Summary and Conclusions

In spite of a recent increased focus on addressing the needs of young children with feeding difficulties in the literature (e.g. Bruns & Thompson, 2010; Howe & Wang, 2013), many gaps remain. Given the immense focus of Part C/early intervention on systems coordination (Mackey-Andrews & Taylor, 2007) and the potential of structural supports to have the greatest impact on long lasting change (Tseng et al, 2007), the most apparent gap in research related to addressing feeding difficulties in young children is the necessary structural supports, including interagency collaboration. Therefore, the aim of this study was to identify systems level structural supports necessary for a coordinated system when addressing the needs of young children, birth to age three, with feeding difficulties.

Chapter Three: Research Design

Introduction

The literature review indicates a need for mixed-method design when examining interagency relationships and transdisciplinary collaborations (Ansari & Weiss, 2005; Cartmel, Macfarlan, & Nolan, 2013; Cross, Dickmann, Newman-Gonchar, & Fagan, 2009; Hong & Reynolds-Keefer, 2013), such as when addressing the needs of young children, birth to age three, with feeding difficulties. Specifically, both qualitative (Hong & Reynolds-Keefer, 2013) and quantitative (Newman et al., 2001; Williams et al., 2006) data are valuable when examining how to optimally address the needs of young children with feeding difficulties due to the transdisciplinary service delivery and problem solving, necessity of interagency collaboration, and the underlying need for quantifiable/target population data.

Participants/Subjects

Target Population

The target population of this study is a criterion-based/purposive sample of *Early On* Coordinators and early childhood administrators who oversee *Early On* only and/or *Early On* with Michigan Mandatory Special Education services for young children, birth to age three. These groups of coordinators and administrators are optimal participants due to their systems level perspectives regarding young children, birth to age three, with feeding difficulties in early intervention in Michigan. Criterion-based/purposive sample was chosen due to the limited number of coordinators and administrators overseeing children in *Early On* and/or birth to age three Michigan Mandatory Special Education.

Participant Recruitment

The 62 *Early On* Coordinators throughout the state of Michigan received a direct email with a description of purpose, methods, human subjects' rights, procedures and link to the survey. *Early On* Coordinator email addresses are available via the internet at 1800earlyon.com. The individuals supervising programs for Michigan Mandatory Special Education for children birth to age three were also were surveyed through direct email. The researcher obtained email and contact for individuals supervising supports and services for Michigan Mandatory Special Education for children birth to age three contacting each of the 56 ISDs through email and/or phone. Please see Appendices A, B, and C for recruitment letters and survey link. Support was granted from the Michigan Interagency Coordinating Council Feeding Ad Hoc Committee and the Michigan Department of Education for support in communicating the need and purpose for the survey (see Appendix B).

Participant Involvement

Participants completed a short electronic survey. The survey took between 5 and 10 minutes based upon input from pilot participants. Participant involvement was voluntary and participants had the option to withdraw at any time. Disclosures were made within the survey specifying voluntary involvement and the ability to skip questions or withdraw at any time.

Financial Cost, Potential Benefits, & Researcher Conflict of Interest

There was no financial cost to participants. Possible benefits to the participants included the opportunity that the information from the study will be utilized by the Michigan Interagency Coordinating Council/Governor's Council for Infants and Toddlers

with Disabilities and *Early On* Training and Technical Assistance (EOTTA) to determine possible trainings and supports for the field related to supporting young children, birth to age three, with feeding difficulties. The researcher is a member of the Michigan Interagency Coordinating Council/Governor's Council for Infants and Toddlers with Disabilities and also is an *Early On* Coordinator and special education supervisor in the state of Michigan. However, no financial gain or incentive is involved related to the information obtained from the study. In addition, no outside funding is provided for this study.

Instrumentation

The self-created survey instrument is based on the aforementioned research questions and review of the literature. It incorporates both qualitative and quantitative data collection methods (see Appendices A and C for survey and introduction letter). The survey question on level of interagency collaboration related to addressing the needs of young children with feeding difficulties is based upon principles in an existing rubric on levels of interagency collaboration, "Levels of Community Linkage," by Cross, Dickman, Newman - Gonchar, Fagman (2009). Permission was granted by SAGE Publishing for use as a foundation for the question on level of interagency collaboration on July 31, 2014 (see Appendices D and E). The map of Michigan used in the survey was approved by the Michigan Department of Technology, Management, and Budget on July 31, 2014 for modification and use in the survey (see Appendix F). The survey was designed to take less than ten minutes to complete with most respondents completing in less than five minutes in order to obtain a higher number of participants.

The survey pilot occurred with a group of five current or former early childhood administrators and/or *Early On* Coordinators prior to distribution to the field. The Early childhood administrators involved in the pilot had experience overseeing services for children birth to age three in Michigan Mandatory Special Education. Distribution of the pilot survey of five administrators and/or *Early On* Coordinators occurred once approval was received from the proposal defense committee and Human Research Review Committee (HRRC). The pilot survey was completed by November 2014.

Data Collection

Study Dates and Location

The study occurred in the state of Michigan. The pilot survey occurred in October 2014. Full survey was submitted to the field in December 2014 after permissions from the Human Research Review Committee at Grand Valley State University.

The 62 *Early On* Coordinators throughout the state of Michigan were emailed directly with a description of purpose, methods, human subjects' rights, procedures and link to the survey. *Early On* Coordinator email addresses are available via the internet at 1800earlyon.com. The individuals supervising programs for Michigan Mandatory Special Education for children birth to age three were also surveyed through direct email. Email and contact for the individuals supervising services for Michigan Mandatory Special Education for children birth to age three were obtained by contacting each of the 56 ISDs through email, phone, or in person.

Survey completion cut-off was 14 days after distribution. Follow up emails and reminders to complete surveys occurred three times after distribution by the principal

investigator. All regions of Michigan were represented in the responses (per map of Michigan demographic question). Therefore, focused follow up with particular regions was not necessary in order to demonstrate representation in the survey from all areas of the state.

Consent Process and Documentation

Due to the level of risk, formal signed consent from participants was not required to collect the data. However, a statement of consent was included in the preamble of the survey which included the required language from the Grand Valley State University Human Research Review Committee:

> You are asked to voluntarily provide specific information to this web site. You may skip any question (*unless the question directs you to another question*), or stop participating at any time. The information collected will be used for the stated purposes of this research project only and will not be provided to any other party for any other reason at any time except and only if required by law. You should be aware that although the information you provide is anonymous, it is transmitted in a non-secure manner. There is a remote chance that skilled, knowledgeable persons unaffiliated with this research project could track the information you provide to the IP address of the computer from which you send it. However, your personal identity cannot be determined. I freely consent to participate: (yes or no).

If the participant opted no, they were opted out of the survey/survey was immediately ended.

Identifiable Information & Data Security

To maintain confidentiality, participant names or emails were not collected in the survey. Participants were also informed they may withdraw at any time from the survey. All participants or potential participants were provided contact to Human Research Review Committee (HRRC) through Grand Valley State University for further inquiry related to protocol review, investigator, or subject rights (see Appendices A and C). Access to study results will be available in the final published thesis via electronic database through Grand Valley State University in May of 2015. Survey results and data are confidential and only accessible by the principal investigator, Grand Valley State University thesis committee members as expert consultants in data analysis, and the statistical analysis experts from the Grand Valley State University Statistical Consulting Center. Data will be maintained in a secure database through the GVSU Statistical Consulting Center and password protected Microsoft Excel files. In addition, only de-identified aggregate data is made public in the final thesis.

Type, Severity and Risk Level

Severity of risk is less than minimal, type 1. Information gathered is mostly public based knowledge. All information is de-identified and not correlated or associated with particular service areas, only state regions. There was no risk of job loss or detriment to programs or services with the information gathered.

Data Analysis

Analysis of the data involved both qualitative data analysis and quantitative data analysis given the mixed-methods design of the study.

Qualitative Data Analysis

According to Maxwell (2013), there are multiple tests to improve qualitative data validity. This study used three of these identified tests to improve validity of qualitative. Specifically, the study used respondent validation, triangulation, and the use of numbers to improve validity.

Respondent validation. Respondent validation occurred with the Michigan Interagency Coordinating Council Feeding Ad Hoc Committee. The committee includes several respondents from multiple service areas and state experts in the field of early intervention. In addition, respondent validation occurred with members from the original survey pilot group.

Triangulation. The study used multiple data sets within the survey to triangulate findings including: 1) fill in fields allowing for coding of rich descriptive data, 2) the use descriptive variables, and 3) quantitative self-rating questions. These data sets were triangulated to determine commonality or lack of commonality across responses to determine validity. Specifically, coding and theming techniques were used for the qualitative data portions per best practice for qualitative data analyses (Maxwell, 2013).

Use of numbers. Numbers were used for descriptive variables, responses, and relationships with the data sets. Cross-tabulation was used to examine variable relationships. Tables with the use of numbers representing data sets and descriptive variables are included within the results section of this study.

