

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 dietitian, 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.