Quantitative Data Analysis

In addition to the aforementioned qualitative methods, quantitative methods were also used in the study. The principal investigator collaborated with the Statistical

Analysis Center at Grand Valley State University for use of the Statistical Package for Social Sciences (SPSS) and Statistical Analysis Software (SAS) to ensure accuracy with quantitative data analysis including statistical analysis and variable relation. Cross-tabulation summarized the data and Fisher's Exact Test was used identify whether a significant association between the categorical variables and levels of interagency collaboration exists.

Summary

The study utilized a mixed-method research design utilizing both qualitative and quantitative methods in the survey design. To ensure accuracy, qualitative and quantitative experts, the use of Statistical Package for Social Sciences (SPSS) software and Statistical Analysis Software (SAS), support from the Statistical Consulting Center at Grand Valley State University, and best practice techniques in data analysis were used. Overall, data analysis aimed to identify: 1) What structural supports are in place in Michigan to address the needs of young children with feeding difficulties, 2) what structural supports for addressing the needs of young children with feeding difficulties are needed, 3) what are the levels of interagency collaboration in Michigan related to addressing the needs of young children with feeding difficulties, birth to age three, 4) what structural supports correlate to higher levels of interagency collaboration related to addressing the needs of young children with feeding difficulties (e.g. proximity of medical centers providing feeding supports, administrator training and/or experience related to addressing feeding difficulties, amount of staff with specialized training related to feeding, administrator participation in collaborative efforts with community partners, administrator training on interagency collaboration, written procedures related to feeding

difficulties, teaming practices of staff) and 5) Is there a relationship between levels of interagency collaboration and reported access to medical evaluation and services for young children with feeding difficulties.

Chapter 4: Results

Introduction

The following details the results of the study. Specifically, it describes the context, detailed analysis of the findings related to the research questions, and a summary of the findings.

Context

Of the 142 recruits, 58 participated in the survey resulting in a 41% response rate. Participants included 38 *Early On* Coordinators, 9 special education administrators, and 11 professionals that cover dual roles as both *Early On* Coordinators and special education administrators overseeing services for young children, birth to age three, in Michigan. The results include responses from all ten regions of Michigan (see Appendix G for Michigan Regions Map).

Ninety-three percent of respondents identified bachelor level degrees, 75% identified graduate degrees, and 55% identified having specialty certifications. Seventy-one percent of respondents reported working as a provider with children birth to age three prior to becoming an administrator. Forty-seven percent of respondents currently supervise preschool services and programs in addition to services for children birth to age three. Twenty percent of respondents currently supervise kindergarten through 12th grade services and programs in addition to birth to three.

Findings

The findings of the study are presented in the following order: 1) structural supports in place and needed in Michigan related to addressing the needs of young children with feeding difficulties, 2) levels of interagency collaboration in Michigan

related to addressing the needs of young children with feeding difficulties, 3) structural supports correlating to higher levels of interagency collaboration when addressing the needs of young children with feeding difficulties, and 4) relationship between levels of interagency collaboration and reported access to medical evaluation and medical services for young children with feeding difficulties.

Structural Supports in Place and Needed

Data for structural supports in place and structural supports needed was coded into organizational categories. Subcategories were derived through coding and examination of question results and qualitative data submitted through the free range comments sections. Organizational categories are "broad areas or issues that you want to investigate…these are often established prior to interview or observations" (Maxwell, 2013, p. 107). Specific categories of structural supports include:

1) direct service provider supports with subcategories of

a) variety of providers represented on staff,

b) training of providers related to addressing feeding,

c) teaming structure, and

d) whether feeding services are provided;

2) administrator supports with subcategories of

a) experience working with young children with feeding difficulties

b) training on addressing feeding difficulties, and

c) training in interagency collaboration;

4) community partnerships with subcategories of

a) level of community collaboration,

b) collaborative council participation, and

c) proximity of community partners

Direct service provider supports. Direct service provider supports include the type of providers represented on staff (e.g. physical therapist, speech-language pathologist, occupational therapist), training of providers related to addressing feeding, teaming processes (formal versus informal), and whether feeding services are provided.

Service providers on staff. Since an interdisciplinary team is a key component when addressing the needs of young children with feeding difficulties, survey respondents were asked to report what type of providers their *Early On* Service Area has hired on staff in both: 1) *Early On* with MMSE for children birth to age three and 2) *Early On* only.

Respondents reported a broad array of service providers hired on staff to provide services for children in *Early On* with Michigan Mandatory Special Education (MMSE) (Table 1). Specifically, a significant amount of respondents reported having the following disciplines on staff: physical therapist (42 responses), occupational therapist (44 responses), speech-language pathologist (47 responses), early childhood special education teacher (41 responses). In addition, a significant amount of responses were also noted for social worker (34 responses), psychologist (35 responses), vision consultant (33 responses), and hearing consultant (30 responses). However, for *Early On* only, the amount of respondents reporting providers hired on staff was minimal compared to *Early On* with Michigan Mandatory Special Education. In fact, as little as $1/10^{th}$ the amount of responses were noted for the different types of providers hired on staff for *Early On* only. Specifically, only six respondents reported physical therapists hired on

staff to serve children in *Early On* only compared to the 42 reports of physical therapists hired on staff in *Early On* with MMSE, only eight reports of an occupational therapist hired on staff in *Early On* only compared to 44 reports of occupational therapists hired on staff in *Early On* with MMSE, only nine reports of speech-language pathologist in *Early On* only compared to 47 reports of a speech-language pathologist hired on staff in *Early On* with MMSE, and only three reports of a psychologist hired on staff in *Early On* only compared to 35 reports of a psychologist hired on staff in *Early On* with MMSE. The only exception where a provider was reported in a higher number in *Early On* only was the notably high amount of *Early On* only service coordinators. The amount of respondents reporting to have *Early On* only service coordinators hired on staff in *Early On* only was 21 compared to only 15 respondents reporting having *Early On* only service coordinators hired on staff in *Early On* with Michigan Mandatory Special Education (Table 1).

Provider training. Sixty-one percent of respondents reported having staff with specialized training, mentoring, or optional certification related to addressing the needs of young children with feeding difficulties. Twenty-eight percent reported they did not have staff with specialized training, and 11% were not sure if they had staff with specialized training in this area. The need for provider training on feeding difficulties was identified as one of the top two priorities. In fact, 62% of respondents reported the need for provider training as a top priority.

A strong need for provider training was also evidenced in the qualitative data. Specifically, comments related to the need for pre-service training included statements alluding to a lack of training and expertise in this area such as, “many in our county do

not feel comfortable or educated in this issue." Others directly stated, "we don't have the training or expertise" when referring to addressing the needs of young children with feeding difficulties. One commenter took it a step further stating outright, "trainings need to take place as well as consultations."

Teaming structure. All respondents identified if provider teaming practices were formal versus informal in their service area (Table 2). Zero "not sure" responses were identified. Respondents identified both formal and informal teaming practices with seven respondents identifying the use of both. For children in *Early On* with Michigan Mandatory Special Education, 73% participate in formal teaming processes. In *Early On* only, respondents reported 69% participate in formal teaming processes.

Table 1

Providers hired directly on staff in respondent service area

Provider	*Early On* with MMSE	*Early On* only	n	Comparative percent of providers in *EO* only versus *EO* with MMSE
Physical Therapist	42	6	43	14%
Occupational Therapist	44	8	6	18%
Speech-Language Pathologist	47	9	49	19%
Early Childhood Teacher (ZA only)	15	2	15	13%
Early Childhood Spec Ed Teacher	41	8	42	20%
Nurses	11	5	13	45%
Social Worker	34	7	37	21%
Psychologist	35	3	35	9%
Vision Consultant	33	5	33	15%
Hearing Consultant	30	5	30	17%
Autism Consultant	25	2	25	8%
Early On Service Coordinator (primary role/not already represented)	15	21	31	140%
Other - Fill In Fields/Comments			10	
Total Question Responses			53	

**n= total number of service areas stating they have the provider hired directly on staff in either Early On with MMSE or Early On only. (Note: one service area may have providers (e.g. nurse) hired on staff for both Early On with MMSE and Early On only. Therefore, n may be less than the two columns combined).*

Table 2

Teaming Practices

Formality of Teaming Practices	*Early On* with MMSE	*Early On* only	Total Respondents*
Teaming is informal (regular teaming times are not scheduled, communication is informal	16	9	18
Teaming is formal (regular teaming times and or procedures related to teaming)	44	20	47
Not sure	0	0	0
Percent with formal teaming practices	73%	69%	72%
Total Question Responses			53

**12 respondents identified both formal and informal teaming practices. This was also noted in the comments.*

In addition, comments reflected similar trends with teaming such as, "we do both formal and informal" teaming practices. In addition, comments noted that although regular teaming times occur, they may "not be utilized as efficiently as they could be."

Feeding services provided. Eighty-one percent of respondents reported that services are provided for children with feeding difficulties. Seventeen percent reported they do not provide services for feeding difficulties and 2% reported not sure.

Administrator supports. Administrator supports were another large area of strength and need identified within the survey. Specifically, the survey identified supports and needs in the areas of: 1) experience working with children with feeding difficulties, 2) training on feeding difficulties, and 3) training on interagency collaboration.

Experience with feeding difficulties. Fifty-five percent of respondents reported supervising professionals who work with children with feeding difficulties. Twenty-six percent also reported direct experience working with young children with feeding difficulties. Twenty-six percent reported no experience with feeding difficulties (either

supervisory or direct). Additional comments included reference to a broad range of experiences related to feeding spanning extensive direct work to very limited experience. Specifically, one respondent noted past work in a clinical setting working with "swallowing disorders" and even experience "conducting modified barium swallow studies." Two other commenters reported acting as a Part C/*Early On* service coordinator for a child with feeding difficulties and working closely with providers to coordinate services. Other comments cited, "limited experience" or "very little experience" related to working with young children with feeding difficulties.

Training on addressing feeding difficulties. Thirty percent of respondents reported receiving training on addressing feeding. If respondents answered yes, they were prompted to specify the type of training. Training experiences ranged from formal professional development courses to less formal peer to peer mentoring from physicians and providers. Forty-two percent of respondents reported professional development for administrators on feeding difficulties as a top priority.

Training on interagency collaboration. Twenty-nine percent of respondents report receiving formal training on interagency collaboration. This training did not need to be interagency collaboration specifically related to feeding difficulties. If respondents answered yes, they were prompted to specify. Respondent experiences ranged from conferences and trainings to college coursework on interagency collaboration.

Community partnerships. Community partnerships were another important strand identified. Specifically, needs and strengths were noted related to levels of community collaboration, collaborative council participation, and proximity of community partners.

Level of community collaboration. Regarding the importance of collaboration and understanding of roles, participants self-ranked their level of interagency collaboration related to addressing the needs of young children with feeding difficulties by using a rubric based question (Appendix F). The rubric is based upon principles in an existing rubric on levels of interagency collaboration, "Levels of Community Linkage," by Cross, Dickman, Newman - Gonchar, Fagman (2009). The rubric was modified with permission from SAGE Publishing to focus on interagency collaboration related to addressing feeding needs (Appendices D and E). There are six total levels with level 0 being the lowest level of interagency collaboration and level 5 being the highest level. The majority of respondents fell into levels 1 and 2 of community linkage related to addressing the needs of young children with feeding difficulties with only five respondents in level 0, six respondents in level 3 and one each in levels 4 and 5 (Table 3).

Table 3

Levels of Interagency Collaboration when Addressing the Needs of Young Children with Feeding Difficulties

Level of Community Linkage	n	Percent of Respondents*	95% Confidence Intervals (Percent Ranges)
0 - Little or no collaboration	5	10	[1.68, 18.32]
1 - Networking	22	44	[30.24, 57.76]
2 - Alliance	15	30	[17.30, 42.70]
3 - Partnership	6	12	[3.0, 21.0]
4 - Coalition	1	2	[0, 5.88]
5 - Collaboration	1	2	[0, 5.88]
Total Question Responses	50		

**percent computed based on 50 total responses to question on community linkage*

Overall, respondents identified a need for role clarification even beyond interagency agreements. Sixty-two percent of respondents identified a need for guidance from the state level on the role of *Early On* and Michigan Mandatory Special Education for

children birth to age three when addressing feeding difficulties, making it one of the top two most needed structural supports. Comments echoed this need for role clarification on a local and state level.

Comments specified a need for clarifying roles with respondent statements such as, "I feel that we need our roles defined more medical versus educational and who should address what," and, "there should be an understanding of what educational and medical therapy is." In addition, one commenter shared more detail on items that should be included in the guidance stating a need for, "clear information from medical partners, special education partners, and insurance companies as to what services each will provide and how it will be paid for." Last, one commenter identified that guidance in this area should be prioritized highly and require state intervention stating, "guidance from the state would be the most beneficial support when it comes to addressing the needs of young children with feeding difficulties."

Collaborative council participation. Only six percent of respondents reported no participation with collaborative councils. The majority of respondents represented a broad range of council participation spanning from 29% of respondents involved with the Human Services Coordinating Council to 92% reporting participation with the Local Interagency Coordinating Council (Table 4). Additional councils and collaborative efforts reported include: child abuse prevention councils, literacy committees, collaborations with other home visiting agencies, and collaborative partnerships for early identification of children with special needs.

Table 4

Collaborative Efforts

Type of Collaborative Effort	n	Percent*	95% Confidence Intervals (Percent Ranges)
NA - Do not participate	3	6	[0, 12.52]
Great Start Collaborative	46	90	[81.77, 98.23]
Local Interagency Coordinating Council	47	92	[84.55, 99.45]
Human Services Coordinating Council	15	29	[16.55, 41.45]
School Readiness Advisory Council	21	41	[27.50, 54.50]
Other/Not Specified - Fill in Fields	10	20	[9.02, 30.97]
Total Question Responses	51		

**percent computed based on 51 total responses to question on collaborative efforts*

Overall, 54% of respondents reported the need for increased time for collaboration with community partners on addressing feeding difficulties. In addition, 54% of respondents identified a need for interagency agreements with medical partners outlining roles and responsibilities when addressing feeding difficulties.

Proximity of community partners. Seventy-three percent of respondents reported having hospitals or medical providers within 50 miles providing services for young children with feeding difficulties with 20% reporting they do not have services available within 50 miles. Sixty-seven percent reported having hospitals or medical providers within 50 miles completing medical feeding evaluations (e.g. swallow studies) with 30% reporting they do not have providers completing medical feeding evaluation in the area. One respondent commented, "many of our feeding clinics are 1-2 hours away."

Structural Supports and Interagency Collaboration

Identifying what structural supports levy greatest impact on interagency collaboration is important when prioritizing organizational supports and procedures. However, due to the limited number of respondents in high levels of interagency collaboration with only two respondents identifying a level of 4 or 5 for community

linkage coupled with the complex nature of the system of services for children birth to three in Michigan (being a two-tiered system of *Early On* with MMSE and *Early On* only where there is separate qualifying criteria, supervision, and rules for each facet of evaluation and service), it was not possible to obtain a statistical relationship between structural supports and levels of interagency collaboration.

Levels of Interagency Collaboration and Access

Next, levels of interagency collaboration related to reported denials or access to medical feeding assessment and treatment were examined by cross referencing the levels of community linkage with the reported access (Table 5). Fisher's Exact Test was used to determine the relationship due to the relatively small sample size. A significant relationship was identified ($P<.05$) with a P value of 0.0247. Overall, the higher level of interagency collaboration noted, the less number of denials reported. However, it is also important to note that a significant number of respondents answered "not sure" (59%) whether children had been denied access to or payment of evaluation or treatment for feeding difficulties.

Table 5

Relationship between Levels of Community Linkage and Reported Access to Medical Feeding Evaluation and/or Treatment

	Yes/No - any children in the service area referred for medical assessment or treatment but denied access to or payment of evaluation or treatment for feeding difficulties			
Levels of Community Linkage	Yes	No	Not Sure	n
0	1	1	3	5
1	2	3	17	22
2+	1	12	9	22
Total	4	16	29	49

**n= total number of respondents who answered both community linkage and medical access questions to allow for cross tabulation and Fisher's Exact Test*

Summary of Findings

In summary, the survey derived a significant amount of data about structural supports in place, structural supports needed, and levels of interagency collaboration. The most identified structural supports needed were provider training on feeding difficulties and guidance from the state level on the role of *Early On* in addressing the needs of young children with feeding difficulties (Table 6). Analysis of the data revealed a significant relationship between the level of community linkage and access to medical feeding assessment and/or treatment. Although relationship probabilities were not obtainable for the relationship between structural supports and levels of interagency collaboration, Chapter 5 will further the conversation about the significance of the findings through the discussion and recommendations.

Table 6

Identified Structural Supports Needed

Area of Support	n	Percent*	95% Confidence Intervals (Percent Ranges)
Interagency agreements with medical partners	27	54	[40.2, 67.82]
Increased time for collaboration w/ community partners	27	54	[40.2, 67.82]
Funding	25	50	[36.1, 63.86]
Training & prof. development on feeding - providers	31	62	[48.55, 75.45]
Training & prof. development on feeding - administrators	21	42	[28.32, 55.68]
Guidance from the state on role of *Early On®* - Feeding	31	62	[48.55, 75.45]
Total Question Responses	50		

**percent computed based on 50 total responses to question on supports needed*

Chapter 5: Conclusion

Summary of the Study

Feeding-related concerns remain one of the most common issues brought to primary health professionals by parents of young children (Arvedson, 2008). Working with young children with feeding difficulties requires collaboration across interagency systems. When interagency collaboration is a vital, structural supports are shown to levy the greatest impact on outcomes (Tseng et al., 2011). However, in spite of structural supports having potential to bring the largest impact on outcomes, there is not currently research that focuses on which structural supports are needed related to addressing feeding difficulties in young children, birth to age three. Therefore, the purpose of the study was to identify systems level structural supports necessary when addressing the needs of young children, birth to age three, with feeding difficulties. Specifically, this study examined five research questions:

1. What structural supports are in place in Michigan to address the needs of young children with feeding difficulties?
2. What structural supports for addressing the needs of young children with feeding difficulties are needed?
3. What are the levels of interagency collaboration in Michigan related to addressing the needs of young children with feeding difficulties, birth to age three?
4. What structural supports correlate to higher levels of interagency collaboration when addressing the needs of young children with feeding difficulties (e.g. proximity of medical centers providing feeding supports, administrator training and/or experience related to addressing feeding difficulties, amount of staff with

specialized training related to feeding, administrator participation in collaborative efforts with community partners, administrator training on interagency collaboration, written procedures related to feeding difficulties, teaming practices of staff)?

5. Is there a relationship between levels of interagency collaboration and reported access to medical evaluation and services for young children with feeding difficulties?

A mixed-method research design was utilized incorporating both qualitative and quantitative methods in the survey design. Data were collected from respondents throughout the State of Michigan through use of an electronic survey. Multiple methods were used to improve accuracy of data including consultations with qualitative and quantitative experts, the use of Statistical Package for Social Sciences Software (SPSS) and Statistical Analysis Software (SAS), support from the Statistical Consulting Center at Grand Valley State University, and best practice techniques in data analysis such as triangulation, respondent validation, and use of numbers. This led to many identified findings.

Findings from the study identified a significant relationship between levels of interagency collaboration and access to medical evaluation and treatment. Findings also identified there are many structural supports already in place in Michigan related to addressing the needs of young children with feeding difficulties. However, the findings additionally revealed there are many structural supports needed related to addressing the needs of young children with feeding difficulties. Last, the study revealed that the

majority of service areas in Michigan are in the beginning levels of community linkage related to addressing the needs of young children with feeding difficulties.

Conclusion

The study identified many notable findings on structural supports needed and structural supports in place related to addressing the needs of young children with feeding difficulties. There was a significant relationship between the levels community linkage and access to medical feeding evaluation and intervention. Specifically, the study identified there are many structural supports in place in Michigan related to feeding. Many coordinators or administrators overseeing the services for young children, birth to age three, not only had direct service experience working with young children, birth to three, and their families, including those with feeding difficulties, as well as, overseeing providers who work with young children with feeding difficulties. In addition, a large number of respondents reported having regular teaming practices in place. Last, for children receiving services in *Early On* with Michigan Mandatory Special Education, there was an array of providers hired on staff. Overall, in spite of the many supports in place related to addressing the needs of young children with feeding difficulties, there were also a significant amount of needs identified.

First, there is a need for a wider array of providers on staff in *Early On* only (no special education). This is not surprising since in Michigan, areas servicing children in *Early On* only receive a mere $1/18^{th}$ to $1/20^{th}$ the funding of other home visiting programs in Michigan or early intervention programs in other states respectively (Michigan Interagency Coordinating Council, 2014). Next, there is a need for improved collaboration and understanding across agencies related to addressing feeding needs,

which was strongly emphasized not only in the comments but also in the identified levels of interagency collaboration. Specifically, the majority of service areas identified a level of community linkage at level 0, 1 or 2 (see Table 2 and Appendix F), at these levels very little collaboration is present. Although some role understanding is emerging in level 2, it is necessary to obtain a level 3, 4, or 5 to maximize collaboration as the roles of all agencies are fully defined and increased collaborative efforts are employed (e.g. procedures, teaming). This is notable because within the survey, role delineation was identified as a significant need in both the quantitative and qualitative research design components, therefore demonstrating a strong need for increased understanding of roles across settings. In addition to role understanding, there is a need for increased knowledge and understanding of the identification and treatment of feeding difficulties in young children.

Last, the study identified a significant relationship between levels of community linkage and access to services and evaluation for feeding difficulties. Specifically, the lower the levels of community linkage related to increased difficulty accessing medical evaluation and services related to feeding. Most service areas in Michigan are currently in the lower levels of community linkage related to addressing the needs of young children with feeding difficulties (level 0, 1, or 2 of community linkage) and therefore it is not surprising that service areas identified difficulties related to addressing the needs of young children with feeding difficulties (Stegenga, 2013). The relationship of lower levels of community linkage to assessment and intervention access for feeding difficulties is notable because quick and early access to services and evaluation improves outcomes for young children with feeding difficulties (Williams et al., 2006).

Discussion

The discussion is presented in the same order as the results: 1) Structural supports in place and needed in Michigan when addressing the needs of young children with feeding difficulties, 2) levels of interagency collaboration in Michigan when addressing the needs of young children with feeding difficulties, 3) structural supports correlating to higher levels of interagency collaboration when addressing the needs of young children with feeding difficulties, and 4) relationship between levels of interagency collaboration and reported access to medical evaluation and medical services for young children with feeding difficulties. In the following, discussion and analysis of the data includes relationship to theories and prior research.

Structural Supports in Place and Needed

Many structural supports and needs related to addressing the needs of young children with feeding difficulties were identified in the survey. Specific categories of structural supports for discussion and analysis include: 1) direct service provider supports with subcategories of a) variety of providers represented on staff, b) training of providers related to addressing feeding, c) teaming structure, and d) whether feeding services are provided; 2) administrator supports with subcategories of a) experience working with young children with feeding difficulties and b) training on addressing feeding difficulties, and c) training in interagency collaboration; and 4) community partnerships with subcategories of a) level of community collaboration, b) collaborative council participation, and c) proximity of community partners.

Direct service provider supports. Direct service provider supports include the type of providers represented on staff (e.g. physical therapist, speech-language

pathologist, occupational therapist), training of providers related to addressing feeding, teaming processes (formal versus informal), and whether feeding services are provided. Notable discussion points are contained within each sub-category.

Service providers on staff. The survey identified a broad array of service providers hired on staff for children in *Early On* with Michigan Mandatory Special Education. This is in alignment with Michigan's long-standing history of providing state ensured/mandated special education services for children birth to age 26 since 1971 (Michigan Department of Education, 2005). However, for children in *Early On* only, the amount of providers in each discipline hired directly on staff in *Early On* only was a fraction of the amount of providers hired on staff in *Early On* with Michigan Mandatory Special Education with the exception of *Early On* service coordinator. This is significant because the amount of children in *Early On* only in Michigan represents two times as many children compared to the number of children in *Early On* with Michigan Mandatory Special Education.

Specifically, when reviewing historical data trends from 2011 to 2014 in Michigan, 60-63% of the children served in Michigan are in *Early On* only (earlyondata.com). This means the majority of children potentially only have access to as little as 10% the array of service providers compared to children who have access to providers hired on staff in special education. This potential lack of service provision and access to providers in *Early On* only was recently identified in the Auditor General's report on Part C in Michigan as a result of limited funding to services for children in *Early On* only (McTavish, 2013). Overall, with less funding and subsequently less services available to children in *Early On* only, there is the potential of children with

feeding difficulties in *Early On* only to wait longer to be identified. This is concerning because early identification, collaboration, and treatment are key to not only progress but the child's overall health if they are experiencing feeding difficulties (Williams et al., 2006).

In addition to the notable lack of providers in *Early On* only, the data identified another difficulty. Specifically, the largest type of provider hired on staff in *Early On* only was the *Early On* service coordinator. Specifically, the amount of *Early On* only service coordinators was 140% the level of those hired in *Early On* with Michigan Mandatory Special Education. *Early On* service coordinators in Michigan are only required to have a high school diploma or pass the General Education Development (GED) test according to the Michigan State Plan for Part C (Michigan Department of Education, 2015). This means the largest group identified as hired on staff in *Early On* only, is not required to have a professional background with experience or specialization in identifying or providing intervention for feeding difficulties.

Provider training. Nearly 30% of respondents reported they do not have staff with specialized training in addressing feeding difficulties in young children and an additional 10% were not sure if they had staff with specialized training in this area. Therefore, it is not surprising respondents identified the need for provider training on feeding difficulties as one of the top two priorities for supports needed. A baseline provider understanding is necessary for early identification and treatment. As mentioned in the literature review, early identification of feeding difficulties can make an immense difference in the trajectory of the child's development (Williams et al., 2006). In addition, with the large range of professional backgrounds for providers and *Early On*

service coordinators, there is a need for baseline training for all providers. This need has also been identified in prior research on preparedness of early intervention providers (Ehardt, Van Dommelen, Zimerle, 2014). In addition, there is a need for specialized training for providers whose professional scope of practice includes feeding and swallowing disorders, such as occupational therapists and speech-language pathologists (AOTA, 2007, ASHA, 2002).

Teaming structure. Respondents identified both formal and informal teaming practices with seven respondents identifying use of both. Rates of formal teaming processes were very similar in *Early On* only and *Early on* with Michigan Mandatory Special Education with 69% and 73% of respondents reporting formal teaming practices respectively. However, in spite of a large number of respondents identifying formal teaming practices in place, nearly 30% of respondents noted teaming practices remain informal or do not exist. In addition, respondents also reported that teaming could be used more efficiently. Teaming is a key component to practices in early intervention (Sheldon & Rush, 2013) and also is a key component addressing the needs of young children with feeding difficulties due to the need for multidisciplinary input (e.g. Bruns & Thompson, 2010; Lefton-Greif & Arvedson, 2008).

Feeding services provided. Seventeen percent of respondents reported they do not provide services for feeding difficulties and two percent reported not sure. This could indicate a need for further training and skill development through both pre-service and post-professional development on identification and intervention of feeding difficulties. The lack of feeling of preparedness has been identified in prior studies (Ehardt, Van Dommelen, Zimerle, 2014) as well as it aligns with many comments in the qualitative

data portion of this study identifying a need for provider training on feeding difficulties. In addition, the lack of service provision for feeding difficulties could indicate the need for guidance from the state on the role of *Early On* in identifying and addressing the needs of young children with feeding difficulties given understanding of roles is a key component of interagency collaboration (Cross, Dickmann, Newman-Gonchar, & Fagan,2009). This also was a strong need identified in the data.

Administrator supports. Administrator supports were another significant area of strength and need identified within the survey. Included in the following discussion are the supports and needs in the areas of: 1) experience working with children with feeding difficulties, 2) training on feeding difficulties, and 3) training on interagency collaboration.

Experience with and training received on feeding difficulties. Although 55% of respondents reported supervising professionals who work with children with feeding difficulties including 26% also reporting direct experience working with young children with feeding difficulties, 26% still reported no experience with feeding difficulties (either supervisory or direct). In addition, only 30% of respondents reported receiving training on addressing feeding. Although this is a significant number of respondents reporting training in the area of feeding difficulties, it also indicates a need for broader training to individuals supervising and coordinating programs and services for young children since 25% still have no training or experience. Providers need administrative support for community partnerships, which are key when addressing feeding difficulties (Bruns & Thompson, 2010; Lefton-Greif & Arvedson, 2008). Therefore, administrators overseeing services for young children with feeding difficulties must demonstrate a baseline

understanding of the need for services and the need for intergency partnerships when addressing feeding difficulties. This finding identifies that administrator training is imperative. Although formalized courses may not be required, a general understanding of feeding difficulties, the need for community partnerships, and the role of *Early On* is needed for program and service oversight, development, and planning. This need aligns with a significant amount of respondents (42%) reporting a need for professional development for administrators on feeding difficulties.

Training on interagency collaboration. Twenty-nine percent of participants reported receiving formal training on interagency collaboration. This training did not need to be specifically related to feeding difficulties. Respondent experiences ranged from conferences and trainings to college coursework on interagency collaboration. With interagency collaboration being key to not only *Early On* services and premises, but also a key when addressing the needs of young children with feeding difficulties, it is an important structural support.

Community partnerships. Community partnerships were another important strand identified. The following discussion focuses on the needs and strengths related to levels of community collaboration, collaborative council participation, and proximity of community partners.

Level of community collaboration. As shown in Table 2, the majority of respondents fell into levels 1 and 2 of community linkage related to addressing the needs of young children with feeding difficulties with some respondents even falling into level 0 which indicates very rare to no collaboration with community partners on feeding difficulties. Level 1 indicates communication occurs with community partners but it is

informal and no procedures are set. Level 2 indicates communication occurs and has evolved to a level to avoid duplication of services. In addition, there are emerging forms of formal communication but is on an as needed basis. However, in spite of some the emerging collaboration, in levels 0, 1, and 2, there is not a noted sharing of resources, any regularity to the communication, and there is not a clear understanding of provider roles. Higher levels of collaboration begin to emerge in levels 3 through 5.

Level 3 is when many key collaboration components begin to emerge. However, the majority of respondents in Michigan identified their service area at a level 0, 1, or 2 of community linkage. Therefore, the majority of respondent service areas are missing key components necessary to achieve a higher level of community linkage and collaboration. This aligned directly with the identified need for role clarification on both the local and state level, which was echoed in the participants' comments. In addition, this need for collaboration between systems working with children with feeding difficulties was also identified by parents in a recent study on supports and barriers to feeding interventions (DuPont, Must, West, 2014).

In spite of many areas indicating a need for an increased level of community linkage related to addressing feeding difficulties, there were two respondents identifying their service areas are at either a level 4 or level 5 of community linkage. These levels of linkage are the highest levels of collaboration and indicate regular communication between agencies, a solid understanding of roles, and written procedures in place. Ultimately, this is important to identify because these areas could potentially serve as models of interaction and collaboration.

Collaborative council participation. The majority of respondents represented a broad range of council participation spanning from 29% of respondents involved with the Human Services Coordinating Council up to 92% reporting participation with the Local Interagency Coordinating Council. However, 6% of respondents reported no participation with collaborative councils. This is concerning because collaboration and interagency partnerships are a key component of early intervention services.

Overall, 54% of respondents reported the need for increased time for collaboration with community partners on addressing feeding difficulties. Furthermore, 54% of respondents suggested participation and interaction needs to be broader than just council participation, identifying a need for interagency agreements with medical partners outlining roles and responsibilities when addressing feeding difficulties.

Proximity of community partners. In order to have collaboration with community partners to address feeding difficulties, there simply needs to be community resources available to partner with. Therefore, the survey examined proximity of local medical facilities where evaluation and services are provided for young children with feeding difficulties. Twenty percent of respondents reported there are not feeding intervention services available within 50 miles and 30% reported there is not access to hospitals or medical providers for medical feeding evaluations (e.g. swallow studies) within 50 miles. This is a huge barrier for young children who need service because there are increased challenges such as: transportation across long distances and more difficulty collaborating and sharing resources since there is not the option for overlap and participation in local interagency councils due to distance.

Levels of Interagency Collaboration and Access

Last, a significant relationship was identified ($P<.05$) with a P value of 0.0247 between the levels of interagency collaboration related to reported denials or access to medical feeding assessment and treatment. Overall, the higher level of interagency collaboration noted, the less number of denials reported. However, it is also important to note that a significant number of respondents answered "not sure" (59%) whether children had been denied access to or payment of evaluation or treatment for feeding difficulties. This is significant because more than half the respondents overseeing services for children birth to age three did not have a current gauge on access to services and/or evaluation with interagency partners. However, this does align with other survey findings that most respondent service areas are only in levels 0, 1, or 2 of the community linkage. In these lower levels of community linkage understanding of roles, services, and access is limited or non-existent.

Summary of Discussion

Overall, the complexity of supports in place and needs identified through the study along with the number of different backgrounds and professions identified as overseeing and being involved in the processes when addressing the needs of young children with feeding difficulties emphasize the need for transdisciplinary research and collaboration on this topic. In addition, since this is the first study to examine systems level structural supports and needs related to feeding difficulties, many recommendations for further research, policy and practice can also be derived from the analysis of the data.

Recommendations

As new knowledge emerges, such as in this study, the identification of further research, recommendations, and policy implications ensue. Therefore, the following includes recommendations on further research, recommendations to the field, and policy implications on the local, state, and federal levels.

Further Research

The study identified needs for further research in multiple areas. Specifically, the areas of structural supports related to levels of interagency collaboration, the system of services in early intervention, and research models in early intervention including research school collaborations, are all areas of need for further research.

Structural supports and interagency collaboration. First, further research is needed to determine which structural supports levy the most significant impact on improving levels of interagency collaboration related to addressing feeding difficulties in young children, birth to age three since this could not be accurately delineated in this study. Feeding difficulties not only impact the daily life of a family but often have long term devastating effects on development and even life (Arvedson, 2008; Newman, L.A., Keckley, C., Mario, P.C., & Hamner, A., 2001; Philipps et al., 2012). Therefore, identifying the most effective and efficient supports allows for cost and time savings while providing largest impact to the outcomes of young children with feeding difficulties.

System of services in early intervention. Next, the two-tiered system of early intervention in Michigan (i.e. *Early On* only and *Early On* with Michigan Mandatory Special Education) and lack of funding for the children in *Early On* only adds

complexities to collaboration and service delivery. In addition, the two-tiered part system presents difficulties in data collection, as exemplified in this study. Clear data sets are needed to accurately identify correlations, needs, and supports within the system. Therefore, further research is needed on optimizing collaboration and fluidity of service delivery and data collection across the two-tiered system. This systemic complexity leads to the need for increased use of transdisciplinary research in early intervention.

Transdisciplinary research. Further research also needs to occur on the use of different research models and guiding theories in early intervention. Particularly, it would be valuable to further explore the use of transdisciplinary research principles in early intervention. Examining the complexities and multiple layers of how to optimally support young children with feeding difficulties exemplifies the need for a multi-modal and transdisciplinary frame of reference. Given the founding principles of early intervention and the reciprocal and dynamic nature of a young child, a significant amount of research in the area of early intervention should be founded on these cross-collaborative principles. This is also emphasized by top research sources such as The World Health Organization. Specifically, they state that interprofessional collaboration is necessary to solve the most complex health and societal issues (World Health Organization, 2010).

Scope of practice. Related to interdisciplinary collaboration when addressing the needs of children with feeding difficulties, further research is needed on professional scope of practice within a transdisciplinary or primary service provider best practice model when highly specialized areas of practice are involved, such as feeding. Although best practice guidance identifies having a primary provider in early intervention service

delivery (Workgroup on Principles and Practices in Natural Environments, OSEP TA Community of Practice: Part C Settings, 2008), recent guidelines cautioning professionals to maintain within their professional scope of practice while utilizing the primary service provider model (AOTA, 2014) have emerged. Therefore, further information and guidance is needed on the amount of teaming and collaboration required in the primary service provider model to ensure access and oversight, determine how to maintain best practice of primary service provider model while balancing and maintaining scope of professional practice, and overall, determine ways to ensure families have access to all types of services and providers under Part C when primary service provider is the service delivery model.

Overall, there are many areas of further research identified from the study information. In addition, study identified multiple implications for recommendations to the field.

Recommendations to the Field

The findings identified many different implications for the practices in the field of early intervention and therapy. Specifically, recommendations related to research school collaboration, professional development on the identification and treatment of young children with feeding difficulties, and interdisciplinary collaboration for certification in feeding.

Research school collaboration. As discussed in the beginning of this thesis, there is very little research on how to address the needs of young children with feeding difficulties and no research that focuses on systems level supports, needs, and interagency collaboration related to addressing the needs of young children with feeding difficulties.

Yet, the field is charged to provide practices in early intervention founded on scientifically based research (IDEA, 2011). Given the complexities of the field of early intervention involving collaboration of multiple disciplines, the need for collaboration across interagency settings, and service delivery provided in multiple environments, there is an immense need for individuals in the field of early intervention to be involved in the research to ensure accuracy and focus of the research. Therefore, the model of research school collaboration outlined by Hinton & Fisher (2008) is immensely compelling.

Teaching hospitals form collaborations between researchers and practitioners to focus directly on service related issues. Yet, schools lack such an infrastructure connecting researchers to providers (Hinton & Fischer, 2008; Ronstadt & Yellin, 2010). Therefore, there has been a call to formalize these relationships between researchers and educators in the field (Ronstadt & Yellin, 2010). Although the research school collaboration model has focused mostly on traditional K-12 education, early intervention should also be considered in this model, encouraging more collaborative action based and field based research between researchers and service providers. Early intervention fits well into the model given early intervention's roots in education and complexity of its system. Early intervention employers could develop combined roles of researcher and practitioner to allow for and encourage action based research collaboration. With some minor changes in the structure of hiring contracts and/or use of professional development days and resources, service areas could add collaborative research opportunities for little added cost.

Professional development on feeding difficulties. Related to increased need for research and understanding on feeding difficulties, the study revealed an imperative need

to increase basic knowledge and proficiency of all early intervention practitioners and administrators related to identifying and addressing feeding difficulties. Research identifies early identification and access to evaluation and treatment as key to improving outcomes of young children with feeding difficulties (Williams et al., 2006). Therefore, developing a general proficiency amongst all early intervention practitioners and administrators about the signs of feeding difficulty, referral process, and collaborative efforts related to feeding difficulties is imperative. In addition, advanced training opportunities for practitioners whose scope of practice incorporates the specialized evaluation and treatment of feeding difficulties, such as occupational therapists and speech-language pathologists, is immensely important. Occupational therapists and speech-language pathologists graduate from their respective professional programs with a baseline understanding of evaluation and treatment of feeding difficulties but identify a need for further post-professional training for optimal proficiency (Ehardt, Van Dommelen, Zimerle, 2014).

Overall, practitioners in early intervention identify post-professional training through weekend courses as the most desirable form of continuing education (Ehardt, Van Dommelen, Zimerle, 2014). Therefore, it is recommended that areas recruit affordable professional development opportunities on addressing feeding difficulties to allow increased access to content on feeding to promote increased understanding. In addition, it is recommended that training efforts for both providers in early intervention and administrators include ongoing coaching. Per recent research, coaching results in the longest lasting results in the highest levels of fidelity of implementation (Moore, 2015).

Interdisciplinary certification in feeding interventions. Related to improving and ensuring understanding and knowledge related to addressing feeding difficulties, it is recommended that an interdisciplinary certification in feeding be developed through interdisciplinary collaboration. Both the American Occupational Therapy Association (AOTA) and the American Speech-Language-Hearing Association (ASHA) identify feeding and swallowing as part of their scope of practice (AOTA, 2007; ASHA, 2002). A joint certification would ensure similar standards for professionals working with the specialized evaluation and treatment of young children with feeding difficulties.

Currently, AOTA and ASHA each have developed and recently revised their own discipline specific certification on feeding (American Occupational Therapy Association, 2014b; American Board for Swallowing and Swallowing Disorders, 2014). However, with such a strong need for interdisciplinary collaboration when addressing feeding (e.g. Williams et al., 2006) and both AOTA and ASHA identifying addressing feeding and swallowing as part of their scopes of practice (AOTA, 2007; ASHA, 2002), a joint effort between the two organizations seems optimal. Pooling resources and time between organizations would save cost and time allowing funds to be allocated for further education and outreach on the topic of feeding difficulties.

There is an interdisciplinary certification for occupational therapists and physical therapists providing hand therapy. Occupational therapists and physical therapists can receive the designation of certified hand therapist (CHT) through hours of experience and assessment (Hand Therapy Certification Commission, 2015). AOTA and ASHA could use this interdisciplinary certification on hand therapy as a platform for the development of the interdisciplinary certification on feeding and swallowing.

Policy Implications

Policy implications occur on many levels related to structural supports and needs when addressing the needs of young children with feeding difficulties. Specifically, the following discussion includes local, state, and federal level implications and recommendations related to addressing the needs of young children with feeding difficulties.

Local implications. The research revealed several implications on the local level. Specifically, there are multiple structural supports recommended on the local level including internal procedures on addressing feeding difficulties, structured time for interdisciplinary teaming, collaboration between local agencies when addressing feeding difficulties, and set roles for feeding team members.

Internal procedures. The majority of respondents reported not having written procedures related to addressing feeding difficulties. Yet, prior research identifies this as a key component when addressing feeding difficulties in the educational setting (Bruns & Thompson, 2014; Homer, 2008). In addition, the study identified a link between higher levels of community linkage and access to evaluation and intervention for feeding difficulties. Written procedures are a necessary component of higher levels of community linkages. Therefore, it is recommended that service areas consider developing written procedures related to addressing feeding difficulties in young children.

Interdisciplinary teaming. Interdisciplinary services are a foundational premise of early intervention (IDEA, 2004). In addition, interdisciplinary teaming is identified as a key component when addressing feeding difficulties in young children (Arvedson,

2008; Bruns & Thompson, 2009; Lefton-Grief, 2008; Lefton-Grief & Arvedson, 2008). The study identified a need for increased time for and quality of teaming practices. Therefore, it is recommended that service areas devote time and training to optimizing interdisciplinary teaming and collaboration.

Collaboration between local agencies. In addition to the need for interdisciplinary collaboration, the study revealed a need for increased time for collaboration with community partners when addressing the needs of young children with feeding difficulties. Interagency collaboration is necessary not only when addressing the needs of young children with feeding difficulties (Bruns & Thomson, 2010; Lefton-Grief & Arvedson, 2008) but also is a foundational premise of early intervention (IDEA, 20054). Therefore, it is recommended that all local service areas consider devoting additional time to collaboration between agencies when addressing the needs of young children with feeding difficulties.

State level implications. In addition, to local level implications, there are several state level implications from the study. Specifically, many structural supports are needed on the state level including adequate funding to ensure an array of services, universal statewide training for providers on the identification of feeding difficulties, training on expectations and use of interdisciplinary councils to promote increased levels of community linkage, and state guidance to the field on addressing feeding difficulties including clarification on the role of early intervention versus other community partners when addressing feeding difficulties.

Funding. Adequate funding structures are needed to ensure access to the full array of providers and services within early intervention/Part C. Efforts are already

occurring in Michigan to examine funding needs in Part C and implications on practices (e.g. McTavish, 2013; Michigan Interagency Coordinating Council, 2014). It is recommended that all states examine funding structures to ensure families receive adequate access to the array of providers and services afforded to them under Part C. Adequate access to trained and qualified providers is an important component to ensure early identification of young children with feeding difficulties (AOTA, 2007, ASHA, 2002).

Increasing the levels of community linkage. As identified in the study, the majority of respondents identified beginning levels of community linkage with only two respondents reporting the highest levels of community linkage. Yet, community linkage levels were directly related to accessing evaluation and treatment of feeding difficulties. Therefore, it is recommended the state focus on improving levels of community linkage between service areas and community partners. Key components in the higher levels of linkage include written procedures that outline roles and sharing of resources. The study identified that service areas are seeking guidance not only on the local level but also on the state level about the role of early intervention versus other community partners when addressing feeding difficulties.

State level guidance on roles when addressing feeding difficulties. The need for state level guidance to the field related to feeding was an apparent need identified in the study. As identified in the literature review, there are very few states with guidance on addressing feeding difficulties. Therefore, it is recommended that all states consider adding guidance on addressing feeding difficulties in young children. Delineation of roles of early intervention and other community partners should be a key component of

the guidance. The need for state guidance was the top identified need in the survey along with education of providers on feeding difficulties in young children. Overall, understanding of roles is shown to be a key component of higher level community linkages and interagency coordination (Metzel, Foley & Butterworth, 2005). In addition, guidance and procedures must also include population served, resources to be committed, and reporting requirements (Metzel, Foley & Butterworth, 2005).

Federal level implications. In addition to local and state policy implications, the study also identified federal level policy implications. Specifically, implications include the need for supports to increase research in early intervention and improved oversight ensuring access to an array of providers.

Supports for research in early intervention. The review of the literature identified a gap in the research related to interagency collaboration and structural supports needed when addressing the needs of young children with feeding difficulties. In addition, it was also apparent that the research on issues in early intervention as a whole contains many gaps. Therefore, there is a need for federal grants that facilitate research school collaborations in early intervention. If research grants contained components encouraging collaboration between providers in the field of early intervention and researchers, it would open the door to real time data in the field, allowing a ground level view of the most pertinent issues in the lives of families and children.

Review of state funding systems. In addition to grant funding requirements, increased federal oversight would be beneficial related to requirements for state funding in early intervention. Many states have narrowed eligibility criteria for Part C services due to lack of funding to meet the needs. Specifically, between 1998 and 2008, 20% of

states narrowed their eligibility criteria and 75% of states enacted or increased family fees (IDEA Infant & Toddler Association, 2008). Meanwhile, the need for services has only continued to grow while funds continue to dwindle for services in Part C (IDEA Infant Toddler Association, 2013). The immense challenge to provide services on such limited funds has even caused ten states in recent years to identify their state is either discussing or making plans to no longer implement Part C services in their state due to the dwindling access to funding (IDEA Infant & Toddler Association, 2013). This is a scary premise because lack of access to qualified providers who can identify and treat feeding difficulties can mean life or death for a child with a feeding difficulty. After all, some feeding difficulties can lead to severe illness or even death if they are not identified and treated (DeLegge, 2002).

Summary of Recommendations

Overall, this study revealed needs for further research, recommendations to the field, and policy implications at the local, state, and national levels. Feeding difficulties are an issue that deserves great attention not only because of the impact on quality of life for the child and family but also because of the immensely significant impacts on health and education.

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Appendix A: Letter to Administrators and Coordinators of Programs for Children in *Early On* or Michigan Special Education, Birth to age three

Dear Administrator or *Early On*® Coordinator,

Did you know?

Up to 80% of children with disabilities have difficulties with feeding (Arvedson, 2008; Williams et al., 2006)! These difficulties can lead to nutritional deficits, developmental delays, or even death (Williams et al., 2006). In addition, we know that inadequate nutrition can negatively impact educational outcomes (Engle & Huffman, 2010)!

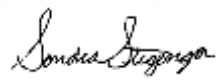
Why does this matter to you?

Early identification of young children with feeding difficulties can have a profound impact on improving outcomes with their feeding and nutritional intake (Williams et al., 2006)! However, addressing feeding difficulties in young children requires coordinated collaboration between health, education, and early intervention/*Early On*. In spite of the fact that systems level supports (e.g. procedures, training, levels of interagency collaboration related to addressing feeding needs, etc) have been shown to provide the greatest impact on long term outcomes in efforts that involve multiple agencies (Adams, R.C., Tapia, C. & The Council on Children with Disabilities, 2013; Tseng, Liu, & Wang, 2011), there is not currently any research about the systems level structural supports necessary to optimally address the needs of young children with feeding difficulties!

Therefore, the purpose of this survey is to identify systems level supports and collaborations currently in place when working with young children with feeding difficulties in Michigan and identify what additional supports are needed. The main audience of this survey is individuals currently in supervisory/administrative roles as *Early On* Coordinators or Special Education Administrators overseeing programs for children, birth to age three, in Michigan. <u>The results of this study will be used to support and assist service areas in the field in Michigan related to addressing the needs of young children with feeding difficulties!</u>

The survey will take approximately 10 minutes to complete. Your participation in and completion of the survey indicates your consent. Study results will be available via electronic database through Grand Valley State University in January 2015. I am currently an *Early On* Coordinator in Michigan and have provided services in the past to children with feeding difficulties and their families in *Early On*. Therefore, this topic is near and dear to my heart and I cannot thank you enough for your time and input!

Sincerely,



Sondra M. Stegenga MS, OTR/L
Grand Valley State University
MEd - Educational Leadership Candidate

**Inquiries about research protocol review, investigator, or subject rights please contact: Grand Valley State University Human Research Review Committee at hrrc@gvsu.edu or 616-331-3197.*

Appendix B: Letter from Michigan Department of Education

STATE OF MICHIGAN
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RICK SNYDER
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MICHAEL P. FLANAGAN
STATE SUPERINTENDENT

May 1, 2014

MEMORANDUM

TO: *Early On*® Coordinators

FROM: Vanessa Winborne, Part C Coordinator
Infant/Toddler & Family Services
Office of Great Start/Early Childhood Education and Family Services

SUBJECT: Research Studies – Addressing Feeding Difficulties in Young Children

Due to recently reported needs from the field, the Michigan Interagency Coordinating Council (MICC) has formed an ad hoc committee with a focus on best practices for addressing feeding difficulties in young children, birth to age three. As part of this work, the committee has partnered with Grand Valley State University to gather information on feeding interventions and needs in the field.

There will be three research studies coming through to *Early On* Coordinators for distribution between June 2014 and September 2014 gathering input from parents, providers, and administrators/program coordinators related to addressing feeding difficulties and supports needed. The information gathered will be utilized to provide guidance and training opportunities.

- The first study aims to recruit 10-15 parents for a simple phone interview.
- The second study will be a short electronic survey to practitioners in the field of *Early On*.
- The third study will be a short electronic survey to early childhood administrators overseeing birth to three services and *Early On* Coordinators.

Thank you for your time and assistance in gathering this important information and your dedication to supporting our youngest learners and their families. Please contact Barb Schinderle, MICC Liaison, at schinderleb@michigan.gov or Sondra Stegenga, Feeding Ad Hoc Committee Chair, at sstegeng@oaisd.org if you have any questions or would like further information.

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Appendix C: Survey

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Stegenga, S. (2014). *Supporting Young Children, Birth through age Two, with Feeding Difficulties: Systems Level Perspectives on Supports, Needs, and Interagency Collaboration* (unpublished thesis). Grand Valley State University, Grand Rapids, MI.

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Thank you very much for your time and consideration.

Kind Regards,



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Appendix F: Levels of Interagency Collaboration – Modified for Survey

Addressing the needs of young children with feeding difficulties often involves interaction with the medical community or other community partners. Therefore, please indicate which of the following best describes your organization's interactions with other agencies when addressing the needs of young children with feeding difficulties? (Select one)

Level of Community Linkage	Description	Key Points
0	Address the needs of young children with feeding difficulties but do not typically work with community partners when addressing feeding difficulties.	• Very rare or no collaboration with community partners related to feeding difficulties
1 (Networking)	Communicate with medical partners and community agencies for a common understanding related to addressing the needs of young children with feeding difficulties. Communication is usually informal/there are not set structures or procedures for communication about feeding difficulties.	• Communicate with community partners for a common understanding • Communication is informal/no set procedures • Communication may not be consistent
2 (Alliance)	Communicate and collaborate for a common understanding and also to avoid duplication of services. Further collaboration does not usually occur related to feeding difficulties.	• Communicate for a common understanding AND to avoid duplication of services • Some emerging forms of formal communication • Communication occurs occasionally/as needed
3 (Partnership)	Communicate and collaborate to avoid duplication and also to coordinate and share resources related to feeding difficulties (e.g. common training, handouts, etc.). Roles of providers are understood (may be written or informal).	• Communicate for a common understanding, avoid duplication, AND to share resources • Communication occurs regularly • Clear understanding of provider roles • Communication occurs frequently
4 (Coalition)	Communicate and share ideas about feeding difficulties (e.g. common training, handouts, etc.). In addition, new resources are created collaboratively. Roles of providers and organizations related to feeding difficulties are defined as part of written procedures. Written procedures may only be for internal use only/not shared (e.g. for school district use only). Communication is common and clear.	• Communicate and coordinate for understanding, avoid duplication, share resources, AND to develop new resources • Communication is common and prioritized • Written procedures are in place but may be for internal use/not share
5 (Collaboration)	Highly developed communication and a shared vision related to addressing the needs of young children with feeding difficulties. This includes mutually agreed upon procedures which are in place for all organizations (e.g. Early On and Medical Providers) and formalized in writing. Communication occurs often, trust level is high, and decisions are consistently shared equally.	• Shared leadership with high trust levels • Highly developed communication • Consensus is used in decision-making • Mutually agreed upon procedures in place and formalized in writing

Adapted from "Levels of Community Linkage" by Cross, J.E. Dickmann, E., Newman-Gonchar, R., & Fagan, J.E. (2009). Using mixed method design and network analysis to measure development of interagency collaboration. *American Journal of Evaluation, 30*, 310-329, copyright ©2009 SAGE Publishing. Modified by permission of SAGE Publications.

Appendix G: Permission Request and Permission for Prosperity Regions Map - Survey

July 30, 2014
[illegible]@michigan.gov

Dear Mr. Chris Haskins,

I am requesting permission to utilize an excerpt from the following work:

Michigan Department of Technology, Management, & Budget (2013). State of Michigan Prosperity Regions Map. Retrieved from:
http://www.michigan.gov/documents/dmb/Prosperity_Map_430048_7.pdf?20140730123127

This request is for permission to utilize the map in a survey for the following Basic Unit presenting:

Stegenga, S. (2014). *Supporting Young Children, Birth through age Two, with Leading Differentiated Systems Level Intervention to Support Needs and Interagency Collaboration* (unpublished thesis). Grand Valley State University, Grand Rapids, MI.

I believe that you currently the holder of the copyright, because the original work states that copyright is held by the State of Michigan (DTMB). If you do not currently hold the rights, please provide me with any information that can help me contact the proper rights holder. Otherwise, your permission confirms that you hold the right to grant this permission.

This request is for a non-exclusive, irrevocable, and royalty-free permission, and it is not intended to interfere with other uses of the same work by you. The permission requested extends to the prospective publication of this thesis/dissertation by the Grand Valley State University Libraries, which will make this work available to the public through its online institutional repository, ScholarWorks@GVSU. I would be pleased to include a full citation to your work and other acknowledgement as you might request.

I would greatly appreciate your permission. If you require any additional information, do not hesitate to contact me at the address and number above.

A duplicate copy of this request has been provided for your records. If you agree with the terms as described above, please sign the letter where indicated below and return via email to Sandra Stegenga at:

stegengas@gmail.com

Thank you very much for your time and consideration.

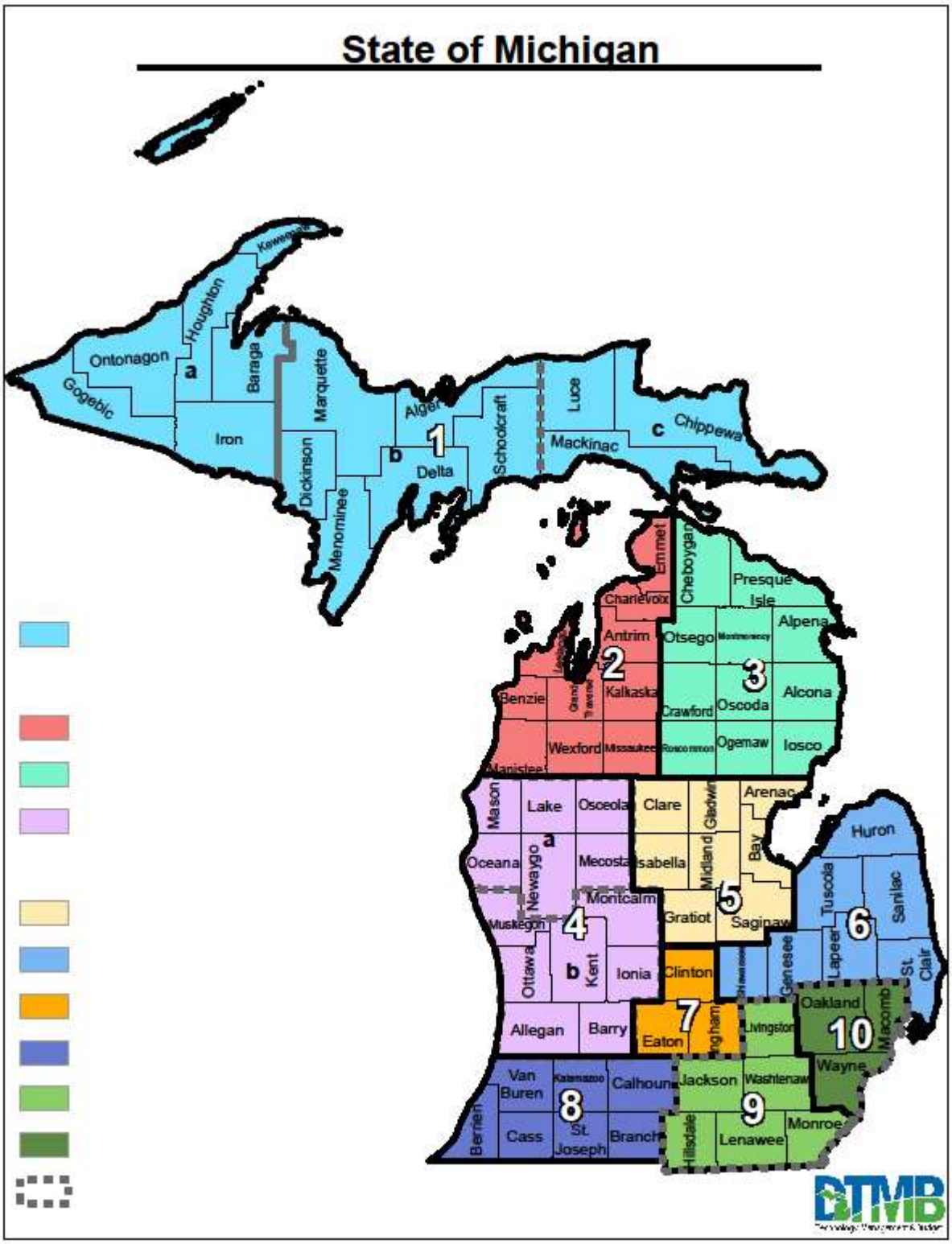
Kind Regards,

Sandra M. Stegenga MS, OTR/L
Grand Valley State University
MTD - Educational Leadership Candidate

Permission is hereby granted:

Signature: [signature]
Name & Title: [illegible]
Company/Affiliation: [illegible]
Date: 7/31/14

Appendix H: Regions of Michigan Map – Modified for Survey



Appendix I: Permission from Human Research Review Board (HRRB)

GRAND VALLEY STATE UNIVERSITY
www.gvsu.edu

DATE:	October 6, 2014
TO:	Sondra Stegenga, MS, OTR/L
FROM:	Grand Valley State University Human Research Review Committee
STUDY TITLE:	[641214-1] Young Children, Birth to Age Three, with Feeding Difficulties: Systems Level Perspectives on Supports, Needs, and Interagency Collaboration in Michigan
REFERENCE #:	15-043-H
SUBMISSION TYPE:	New Project
ACTION:	EXEMPT
EFFECTIVE DATE:	October 6, 2014
REVIEW TYPE:	Exempt Review

Thank you for your submission of materials for your planned research study. It has been determined that this project: *IS ARGUABLY COVERED* human subjects research* according to current federal regulations and MEETS eligibility for exempt determination under category 45 CFR 46.101(b)(2). **It may not be human subjects research since the secure, anonymous, online survey asks mostly system service type questions and not personal opinions of information from or about individuals. Nevertheless it is determined to be exempt under category 2 just in case.**

Exempt protocols do not require formal approval, renewal or closure by the HRRC. Any revision to exempt research that alters the risk/benefit ratio or affects eligibility for exempt review must be submitted to the HRRC using the *Change in Approved Protocol* form before changes are implemented.

Any research-related problem or event resulting in a fatality or hospitalization requires immediate notification to the Human Research Review Committee Chair, Dr. Paul J. Reitemeier, 616-331-3417 **AND** Human Research Protections Administrator, Mr. Jon Jellema, in the Office of the Provost, 616-331-2400. See *HRRC policy 1020, Unanticipated problems and adverse events.*

Exempt research studies are eligible for audits.

If you have any questions, please contact the Research Protections Program, Monday through Thursday, at (616) 331-3197 or rpp@gvsu.edu. The office observes all university holidays, and does not process applications during exam week or between academic terms. Please include your study title and reference number in all correspondence with our office.

*Research is a systematic investigation, including research development, testing and evaluation, designed to develop or contribute to generalizable knowledge (45 CFR 46.102 (d)).

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